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## 2<sup>ND</sup> EUROPEAN CONFERENCE ON FASD

**“FETAL ALCOHOL SPECTRUM DISORDERS:  
CLINICAL AND BIOCHEMICAL DIAGNOSIS  
SCREENING AND FOLLOW-UP”**

**OCTOBER 21-24, 2012**

**BARCELONA, SPAIN**

PARC DE RECERCA BIOMEDICA



## WHAT IS HAPPENING IN MY COUNTRY ?

CHAIR: GISELA MICHALOWSKI

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### Promoting alcohol free pregnancy and preventing FASD in Norway

Marianne Virtanen

The Norwegian Directorate of Health, Norway

**Objective:** The national guidelines for pregnancy care were renewed in Norway in 2005, and it was recommended that women abstain from alcohol during pregnancy. Our task has been to make this recommendation well-known amongst health care professionals, to inform women in childbearing age and to motivate them to an alcohol free lifestyle during pregnancy. The Directorate of Health in Norway has worked to increase awareness, change attitudes and behaviour according to the recommendation.

**Materials & Methods:** There was an expert committee which wrote the report Alkohol og graviditet (Alcohol and Pregnancy) in 2005. They proposed several measures to prevent FASD. Norway has an action plan for alcohol and drugs field 2007-2012, and it gives the mandate to our work. There have been four mass media campaigns and the fifth one will be in October. The campaigns have been highly visible ones and the message has been spread on many channels: magazines, cinema, television, interviews, films, internet, folders etc. Health professionals have been informed about the campaigns in advance.

**Results:** We have started our campaigns with a seminar to journalists, and they have written a lot of articles (more than 100 last year) and the message of alcohol free pregnancy has got wide publicity. We have experienced that opinion towards alcohol in pregnancy is restrictive now. Marketing research shows that women, who are pregnant or have got babies, answer that they don't drink alcohol after they got to know that they are pregnant. However one of three women was worried because she had been drinking before the pregnancy test. After the very first campaign there were people who meant that it was an extreme message to propose total abstinence from alcohol – today we don't hear those voices.

**Conclusion:** After six years of continuous work we can say that there is an awareness of the risk of FASD. The message of alcohol free pregnancy has reached most women thru mass media. We are now proposing screening and early consulting in the health care. Our goal is to ensure that all women will be asked about drinking of alcohol. Furthermore every woman should get information from her midwife or MD about alcohol

and other substances which are dangerous for their unborn child. Women who drink can be identified and get a proper follow-up locally or to be sent to a clinic for rehabilitation.

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### What is happening in Italy concerning Fetal Alcohol Spectrum Disorders?

Simona Pichini

Istituto Superiore di Sanità, Rome, Italy

**Objective:** In 2012, in Italy there is not yet a national network on problems related to Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD). No national no-profit (parental) organization exists and no national data on FAS/FASD prevalence.

**Materials & Methods:** The past September 9<sup>th</sup> 2011, for the first time Italy celebrated the Awareness Day on FASD and we had a press release at the National Institute of health in Rome, where the Italian Societies of Neonatologists, Paediatricians and of Gynaecologists and Obstetricians jointly presented the "Guide for Early Diagnosis of FASD" which has been distributed in 2000 copies to different hospitals, local health services and regional health offices. The first national cohort study on newborns in utero exposed to maternal alcohol has been published this year and showed an overall prevalence of newborns prenatally exposed to maternal ethanol was 7.9% with a considerable variability in the prevalence of fetal exposure to ethanol in different Italian cities, as determined by the objective measurement of biomarkers in meconium.

**Results:** In September 2010, a scientific society for the formation, information and coordination of health personnel involved in prevention, diagnosis and follow-up concerning FASD has been created, the SIFASD. Thanks to the involvement of different stakeholders interested in FASD, the European Alliance on FASD decided to celebrate the 3<sup>rd</sup> European FASD Conference in Rome.

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### Towards FASD prevention in Russia

Elena A Varavikova<sup>1</sup>, Julia Krikorian<sup>2</sup>, Galina B Dikke<sup>3</sup>

<sup>1</sup>Public Health Research Institute for organization and information CNIOIZ, Moscow, Russia; <sup>2</sup>Head of Representative Office, Medicines du Monde (France), Russia; <sup>3</sup>Association "Population and Development", Russia

**Objectives:** Alcohol consumption in Russia triggers for serious risk for the population health and health of the future generations. There are research (T. Balachova et al, 2012) data on extremely dangerous drinking patterns among pregnant and non-pregnant women of childbearing age in Russia. These results raised concerns among health researchers in Moscow. We faced the need for immediate information and organisation of medical and social community. The aim was to develop mechanism for collaboration for the development of FASD prevention inside the health system, as the first step towards development of the National FASD prevention programme.

**Materials & Methods:** The International Board for prevention of FAS/FASD and alcohol harm was organised in the early 2011 in Public Health Research Institute CNIOIZ in Moscow. Collaboration with our colleagues from other countries and organizations: WHO, NIAAA, USA; Medicines du Monde, INPES, SAF France (France), brought the information, knowledge and created the platform for the discussions. Related research groups and Institutions were invited and become devoted collaborators for the FASD prevention. Now we are actively working with obstetricians, gynaecologists, planning to work with journalists. Among the activities were seminars, conferences, First School for FAS/FASD prevention and research projects.

**Results:** In the absents of the National statistics and prevalence data for FAS/FASD in the country the prevention strategy is being introduced through the collaboration of the Public Health and medical research institutes, professional societies and regional health authorities. Ministry of Health supports this development. International collaboration, best expert's involvement and attention from WHO, were important for the success of the collaboration for FASD prevention in Russia. This framework allows us to improve management of implementation research and practise for FASD prevention in Russia.

**Conclusion:** The framework for productive collaboration for FASD prevention in Russia developed in the form of the International Board in the Public Health research Institute.

#### 4

#### **Universal prevention is associated with lower prevalence of FASD in Northern Cape, South Africa: a multicentre before – after study**

Leana Olivier<sup>1</sup>, Matthew F Chersich<sup>2,3</sup>, Michael Urban<sup>4</sup>, Leigh-Anne Davies<sup>5</sup>, Candice Chetty<sup>6</sup>, Denis Viljoen<sup>1</sup>

<sup>1</sup>Foundation for Alcohol Related Research (FARR), Cape Town, South Africa, <sup>2</sup>Centre for Health Policy,

School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, <sup>3</sup>International Centre for Reproductive Health, Department of Obstetrics and Gynaecology, University of Ghent, Belgium, <sup>4</sup>Division of Molecular Biology and Human Genetics, Faculty of Health Sciences, University of Stellenbosch, Tygerberg, South Africa, <sup>5</sup>Department of Psychology, School of Human and Community Development, University of Witwatersrand, Johannesburg, South Africa, <sup>6</sup>The Arum Institute, Johannesburg, South Africa

**Objectives:** The purpose of this study was to assess the effectiveness of comprehensive community-based interventions to reduce fetal alcohol spectrum disorders in two populations from the Northern Cape Province in South Africa.

**Materials & Methods:** Changes in the prevalence of FASD, and in maternal knowledge and drinking behaviour, were assessed in De Aar and Upington, Northern Cape Province, before and after an intensive community-level intervention. Eight community workers implemented educational activities to raise awareness of the risks of maternal drinking and to alter community norms about alcohol use in pregnancy. All children were examined by two dysmorphologists at 9 months of age and those with evidence of FASD were reassessed at 18 months. Neuropsychometrists evaluated infant neurodevelopment. Structured maternal interviews with FASD cases and matched controls determined patterns of alcohol use and knowledge about FASD.

**Results:** At baseline, 809 children were evaluated, 751 after intervention. FASD prevalence pre-intervention was 8.9% (72/809) and 5.7% post intervention (43/751; P=0.02). In multivariate logistic regression, controlling for maternal age and ethnicity, FASD prevalence was 0.73 fold lower post-intervention than pre-intervention (95%CI=0.58-0.90; P=0.004). Dysmorphology scores reduced from 4 at baseline (IQR=2-7) to 3 (IQR=1-6; P=0.002). After intervention, a large proportion of women reported having received educational messages, levels of knowledge about alcohol increased and some changes were detected in attitudes to drinking.

**Conclusion:** Comprehensive community-level interventions might reduce the burden of FASD in heavily-affected areas of South Africa, by about 30%. This, the first study ever to document the effectiveness of FASD prevention using clinical outcomes, suggests that comprehensive community-level services should be implemented in similar settings to reduce this very common, oft neglected, disorder.

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### What's happening in the Netherlands?

Martha Krijgsheld<sup>1</sup>, Nickie van der Wulp<sup>2</sup>, Rudi Kohl<sup>3</sup>  
<sup>1</sup>Fetal Alcohol Syndrome Foundation of the Netherlands, Uithuizen, the Netherlands; <sup>2</sup>Dutch Institute for Alcohol Policy, Utrecht, the Netherlands; <sup>3</sup>FAS Clinic, Jonx/Lentis, Winschoten, the Netherlands

**Background:** Activity concerning the issues of alcohol and pregnancy has grown in the Netherlands over the past two years, with several key players.

**Materials & Methods:** The FAS Foundation has several areas of action. First, the Foundation promotes prevention, by providing gratis information packets to professionals as well as gratis folders and flyers for use in counseling pregnant women. Second, the Foundation supports parents raising children with FAS with an e-mail support group, and books in the Dutch language. here is also a support group for adults with FASD. The first Dutch family weekend will be held in September 2012. Third, the Foundation works to promote wider awareness of FASD, for example, by participating in the European level labelling action and working with free-lance photographer Allard de Witte to create a photo exhibition on the lives of children with FASD.

**Results:** These photos won the prestigious Silver Camera award. Finally, the Dutch television show “De Wandeling” [The Walk] interviewed a birth mother over her alcoholism and birth of a child with FAS. The Dutch Institute for Alcohol Policy is also active in FAS prevention, through a website, flyers and supporting research. For her doctoral research, Nickie van der Wulp has developed educational materials for midwives and an internet program for pregnant women to inform pregnant women about the dangers of drinking during pregnancy. In addition, Nickie has investigated the determinants of Dutch pregnant women using alcohol and the determinants of partner support in alcohol abstinence during pregnancy through questionnaires. Furthermore, she interviewed Dutch midwives about their attitude towards alcohol use during pregnancy. The FASD clinic from Jonx/Lentis in Winschoten is one of only two dedicated diagnostic centres in the Netherlands. It provides a multidisciplinary one-visit diagnostic service. As it is run from a mental health institution, in addition it provides long term guidance and support in a broader sense. Furthermore, additional neuropsychological testing is provided to specify strengths and weaknesses for each individual. The two FASD clinics and the FAS Foundation are working together to create an informative brochure for parents of children who have just received a diagnosis, “So you have FAS—and what now?”

**Conclusions:** Unfortunately, all activity around FASD

in the Netherlands, that still remains only the domain of the clinics and foundations. Though the Health Ministry advised in 2005 that pregnant women should not drink, there is still no governmental support for public education or for labelling.

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### Improving FASD knowledge in general population and healthcare professionals in Murcia (SE Spain)

Maria Falcón<sup>1</sup>, Miguel F Sánchez<sup>2</sup>, Ana. B Villar<sup>3</sup>, Juan Jimenez-Roset<sup>3</sup>, Virtudes Gomariz<sup>2</sup>, Alicia Cánovas<sup>2</sup>, Juan A. Ortega<sup>2</sup>, Aurelio Luna<sup>1</sup>

<sup>1</sup>Legal Medicine Department, University of Murcia, Spain; <sup>2</sup>Pediatric Environmental Health Specialty Unit, Virgen de la Arrixaca University Hospital, Murcia, Spain, <sup>3</sup>Regional Drug Plan for the Region of Murcia Spain.

**Background:** The University of Murcia, the Regional Drug Plan for the Region of Murcia, the Pediatric Environmental Health Specialty Unit. (PEHSU), and the fetal unit in the Virgen de la Arrixaca University Hospital are working together to increase the awareness on the FASD issue in this Mediterranean Spanish area. This multidisciplinary team (clinic, research, public health and university professionals) is developing different projects to reach a main objective focused on reducing alcohol and other drug abuse substance consumption during pregnancy.

**Objectives:** The aim of this presentation is to summarize the results of this collaboration and to improve the general public/health professional knowledge about consequences of alcohol use during pregnancy

**Materials & Methods:** Review of the activities and programs developed by these institutions (2010-2012).

**Results:** The interventions include among others:

1) Teaching and training network for health professionals (pediatricians, gynecologist, obstetricians, nurses, midwives, general practitioners and social workers) to make easier for them to prevent, detect and diminish alcohol exposure during pregnancy and give advice and treatment when necessary to woman-family, to reduce risk and harm to the fetus.

#### **Training courses and conferences:**

a) Continuing Education Courses: 5 Courses. Attendance: 101 general practitioners

b) Courses “Training Course for Trainers”: Attendance: 60 general practitioners

c) Pediatric Environmental Health: training program for residents of pediatrics in our hospital. 50 students

d) Workshop: “Reproductive Environmental Health prevention of alcohol and other abuse substances exposure during pregnancy and lactation”. 40 students.

e) Specific curricula subjects in Medicine, nursery and social work degrees.

f) Specific curricula subjects in PhD students (50 students)

g) Courses for dissemination of prevention messages and health education purposes: 85 persons

2) Media publications and presentations to improve general population awareness of alcohol exposure consequences during pregnancy and fostering the whole community involvement in the protection of the newborn. Information materials for pregnant woman and professionals reaching all the health areas of the Region with more than 13.713 families targeted.

Radio interviews: 2.

Newspapers interviews: 4.

**Conclusion:** The synergy between different institutions makes easier the implementation of educational initiatives to reach both general population and health related professionals.

## PLENARY SESSION I

### PROGRESS IN PREVENTION

CHAIR: JOAN COLOM

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#### Progression of French national plan for FASD Prevention (2010/2020)

Denis Lamblin<sup>1</sup>

<sup>1</sup>Medical Director of the CAMSP (Fondation du Père FAVRON) Reunion Island, Saint Louis, France, SAF France President

**Objectives:** Initially review the actions put in place during the first 2 years of the “ten-year plan”.

**Materials & Methods:** Firstly it will highlight SAFFRANCE strategies to enhance the awareness nationwide:

1. The tools already tested (regional and international conferences, the dissemination of a guide to facilitate identification of women at risk),

2. The tools in process of development (training center for instructors, public access website),

3. The national partnerships: INPES (National Institute of Prevention and Education for Health), CNSA (National Solidarity Fund for Autonomy), IAD (International Adoption Service), CFA (French Adoption Agency).

4. The international Partnerships (Canada, USA, Israel, Brazil, Russia ...) the obstacles that SAFFRANCE is facing are institutional, political, economical; medias...

Secondly, there will be discussion regarding the priority actions for the next 2 years (creation of centers of reference ...)

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#### Making a difference: twenty three years of FASD policy and prevention in the United States

Kathleen Tavenner Mitchell

**Objectives:** Participants will hear a personal and motivational testimonial about the speaker’s journey through years of addiction and her discovery that her 16 year old daughter had FAS, not Cerebral Palsy. The presenter, Kathy Mitchell, will describe how her family’s story led her to become an advocate and a voice of change. She will describe over two decades of involvement with the National Organization on Fetal Alcohol Syndrome (NOFAS). Attendees will be provided with an overview of the historical timeline of NOFAS and FASD policy and prevention efforts in the United States.

**Materials & Methods:** The speaker will use a Power Point presentation including personal photos while describing her personal journey, 23 years of photos and campaigns from NOFAS projects, and policy and historical timelines. Participants will receive free FASD prevention materials from NOFAS and the Centers for Disease Control (Fact Sheets, brochures, FASD Diagnostic publications, posters, DVD’s – English and Spanish).

**Results:** Conference participants will be able to describe the history of NOFAS and how the U.S. has adapted policy and programs to address FASD. The audience will be introduced to innovative approaches to FASD prevention designed to for specific target groups.

**Conclusion:** The audience will learn twenty three years of lessons learned about FASD prevention efforts in the U.S. and will be able to discuss how even a small group of committed individuals can make a difference to create change.

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#### Developing FASD prevention in Russia

Tatiana Balachova<sup>1</sup>, Barbara Bonner<sup>1</sup>, Mark Chaffin<sup>1</sup>, Galina Isurina<sup>2</sup>, Larissa Tsvetkova<sup>2</sup>, Elena Volkova<sup>3</sup>

<sup>1</sup>The University of Oklahoma Health Sciences Center; <sup>2</sup>St. Petersburg State University; <sup>3</sup>Nizhny Novgorod State Pedagogical University

**Objectives:** Prenatal alcohol consumption can result in a range of adverse pregnancy outcomes including stillbirth and Fetal Alcohol Spectrum Disorders

(FASD). Russia is a country with high alcohol use and hazardous drinking in women. FASD prevention and data on risk for alcohol-exposed pregnancies (AEP) in Russia are limited. The study is aimed at developing FASD prevention in Russia.

**Materials & Methods:** An assessment-based strategy was used to translate knowledge and develop culturally appropriate FASD prevention in Russia. A line of research projects has been designed by researchers from the University of Oklahoma Health Sciences Center (OUHSC), St. Petersburg State University, and Nizhny Novgorod State Pedagogical University (research grants NIAAA/Fogarty International Center R21TW006745 and R01AA016234 and CDC/NCBDDD/AUCD RTOI 2005-999-01 and RTOI 2007-999-02 to Balachova and Bonner at OUHSC). The studies involved mixed methods including:

- 1) Formative assessment to collect data critical to developing FASD prevention,
- 2) Development and evaluation of FASD education materials, and
- 3) Designing and evaluating a prevention intervention.

The first study (2003-2005) involved focus groups and a cross-sectional survey exploring knowledge, attitudes, behaviors, and receptivity to prevention among women and physicians in two regions in Russia. The second (2006-2007), developed and evaluated in randomized trials FASD education for women and physicians. The third study (2007-2012) is a two-arm site-randomized controlled clinical trial at 20 women's clinics in two regions. A total of 1,889 women and 341 physicians participated in the studies.

**Results:** The initial study found that although many women reduced alcohol consumption after pregnancy identification, few recognized the risks involved in combining alcohol use with the potential to become pregnant. Among nonpregnant women, 43% were drinking at-risk along with a possibility to become pregnant posing risk for AEP. Based on the study findings, a preconceptional intervention to reduce the AEP risk was indicated. The intervention components were drawn from a brief physician intervention (NIH, 2005) and a motivational AEP prevention intervention (Project CHOICES, 2003) to design a dual-focused brief physician intervention (DFBPI). Physicians who were trained in DFBPI demonstrated significantly improved skills and competency in FASD prevention. Preliminary results of the DFBPI clinical trial will be reported.

**Conclusions:** AEP prevention is an important public health issue. The study is the first randomized trial targeted at AEP and preventing FASD in Russia. The research collaboration highlights importance of formative assessment for international translational research. Assessment driven translational research is a

promising approach for developing prevention interventions.

## PLENARY SESSION II –

### POLITICS AND STRATEGIES IN PREVENTION

CHAIR: PAUL PETERS

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#### The politics of alcohol and pregnancy campaigns

Nancy Poole<sup>1,2</sup>, Tasnim Nathoo<sup>1</sup>

<sup>1</sup>BC Centre of Excellence for Women's Health, Vancouver, Canada; <sup>2</sup>Canada FASD Research Network, Vancouver, Canada

**Objectives:** Research evidence suggests that alcohol and pregnancy awareness campaigns increase knowledge of the risks of drinking during pregnancy but have little impact on women's behaviours. Yet, awareness campaigns remain a popular prevention strategy for governments, public health and FASD advocacy groups and are frequently supported and funded by the alcohol industry. The purpose of this presentation is to begin a conversation about the challenges and controversies associated with alcohol and pregnancy campaigns and to discuss strategies for more effective broad-based prevention efforts.

**Materials & Methods:** Using examples from campaigns around the world (including but not limited to Italy, Canada, South Africa, and Norway), different messages (e.g., fear-based vs. support-based), approaches (e.g., zero-tolerance vs. harm reduction-oriented) and intended audiences (e.g., all women vs. pregnant women and their partners vs. women with addiction concerns) will be explored.

**Results:** Alcohol and pregnancy campaigns are uniquely developed to reflect the concerns, resources, and natural partnerships within local communities and regions. However, many campaigns may have unintended "side effects" such as increased stigma about alcohol use in pregnancy, increased fear of disclosure of alcohol use in pregnancy, and overemphasis on individual choice around alcohol use without adequate supports and policies.

**Conclusion:** Individuals and groups who are planning or expanding FASD prevention activities may benefit from the examining the efforts and outcomes of alcohol and pregnancy campaigns in other jurisdictions. Given the dearth of evidence on effective messaging, long-term outcomes, and preferred types of media, future campaigns should strive to incorporate an evaluation component that explicitly examines changes in women's drinking behaviours on a population level.

## 11 New strategies of intervention to create empowerment and involvement in the citizens

Francesco Marini<sup>1</sup>, Giuliana Moino<sup>2</sup>, Patrizia Riscica<sup>2</sup>, Stefania Bazzo<sup>3</sup>, Giuseppe Battistella<sup>4</sup>, Mariasole Gerome<sup>5</sup>, Gianluigi Scannapieco<sup>1</sup>, Giuseppe Dal Pozzo<sup>6</sup>, Loredana Czerwinsky<sup>3</sup>

<sup>1</sup>Department of Innovation, Development and Planning, Local Health Authority of Treviso, Veneto Region, Italy; <sup>2</sup>Addiction Department, Local Health Authority of Treviso, Veneto Region, Italy; <sup>3</sup>Doctoral school in Sciences of Reproduction and Development, University of Trieste, Italy; <sup>4</sup>Epidemiologic Unit, Local Health Authority of Treviso, Veneto Region, Italy; <sup>5</sup>University of Udine, Italy; <sup>6</sup>Obstetrics and Gynaecology Unit, Local Health Authority of Treviso, Veneto Region, Italy

**Objectives:** The campaign ‘Mamma Beve, Bimbo Beve’ in 2010 was based on a strong visual and its impact. The year 2011 was devoted to maintenance of attention: the project organized a short film involving two local well-known comedians and sportsmen to deliver the message. To produce the short film, we also started involving citizens for ‘guest appearances’ in the video.

**Materials & Methods:** In 2012, we based our action on two concepts: *empowerment* of the citizen with a goal of giving them awareness of the risks of alcohol during pregnancy; *active citizenship*, by involving the citizens in spreading the health message in the community. So we created the role of *ambassador* of the message. To achieve this goal, we developed a viral marketing action in public bars, restaurants, and discos, inviting people to take a photo with the visual of the campaign and send it to a dedicated web-site. All people who send the photo will be the protagonists of an event on 29 June 2012, the ‘M’ama day’. This big festival includes entertainment by eight comedians engaging in a cabaret championship on the theme of women. During this event, we plan a choral action of the participants to create engaging, viral videos. On 9 September (the International Day for Prevention of FASD), the video will be launched and shown on various media. This project was sponsored through a network of partners and sponsors, like ‘Fondazione Zanetti’ (foundation of Segafredo Zanetti Group), ‘Ascom’ (syndicate of restaurants, bars and discos). The ‘Gruppo Alconi’ provided the locations and produced the final video, while ‘Claim Adv.’ was a creative partner. Furthermore, the project has the patronage of the most important associations for health professionals.

**Conclusion:** This campaign has two innovative

concepts: the active role of the citizen, and maintenance and development of the network created two years ago. New partners were chosen for different requirements of the project, thus keeping the cost at zero for the community.

## 12 Effect of participating in a survey on women’s attitudes toward alcohol consumption

Elena Kosyh<sup>2</sup>, Elena Volkova<sup>2</sup>, Tatiana Balachova<sup>1</sup>

<sup>1</sup>University of Oklahoma Health Center, Oklahoma City, USA; <sup>2</sup>Nizhny Novgorod State Pedagogical University, Nizhny Novgorod, Russia

**Background:** Alcohol use is a major public health concern in Russia and permissive attitudes toward alcohol and drug use, smoking, and other unhealthy behaviors may contribute to unhealthy life styles. Increasing alcohol consumption in women changes traditional roles in the society, can affect women’s health, and increase the risk of fetal alcohol spectrum disorders in children. This study is part of a randomized controlled clinical trial aimed at evaluating an FASD prevention intervention for nonpregnant childbearing age women at risk for alcohol-exposed pregnancies (1).

### **Objectives:**

- 1) Explore attitudes toward alcohol among childbearing age women
- 2) Determine if women who consume larger amount of alcohol have a more favorable attitude toward alcohol use during pregnancy
- 3) Examine if answering a survey questions focused on women’s alcohol use and their risk for alcohol-exposed pregnancy results in changes in social attitudes towards alcohol consumption

**Materials & Methods:** A subset of women recruited for the clinical trial at clinics was used for this study. Women assigned to the study control condition (assessment only) in the Nizhny Novgorod region (N=175) were included in this analysis. Women completed four waves of a survey: baseline at enrollment to the study and at 3, 6, and 12 months after the baseline. The survey included demographic questions (living environment, marital status, education, employment, age, ethnicity etc.), questions about family planning/contraception, attitudes toward alcohol consumption, and alcohol consumption measures including quality-quantity questions, Timeline Follow Back (TLFB), and AUDIT,

### **Results:**

- 1) Women’s responses indicated negative attitudes toward drinking hard liquor during pregnancy; however their attitudes toward drinking wine were

more permissive.

2) Women with higher alcohol consumption demonstrated significantly more favorable attitudes to alcohol use in general and toward drinking wine.

3) There were significant changes in attitudes of women who participated in assessment only condition with attitudes toward drinking wine becoming more restrictive.

**Conclusions:** Previous studies reported that women may reduce alcohol consumption after answering questions about their alcohol use. The current study indicated changes in problematic attitudes toward alcohol consumption during pregnancy, particularly wine drinking. The role of these changes in attitudes in reducing alcohol use among women, possible mechanisms, and implications to prevention are discussed.

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#### UK Midwives FASD prevention programme

Susan Fleisher

NOFAS-UK (National Organisation for Foetal Alcohol Syndrome); International FASD Medical Advisory Panel, Member: European FASD Alliance. Publisher: International e-publication: FETAL ALCOHOL FORUM, Member: UK Department of Health Advisory Group on Fetal Effects of Alcohol. Member: Alcohol Health Alliance (Royal College of Physicians). Proud Adoptive Mother of a 24 year old daughter with FAS

NOFAS-UK, National Organisation for Fetal Alcohol Syndrome-UK, 165 Beaufort Park, London

**Website:** [www.nofas-uk.org](http://www.nofas-uk.org)

**Objectives:** THE UK MIDWIVES FASD PREVENTION PROJECT was created to provide specialist FASD Education for midwives who support pregnant women. Midwives are on the front lines of FASD Prevention.

**Materials & Methods:** The Project is delivered as a conference in three major cities each year to enable midwives attend from around the UK. The programme is delivered by FASD Experts, Doctors adoptive parents and birth mothers of children with FASD. Films are shown of the fetus under the influence of alcohol, parents, children with FASD and we screen the new film: *NO ALCOHOL, NO RISK – Information for Midwives*. Midwives also take part in discussion groups and develop strategies to talk to pregnant women. To help understand the impact FASD may have on later life, rolls are reversed and midwives are treated like children who have FASD to see how it feels on the other side.

**Results:** Midwives report that, before the training, they had some knowledge of alcohol in pregnancy. However, they were unaware of the long-term prognosis. They found the trainings informative, powerful and empowering. They felt they now had the confidence to discuss alcohol with pregnant women. Invariably they reported that, as a result of the training, they would change their practice to include alcohol education for pregnant women, as well as fellow midwives.

**Conclusion:** There is no doubt that FASD prevention is vital. It will literally save lives, lifelong hardship for individuals, their families and their communities. For every child born with FASD it is estimated that they will cost the government between \$200,000 and \$2,000,000 over their lifetime. FASD is costly to all of us. The debate will go on, but the conclusion is foregone: We must strive to prevent FASD whenever and wherever we can, to save human and financial hardship. Midwives stand on a powerful platform to reach pregnant women and their families. By 2015 NOFAS-UK will have provided FASD information to 10,000 UK Midwives who, in turn, are expected to provide FASD information to one million pregnant women.

## PLENARY SESSION III

### ISSUES IN DIAGNOSIS

**CHAIR: DENIS LAMBLIN**

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#### Enhancing early detection of newborns exposed to alcohol

Natalya Zymak-Zakutnia<sup>1,2</sup>, Lyubov Yevtushok<sup>1,3</sup>, Kenneth Lyons Jones<sup>4</sup>, Christina Chambers<sup>4</sup>, Wladimir Wartelecki<sup>1</sup>

<sup>1</sup>OMNI-Net Birth Defects Program, Ukraine; <sup>2</sup>Perinatal Centre, Khmelnytsky, Ukraine; <sup>3</sup>Medical Diagnostic Centre, Rivne, Ukraine; <sup>4</sup>Department of Pediatrics, University of California San Diego, La Jolla, CA, USA

**Objectives:** To prompt earlier detection by neonatologists and pediatricians of newborns and infants exposed to alcohol.

**Materials & Methods:** In 2000, we established the OMNI monitoring system, a population-based birth defects surveillance program inclusive of FAS, in the Rivne and Khmelnytsky regions of Ukraine. From the onset, professional and public education programs included an emphasis on the imperative to prevent FAS. In 2005, the OMNI monitoring system became a full member of the European Surveillance of



Congenital Anomalies (EUROCAT) which facilitates cross-comparisons of FAS rates in Europe. Also in 2005 the OMNI system became a partner of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD). For all infants born in Rivne and Khmelnytsky, neonatologists are mandated to complete a report including indication of risks of fetal alcohol exposure that has been designed by OMNI and approved by the Ministry of Health. All reports are forwarded for review by OMNI medical geneticists. We conduct ongoing training of neonatologists to fulfill this mandate as well as small group diagnosis skills training sessions. We analyzed 177,149 prospectively collected neonatal reports, clinical data regarding the diagnosis, and the type of clinician who first suspected FAS. We also analyzed the results of systematic screening of 7,218 pregnant women for alcohol use.

**Results:** The 2005-2010 population rates of FAS detected by OMNI are among the highest in Europe. The average population rate from 32 other partners of EUROCAT is 0.44 per 10,000 births and in the Ukraine it is 5.1. OMNI detected 97 FAS individuals in 28 cases. The diagnosis was suspected during the initial neonatal examination and in only 18 cases FAS was first suspected by medical geneticists. Notably in 50% of cases FAS is suspected by other health care professionals. The importance of children's state homes (former orphanages) is underscored in that 32 (33%) of FAS children are not cared for at home and that 9 are deceased (9%). The screening of pregnant women indicates that in Rivne and Khmelnytsky 3.3% and 4.6% fetuses respectively were exposed to risky levels of alcohol and require thorough neonatal examination and pediatric developmental follow-up.

**Conclusion:** Population rates of FAS in Ukraine are among the highest in Europe. Primary care neonatologists have an important role in the early detection of FAS. The screening of pregnant women for alcohol use is likewise effective. Further investment to enhance and link such implementations is justified and the impacts statistically testable.

## 15

### Diagnosing adolescents and young adults with FAS is ethically challenging

Ilona Autti-Rämö

The Social Insurance Institution, Research Department, Helsinki, Finland

**Objectives:** The true prevalence of FASD is so far unknown and the current estimate (1/100) may be an underestimate. Knowledge of the long-term effects of FASD has increased during the recent years and special

interest has been focused on adolescents and young adults with neurobehavioral and psychosocial problems without any prior FASD diagnosis. There are, however, no specific systems to diagnose FASD in young adults without the facial features related to FASD. Diagnosing FASD in young adults is not only medically but also ethically challenging.

**Method:** The ethical challenges when making or excluding the diagnosis FASD in young adults is analyzed using the EunetHTA core model for diagnostics ([www.eunethta.eu](http://www.eunethta.eu))

**Results:** Several ethically important issues were identified that are of concern not only for the patient but also for the multi-professional team and the patient-physician relationship. The moral values in the society are also reflected in the willingness to provide resources for diagnostic possibilities that are based on multiprofessional expertise. The psychosocial and legal consequences of FASD diagnosis in adult age may be unpredictable, and misdiagnosing either way may lead to unintended consequences.

**Conclusion:** The medical and ethical challenges when diagnosing FASD in young adults need to be taken into account when deciding on the resources required for a FASD clinic.

## FAMILIES LIVING WITH FASD

CHAIR: SUSAN FLEISHER

## 16

### European Birth Mother Support network - FASD

Philippa Williams

European Birth Mother Support network FASD

**Objectives:** *Brief History of the European Birth Mothers Network.* Presenting how the network is increasing understanding and support for birth mothers in Europe and decreasing the stigma that birth families may experience. Including a brief story of my personal journey as a birth mother, along with the growing numbers of birth mothers contacting us in Europe.

**Materials & Methods:** Presentation

**Result:** European Birth Mother Support Network – FASD taking part in conference, raising awareness and understanding

**Conclusion:** The more awareness is raised, the more it decreases stigma. We are aware and focused on the need for support for mothers.

17

**The shame can disappear, dare to ask for help**

Debby Kroon  
Birth mother, Netherlands

**Background:** I have a seven-year-old son with FAS. During my pregnancy, I was an alcoholic and continued drinking throughout the pregnancy. When my son was seven months old, I succeeded in stopping drinking. I also became aware then of the damage I had caused. From that moment, I was honest with the social workers and have done everything to make my son's life as worthwhile as possible. When my son was three years old, I had another child, a boy, and decided to leave my partner (their father). In the last few years, I have been solely responsible for bringing up and caring for the children (now I have a new partner). This has been a difficult period in my life, but also a time in which I could invest a lot in my children. Now I have regular contact with the FAS Foundation of the Netherlands, and they have put me in contact with journalists who want to know more about FAS and having a child with FAS.

**Conclusions:** My son is doing well, but one of the big problems in our daily life is the lack of knowledge among doctors, teachers, etc. Examples of this are the school doctors, the medical kindergarten, and personnel in special education (teachers, physiotherapists and speech therapists). Due to my openness over the fact that I am a mother who drank during her pregnancy, I hope to be able to help other people. My motto is that the shame can disappear, dare to ask for help, the child deserves it.

18

**Living and learning with Fetal Alcohol Syndrome**

Robert Yves Wybrecht  
First infant diagnosed with Fetal Alcohol Syndrome in the United States in 1973, FAS activist

**Objectives:** The goal of this presentation is to share how it has been growing up with FAS. It will include what works and doesn't work when living with, teaching, and employing a person with an FASD. Emphasis on early diagnosis will illustrate that greater success is achieved when diagnosis occurs in the pre-school years.

**Materials & Methods:** Rob will participate as a member of a panel which will include birth parents, adoptive parents and an adult with full FAS. He will share concrete tools that help him learn and then remember what he has learned.

**Results:** This presentation will give hope to both parents and professionals as well.

as researchers. With life long interventions and supports many individuals with an FASD can live productive lives.

**Conclusion:** *Living and Learning with Fetal Alcohol Syndrome* continues to be a life long challenge. Listening to an adult, diagnosed at birth, makes the research come alive, and will hopefully inspire new research in the areas of diagnosis and interventions, as well as prevention.

19

**Challenges of being a mother with FAS**

Lena Larsson, Norway

**Background:** Lena Larsson is a 35 year old Swedish/Norwegian woman with FAS. She is also the mother of a 9-year-old son. Lena will talk about her childhood in foster care and the many challenges of her life as an adult woman and mother. The challenges of running a home, the challenges of being a parent and set boundaries for her son and the challenges of social life. Lena will also discuss: the physical and mental health problems FAS gives her; and the effects of a diet free from gluten; milk and soy; and last but not least, what gives her the strength to cope with her situation.

**PARALLEL SESSION I.A.**

**DIFFICULTIES WITH DIAGNOSIS**

**CHAIR: ILONA AUTTI-RÄMÖ**

20

**Using facial analysis software to identify facial features of Fetal Alcohol Syndrome in newborn infants**

Ewan Gourlay<sup>1</sup>, Katrine Thorup<sup>1</sup>, Verity Monk<sup>1</sup>, Neil Aiton<sup>2</sup>

<sup>1</sup>Brighton & Sussex Medical School, Brighton, United Kingdom; <sup>2</sup>Brighton & Sussex University Hospitals, Brighton, United Kingdom

**Objectives:** Diagnosis of Fetal Alcohol Syndrome (FAS) is complex, with numerous competing diagnostic systems. All recent diagnostic systems require the presence of growth restriction, mental retardation and 3 characteristic facial features. Software developed at the University of Washington has been created to objectively analyse digital photographs, measuring for the unique triad of FAS facial features: small palpebral fissure length (PFL), thin upper lip and smooth philtrum. This software has

been validated in older children, but has not been used in neonates. We are unable to find neonatal normal reference ranges for measures except PFL. Early diagnosis in children has been associated with better outcomes. This study aims to determine the feasibility of using the facial analysis software to identify features associated with fetal alcohol exposure in normal neonates and if successful to develop normal reference ranges for Caucasian neonates.

**Materials & Methods:** Ethics approval and informed consent was obtained. Healthy Caucasian neonates were photographed according to a standardised protocol. Mothers were asked to fill out an anonymous lifestyle questionnaire including questions on alcohol consumption in pregnancy. Standard physical measurements of the baby were taken. PFL and upper lip circularity (LC) were measured using the software. Philtrum smoothness and LC was assessed on a 5 point likert scale using reference photos. Statistical analysis was performed using SPSS.

**Results:** 33 neonates were recruited. PFL was measurable in 24 photographs (72.7%). Mean PFL was 15.5mm (95% C.I 13.1 – 17.9mm). LC was measurable in 33 photographs (100%). Mean LC was 59.4 (95% C.I. 18.1 – 100.5). Median LC and philtrum smoothness Likert ranks were both 3. 4 neonates were assessed as having FAS type features according to Likert ranking including 2 with abstinent mothers. 7 mothers (21.2%) reported drinking alcohol during pregnancy.

**Conclusion:** It was possible to measure a full data set on just over ¾ of neonates, demonstrating the feasibility of this method at this age. Mean PFL from this pilot study was significantly below previous published reference ranges. Current Likert scale reference photos may not be appropriate for neonates. Further data collection is required for development of robust reference ranges using this method.

## 21

### **Difficulties in diagnosing adolescents and adults with FASD**

Jessica Wagner<sup>1</sup>, Hans-Ludwig Spohr<sup>1</sup>

<sup>1</sup>FASD-Center, Berlin, Charité university hospital, Berlin

**Objectives:** The diagnosis of FASD in adolescents and adults is often difficult due to missing data from childhood and lack of normative data. Therefore, the diagnosis of adults is more challenging than of children. Nevertheless, there is a growing demand for diagnosis in this population not only in Germany, which can be attributed to a growing awareness of FASD. In this study, diagnosis of adolescents and

adults were compared to investigate the differences and problems arising in the diagnostic process of FASD at different ages. Additionally, patients with FAS and other FASD-diagnoses were compared with respect to their neuropsychological outcome.

**Materials & Methods:** All patients were diagnosed at the FASD-center in Berlin. Subjects included 20 adolescents (ages 14-17, 11) and 20 adults (ages 18-29, 11) with fetal alcohol spectrum disorders. 19 patients were diagnosed as FAS, 21 patients as partial FAS, ARND or static encephalopathy (alcohol-exposed). FASD-diagnosis was based on the 4-digit diagnostic code (Astley, S. et al., 2004). A variety of standardized neuropsychological tests were administered to evaluate the CNS-score, including a verbal learning and memory test (VLMT), the developmental test of visual perception for adolescents and adults (DTVP-A), a word fluency test, a computer-based test battery to test attention and executive functioning (TAP) and the child-behavior checklist (CBCL). IQ-scores were available from earlier reports.

**Results:** Results indicated that the different age groups did not differ significantly with regard to their neuropsychological outcome. This shows that the same deficits can also be detected in older patients with consequences for daily living. Only 3 patients were able live on their own; most patients lived either in their foster family or in assisted living residences. In 95 % severe behavioural disorders were reported. Severe deficits in executive functioning occurred in 67, 5 %; in attention and visual perception in over 30 % and severe learning and memory problems were shown in 15 %. Further results will be presented in Barcelona.

**Conclusion:** In our center, we all have an increasing problem to deal with the diagnosis of adult patients without having clear diagnostic instruments at hand. The 4-digit diagnostic code is of limited use in adults and we have to increase our knowledge in this new population.

## 22

### **FASD multidisciplinary diagnostic clinic model in a rural setting and outcome of first 100 pediatric patients seen in clinic 10 years from diagnosis**

Hasu Rajani<sup>1</sup>, Brent Symes<sup>1</sup>, Audrey McFarlane<sup>2</sup>

<sup>1</sup>Edmonton, AB Canada; <sup>2</sup>Lakeland Centre for FASD, Cold Lake, AB Canada

**Objective:** To share the results of satisfaction of the diagnostic process, the value of diagnosis and the outcomes of the patients after 10 years past diagnosis from a rural multidisciplinary team. In Canada where there are large areas of sparsely populated regions the development of a Multidisciplinary clinic presents its

own unique challenges. In addition to the look back at these patients, an overview of the rural community based multidisciplinary team approach will be described.

**Materials & Methods:** We have visited the first 100 children who went through the diagnostic process from 2000 to 2003. A review was conducted of files and follow interviews with families was completed for 100 patients diagnosed at the Lakeland Centre for FASD.

**Results:** FASD diagnosis is a complex process requiring a multidisciplinary team. The review and interviews revealed some very interesting results: including where the individuals are today, how many completed school, trouble with the law, common psychological profiles, the value of the diagnosis, and whether the families were satisfied with the process of diagnosis/assessment.

**Conclusion:** The Lakeland Centre for FASD has developed a unique model that has sustained 12 years and we are eager to share our findings.

## 23

### **Drugs consumed by Roma, non-Roma and Latin-American female adolescents: comparing two Spanish areas**

Carmen Meneses<sup>1</sup>, Eugenia Gil<sup>2</sup>, Nuria Romo<sup>3</sup>

<sup>1</sup>Departamento de Sociología y Trabajo Social, Universidad P Comillas, Madrid, SPAIN;

<sup>2</sup>Departamento de Enfermería, Universidad de Sevilla, Sevilla. SPAIN; <sup>3</sup>Departamento de Antropología. Instituto Universitario de Estudios de la Mujer. Universidad de Granada, Granada. SPAIN

**Objectives:** National Surveys show high consumption of legal drugs in female adolescents as a group. This work describes and analyzes the drugs consumed by female adolescents of different ethnic groups (Roma host society, non-Roma in host society and Latin-American), what do you mean by “host society”? pointing out differences in two areas of Spain (Andalucía and Madrid).

**Materials & Methods:** We carried out a survey among secondary school students where the student had to identify herself as belonging to one ethnic group. The sample was constructed from this ethnic identification. The questionnaire was collected in different schools where there were many Roma and Latin-American adolescents. The survey had the approval of parents and school principals. Data were analysed by bivariate analysis with chi square and Student's *t* test. P-values smaller than 0.05 were considered statistically significant

**Results:** The sample consisted of 1,532 female adolescents, belonging to Roma (n=223), non-Roma

(n=862) and Latin-American ethnicity (n=447), with an average age of 15 years old. In the last year, 58% had drunk alcohol, without any difference by ethnicity; 35.8% got drunk in the last year, with a higher rate in non-Roma; 10.5% drank alone in the last year; 21.9% drank in the family context, and 48.2% outside; most Roma females drank with family, and the non-Roma and Latin-Americans drank more outside the family (p=0,000). About 15.6% of the girls smoked, this value being higher in the Roma (18.8%). About 9.8% smoked daily, and this number was higher among non-Roma girls (12.2%). 50,9% of the adolescents' parents smoked, being higher in Roma (64%) and non-Roma parents (61,6%); The mothers of non-Roma (27,3%) and Latin-American (23,5%) girls smoked more than the Roma girls' mother (15,8%). The boyfriends of Roma girls (45,4%) smoked more than in other groups (21.8% Latina, 31.6% non-Roma). Female adolescents used cannabis in the last year; there was no difference by ethnicity. The illegal drug consumption was smaller. Analgesics (22,5%) or tranquilizers (7,2%) were more frequently consumed by Latin-American females.

**Conclusions:** The drugs consumed by female adolescents were legal drugs. The cultural differences found were modeled on the parents and/or peer group of each ethnic group. Family cohesion is more important for Roma and alcohol use occurs in the family context. It is essential to address the health and development needs of adolescents to make a healthy transition to adulthood. Societies must tackle the factors that promote potentially harmful behaviors in relation to sex and ethnicity.

\*This work belongs to a National Project I+D+I, “Risk, Adolescents and ethnicity: comparing three Spanish areas” subsidized by the Ministerio de Ciencia e Innovación Ref.CSO2009-07732.

## 24

### **Evidence- and consensus-based guideline for the diagnosis of Fetal Alcohol Syndrome in Germany**

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<sup>1</sup>Department of Pediatric Neurology, Developmental Neurology and Social Pediatrics, Hauner Children's Hospital, Ludwig-Maximilians-University of Munich, Germany

**Objectives:** Fetal Alcohol Syndrome (FAS) is a very common and completely avoidable disease. FAS has severe consequences not only for the individual and its direct environment but also for the health and social system in Germany.

**Aims:** The first aim of the development of the German guideline was the determination of evidence-based and in practice easily applicable diagnostic criteria for the

identification of FAS in children and adolescents in Germany. With help of the defined diagnostic criteria FAS should be diagnosed and treated earlier, so secondary complications can be reduced. The second aim was to create awareness in the German society of the severe complications of intrauterine alcohol exposition in order to decrease the prevalence of alcohol consumption during pregnancy and diminish the incidence of FAS.

**Materials & Methods:** A steering group in Munich and a consensus group consisting of representatives of the German Federal Ministry of Health, the German Professional Societies of Pediatrics, Neuropediatrics, Social Pediatrics, Gynecology, Neonatology, Child and Adolescent Psychiatry, Addiction Research and Therapy, Addiction Medicine, Addiction Psychology, Midwife Sciences, Midwives, Doctors of the Public Health Service, of the Patient Support Group FASworld Germany and additional FAS experts have been established in 2011. The AWMF (Association of the scientific medical societies) was responsible for the methodological guidance. Systematic literature retrieval and determination of levels of evidence were conducted by the ÄZQ (Medical Center for Quality in Medicine).

**Results:** The methodological quality of the international and especially the German publications about the diagnostic criteria are rather poor. Most of the existing international guidelines for the diagnosis of FAS are consensus- but not strictly evidence-based. Evidence- and consensus-based criteria for the diagnosis of FAS were evaluated and established for Germany. The methodological process is described. The implication of the guideline is performed by algorithms for pediatricians and general practitioners for the referral of children with suspected FAS. Another algorithm including the defined diagnostic criteria of FAS has been developed for experts

**Conclusion:** There is great need for a standardized, multidisciplinary, quality assured and implementable prevention of FAS in Germany. The first step was the development of an evidence- and consensus-based diagnostic guideline for children with FAS in Germany.

Larisa Skitnevskaya<sup>2</sup>, Elena Volkova<sup>2</sup>, Tatiana Balachova<sup>1</sup>

<sup>1</sup>University of Oklahoma Health Center, Oklahoma City, USA, <sup>2</sup>Nizhny Novgorod State Pedagogical University, Nizhny Novgorod, Russia

**Objectives:** Alcohol consumption is one of the most pressing medical and social problems in Russia. This study is part of an ongoing clinical trial.. One of the goals of the study is to identify social and psychological factors have an impact on alcohol consumption in childbearing women.

- 1) To describe socio-demographic characteristics of childbearing age women who drink at risk
- 2) To study some personality characteristics of women who drink at risk
- 3) Identify if partner's alcohol consumption affects women's alcohol consumption levels
- 4) Propose a socio-psychological model of at-risk drinking among childbearing age women.

**Materials & Methods:** The studies used self-report measures of alcohol consumption. Self-report measures of alcohol consumption are well-supported when used in healthcare settings (Babor et al., 2000; Fleming & Manwell, 1999; Sobell & Sobell, 2003). The survey included demographic questions (living environment, marital status, education, employment, combined yearly income per person in the family, age, ethnicity), alcohol consumption measures, identifying partners' alcohol consumption and women's' personality characteristics.

**Results:** A subset of non-pregnant women recruited for the study in the Nizhny Novgorod Region (N=360) were included in this analysis. Analysis of socio-demographic characteristics of women showed that some characteristics including residence (rural vs. urban), age, and having a child/children had an effect on women's consumption. Women living in small towns, between 23 to 44 years of age were more likely to drink at risk. Women who have a child/children were less likely to drink at-risk. Women who reported at-risk alcohol use reported more intense emotions, emotional instability, lower self-control of behaviors, and expressiveness. The level and frequency of alcohol consumption in women were associated with the characteristics of "introversion-extraversion" Risky alcohol use in women was associated with women's higher perceptions of alcohol use by others including alcohol use by spouses, friends, and girlfriends. These perceptions significantly affected women's own consumption (p <0.01, p <0.05).

**Conclusions:** Socio-psychological factors affect women's alcohol consumption level. A model of alcohol use among women has been proposed to

## PARALLEL SESSION I.B.

### CHARACTERIZATION OF WOMEN WHO DRINK

CHAIR: MIREIA JANÉ

25

**A socio-psychological model of risky drinking among childbearing age women in the Nizhny Novgorod Region in Russia**

increase understanding of at-risk alcohol use among childbearing age women.

## 26

### **Patterns of alcohol use among women of childbearing years in Canada: Implications for FASD prevention**

Nancy Poole<sup>1,2</sup>, Gerald Thomas<sup>3</sup>, Lorraine Greaves<sup>1</sup>, Lauren Bialystok<sup>1</sup>, Colleen Dell<sup>3</sup>, Anne-Marie Bedard<sup>4</sup>, Heather Caughey<sup>4</sup>

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**Objectives:** Alcohol use in pregnancy arises against a complicated backdrop of social and economic influences on women's drinking patterns throughout the childbearing years. The objective of this study was to analyze population-level health data and trends and to synthesize academic literature on influences on women's drinking in order to describe the factors that influence women's patterns of alcohol use before and during pregnancy.

**Materials & Methods:** Available regional and national survey data, including the Canadian Community Health Survey (2003, 2005, 2007/08 & 2009/10) and the Canadian Maternity Experiences Survey (MES) (2006-07), were used to explore trends and patterns in alcohol consumption among women in their childbearing years (ages 15-44) from 1989 to 2010. Findings from a review of academic and grey literatures were used to contextualize the analysis.

**Results:** Both occasional and regular risky drinking by women of childbearing ages is a large and growing concern in Canada. Further, the distribution of alcohol-related risk in women ages clearly embodies the prevention paradox (i.e., a large number of drinkers exposed to a moderate risk). The proportion of women who reported drinking alcohol during pregnancy was 10.5%, compared with 62.4% of women who reported drinking alcohol during the three months prior to pregnancy. Interestingly, alcohol use during pregnancy increased as age and income of the woman increases.

**Conclusion:** This study suggests that there are three groups of women of particular interest in efforts to reduce the harms and costs associated with alcohol use: underage girls, occasional risky drinkers who experience increased risk of acute harms, and regular risky drinkers who incur greater risk of both acute and chronic harms. Efforts to reduce alcohol related risk must necessarily include both policy interventions to lower consumption across the population and

programmatic interventions to address the needs of girls and women who drink in high-risk patterns. Implications of these findings for multilevel FASD prevention efforts will be discussed.

## 27

### **Preventing FASD in Catalonia: From raising awareness to promoting antenatal professionals' intervention**

Lidia Segura, Ana Ibar, Mireia Jane i Joan Colom

Public Health Agency of Catalonia *on behalf of the working team of the alcohol and drugs free pregnancies programme*

**Background:** The consumption of alcohol and drugs is one of the main causes of morbidity-mortality in developed countries. The number of women who consume alcohol and drugs at levels which are considered unhealthy has risen and a significant number continue to do so during pregnancy. Since many pregnancies are unplanned, many foetuses may have been exposed to drugs before the pregnancy has been confirmed. The consumption of alcohol and drugs is directly related with a series of alterations to women's reproductive health and with adverse effects on gestation and the development of the baby. The most severe forms of harm are produced at high doses but also at lower doses, and particularly during the first trimester of the pregnancy, there is an increased risk of miscarriage, premature birth, etc. The harm caused by pre-natal exposure such as the disorders of the foetal alcohol spectrum (TEAF) which "presumably" affect 1% of the population of Europe (5 million people), can be completely prevented with an adequate intervention.

**Aims:** In Catalonia, the "Alcohol and Drug Free Pregnancy" programme is set to be launched next year, seeking to raise the awareness of the general population regarding the harm associated with the consumption of alcohol during pregnancy, to train professionals with regard to how to carry out early detection and brief interventions in order to reduce the number of pregnancies and newborns exposed.

**Materials & Methods:** The programme, which is inspired by the already existing Smoke Free Pregnancy Programme and which has been agreed upon by a specific work group, consists of an implantation protocol, a guide with recommended courses of action for professionals and information leaflets for the general public. Its implementation includes an exhaustive evaluation protocol which includes a before and after study of the attitudes, behaviour and knowledge of professionals and of the general public and an evaluation of the effectiveness of the intervention by means of biological markers. We will

present the main lines of action proposed and the current baseline situation.

## 28

### Alcohol consumption during pregnancy and risk factors

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**Objectives:** 1) to screen alcohol consumption in a population of pregnant women attending an antenatal clinic in a major hospital in Rome. 2) to identify risk factors for alcohol consumption in pregnancy.

**Materials & Methods:** a screening system has been established in an antenatal clinic in Policlinico Umberto I in Rome. Each woman attending the clinic was asked to participate to the survey. Through a semi-structured interview they were asked about their alcohol consumption before and during pregnancy, according to a quantity-frequency method. The T-ACE question about tolerance was also embedded in the questionnaire.

**Results:** 991 pregnant women, aged from 17 to 47 (mean=32,3; SD=5,7) were screened during a 18 months period. Among them 73,2% were Italian. The majority (67,3%) was interviewed during the third trimester of pregnancy. Participation was voluntary and 100% of women accepted it. Main results are presented divided by trimesters of pregnancy. While 68,6% drank before pregnancy, 33,9% were still drinking during the first trimester, 36,4 during the second one and 38,7 during the third; 2,3%, 2,1% and 1.3% drank more than one drink per occasion, respectively during the first, the second and the third trimester. Women were also asked to answer to the question “How many drinks does it take to make you feel high?”, as stated in the T-ACE questionnaire: 55,6% scored positive (more than two drinks) during the first trimester, 40,5% during the second and 38,5% during the third one. Frequency of consumption decreased by trimester: from 13,5% drinking at least 4 times a week in the first trimester to 6,4% in the second and 3,6% in the third one. The most recurrent risk factors, significantly correlated with a number of variables measuring drinking behaviour (i.e. drinking more than one drink per occasion, positive score to the tolerance question, number of alcoholic beverages consumed) were: being younger (under 30), having an unplanned pregnancy, being unemployed,

having a lower educational qualification, being single and being Italian compared to foreigners.

**Conclusions:** a significant number of women keep on drinking during pregnancy. Their drinking behaviour put their babies at risk for FASD, as resulting also from the high percentage of women scoring positive to the tolerance question. Implications for prevention include targeting young women, recommending the adoption of birth control methods, informing that even small quantities can affect the baby as there is not a safe and firm threshold.

## 29

### Features of maternal alcohol consumption and Fetal Alcohol Syndrome in the Sakha Republic

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**Objectives:** This investigation’s aim is to study features of maternal consumption of alcohol and Fetal Alcohol Syndrome (FAS) in the Sakha Republic (Yakutia, Russia).

**Materials & Methods:** Quality and rate of Maternal Alcohol Consumption observation in 11 regions (uluses) by means of the interviews, physical assessment and study of case histories according to CDC recommendations (2004). Incidence and clinical features of FAS study in 13 uluses, orphanages and National Medical Center. 26 caucasian, 18 sakha and 12 native (evens, evenks) with FAS aged from 40 postmenstrual weeks to 7 years detailed observation by means of 4-digit Diagnostic Code, routine and age-dependent developmental neurological assessment, brain ultrasonography, MRI, Denver test and Zhurba Scale.

**Results:** Analysis of maternal alcohol consumption shows that from 0.7 to 6.1% of pregnant women in different uluses used alcohol, and from 0.2 to 4.5% drank heavily. There are no significant differences in maternal alcohol consumption in different ethnical groups. Incidence of FAS varies from 0.06 to 0.9% in child population of different uluses. We haven't found significant correlation between maternal alcohol consumption level and incidence of FAS in the uluses ( $r = 0.559$ ;  $p = 0.093$ ). Incidence of FAS varies from 0.3% in National Medical Center to 11.3–34.0% in orphanages. Our investigation demonstrates that native babies with FAS were born pre-term much oftener than

sakha infants ( $\chi^2 = 4.54$ ;  $p = 0.033$ ). Sakha children with FAS have smaller birth weight and height than caucasian ones ( $\chi^2 = 4.35$ – $5.90$ ;  $p = 0.037$ – $0.015$ ). Clinical assessment and neurovisualization show that caucasian patients have ptosis and ventriculodilatation significantly more frequently than sakha babies ( $\chi^2 = 5.11$ – $5.97$ ;  $p = 0.024$ – $0.015$ ); sakha infants have much more frequently muscle tone deviations, inborn heart defects, visual nerve atrophy and subarachnoid space dilatation than other ones ( $\chi^2 = 11.55$ – $4.10$ ;  $p = 0.0007$ – $0.043$ ). Native children demonstrate better quality of social adaptation than caucasian babies ( $\chi^2 = 10.26$ – $4.10$ ;  $p = 0.0014$ ).

**Conclusion:** Our investigation shows the necessity of taking into account ethnical and regional features of maternal alcohol consumption and FAS manifestation in epidemiological and clinical study.

### 30

#### Recognition of alcohol-use disorders in pregnant women: a population-based cohort study 1985-2006

Colleen O'Leary<sup>1</sup>, Jane Halliday<sup>2</sup>, Anne Bartu<sup>3</sup>, Heather D'Antoine<sup>4</sup>, Carol Bower<sup>5</sup>

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**Objectives:** We examined the trends and extent of under-reporting of maternal alcohol-use disorders during pregnancy using Western Australian linked health, mental health, and drug and alcohol data (1985-2006).

**Materials & Methods:** Women with an International Classification of Diseases 9/10 alcohol-related diagnosis, indicating heavy alcohol consumption, recorded on population-based health datasets (1985-2006) were identified through the Western Australian data-linkage system. These mothers and all their children whose birth was recorded on the Western Australian Midwives Notification System, a statutory notification system, comprised the 'exposed' cohort (Mothers  $n=8422$ ; Children  $n=21,336$ ). A randomly selected cohort of mothers without an alcohol-related diagnosis was frequency matched (on maternal age, year of birth of offspring, Aboriginal status) with exposed mothers. These mothers and their children comprised the comparison cohort (Mothers  $n=41,984$ ; Children  $n=54,963$ ). Children with Fetal Alcohol

Syndrome (FAS) were identified through linkage with the Western Australian Register of Developmental Anomalies ( $n=114$ ).

**Results:** The proportion of Aboriginal mothers in Western Australia with an alcohol diagnosis (23.1%) is 10-times greater than for non-Aboriginal mothers (2.3%). Three-quarters of the women had an alcohol diagnosis indicating acute alcohol intoxication; however only a small proportion had an ICD code indicating counselling/rehabilitation. There have been steep increases in the proportion of births where the mother had an alcohol diagnosis recorded on health datasets during pregnancy, particularly for Aboriginal births. There was evidence that maternal alcohol-use disorders during pregnancy were not well detected, with over two-thirds (70%) of the mothers of children diagnosed with FAS not having an alcohol diagnosis recorded during pregnancy.

**Conclusions:** Maternal alcohol exposure during pregnancy is significantly under-ascertained. Heavy prenatal alcohol exposure increases the risk of fetal effects so assessment and recording of alcohol use should be routinely undertaken in maternity and other health settings. Brief interventions, counselling, and rehabilitation should be provided where indicated.

## PARALLEL SESSION I.C.

### INTERVENTIONS FOR FASD

CHAIR: MIGUEL DEL CAMPO

### 31

#### Toward enhanced teacher preparation for meeting the needs of students with FASD: A comparison of two professional learning approaches in Alberta, Canada

Jacqueline Pei, Cheryl Poth, Stephanie Hayes

Department of Educational Psychology, University of Alberta, Edmonton, Alberta, Canada

**Objectives:** This presentation compares two approaches to enhancing teacher preparedness for meeting the individualized needs of students with FASD in the classroom. Students with FASD experience a wide range of serious and lifelong challenges including cognitive, behavioural, and academic difficulties. Although teachers and educational assistants have identified the need for opportunities for them to collaboratively gain knowledge and skills related to FASD, there is a paucity of research to guide how to go about structuring these professional learning opportunities.



**Materials & Methods:** Two approaches were undertaken through partnering with local school boards. Common across both approaches was the identification of key contacts who contributed to the planning and recruitment of teachers and educational assistants. Whereas one approach involved a school-wide initiative the other was based out of one school. For the latter, we conducted three sessions whereas the former involved four sessions during the winter term 2012. Altogether, 30 participants were involved and data was collected using four sources to assess the impact and document the process: field notes, meeting summaries, focus groups, and a final survey. Each approach was first analyzed separately using constant comparison inductive procedures and then a cross comparison of the approaches was conducted.

**Results:** We have completed the separate analysis and the cross analysis is currently ongoing. Preliminary results highlight the positive impact a collaborative approach has on supporting the individualized needs of participants and reducing their feelings of isolation. Specifically, participants generated tools that they then used in their classrooms and made available publically. Following the final session, participants reported feeling supported and that the experience of working collaboratively with others who have a similar background increased their confidence in their abilities as educators, and advocates for the needs of their students with FASD.

**Conclusion:** In contrast to traditional models of professional learning where the experience is facilitated, this project sought to compare two approaches to a more “grassroots” collaborative initiative. Working together, researchers and educators had an opportunity to discuss and brainstorm, provide feedback about what is helpful and relevant to classroom-practice, and generate tools to support their work with students with FASD.

### 32

#### The Fetal Alcohol Questionnaire (FASQ)

Reinhold Feldmann

Department of Pediatrics, University Hospital Muenster

**Objective:** The Fetal Alcohol Syndrome (FAS) is diagnosed throughout measuring physical issues as facial stigmata, growth, head circumference, CNS abnormalities and, if data are available, prenatal alcohol exposure. There are few diagnostic instruments measuring the behavioral phenotype of FAS. This seems to be a diagnostic flaw as children with FAS (and their environment) suffer much more from the

burdening behavioral problems of the FAS children rather from their facial alterations.

**Materials & Methods:** We collected 100 typical parental reports on behavior and social and emotional problems in their children with FAS. Factor analysis reduced the data to two behavioral factors yielding a questionnaire (FASQ) that consists of 38 items. The questionnaire was administered to parents of children with FAS, Autism, Attachment disorder, and to parents of healthy children.

**Results:** Children with FAS scored significantly higher than children with no or other disorders. Scores showed a typical behavioral phenotype in FAS (including lack of social distance, careless risk behavior, no concept of time or money, would go with anyone, easily talked into things) that was not reported for other disorders.

**Conclusions:** The FASQ may contribute to a diagnostic process that is not restricted to body measures. This may be true particularly in case of children with FAS who suffer from severe consequences of the prenatal alcohol exposure but show minor stigmata only, and who, thus, still obtain an insufficient diagnosis, if any.

### 33

#### Use of visual methods for capturing the multifaceted and complex nature of work with individuals with FASD: Practical guidelines for weaving quilting and photography

Jenelle Job<sup>1</sup>, Teresa O’Riordan<sup>2</sup>, Lin Taylor<sup>3</sup>, David St. Arnault<sup>1</sup>, Cheryl Poth<sup>1</sup>, Jacqueline Pei<sup>1</sup>

<sup>1</sup>Department of Educational Psychology, University of Alberta, Edmonton, Alberta, Canada; <sup>2</sup>Northwest Central Alberta FASD Services Network, Edmonton, Alberta, Canada; <sup>3</sup>Edmonton, Alberta, Canada

**Objectives:** This presentation reports a study using visual methods with program personnel providing services for individuals with Fetal Alcohol Spectrum Disorders (FASD). Through detailing our experiences, we will provide practical guidelines for implementing quilting and photography as appropriate methods for capturing the multifaceted and complex nature of work with individuals with FASDs. This project extends the notion: “*Our lives are like quilts - bits and pieces, joy and sorrow, stitched with love*” Author Unknown.

**Materials & Methods:** Visual methods within the field of qualitative research have been gaining momentum because of its usefulness of documenting and representing the social world. The result has been improved understanding of participant experiences and relationships (Banks, 2001; Rose, 2001). Two such visual methods are *quilting* and *photography*—innovative techniques that allow the researcher to

integrate participants' stories into a meaningful collective experience (Koelsch, 2008). Specifically, this research embedded the process of engaging in quilting as a means for service providers to relay their programmatic experiences working with woman engaged in high-risk behavior to prevent future births of children prenatally exposed to alcohol and drugs. Photographs of this exercise were taken as a means of documenting the process.

**Results:** Constant comparison and inductive qualitative analysis across methods reveals participants' emotion, candor, and passion, emphasizing their commitment to the care and advocacy of at-risk women and children. The analysis of quilting squares ( $n = 46$ ) and photographs revealed six themes: healing, love, connectedness, grief and pain, growth, and hope and vision. Despite the challenges experienced in working with this specialized population, an overall message of optimism was apparent. This demonstrated participants' belief in the potential for change and importance of their work. Key factors and related research and practice implications will be discussed.

**Conclusions:** Used in combination with focus groups, visual methods were employed to allow for the triangulation of data sources in order to generate a comprehensive and shared understanding related to best practices in FASD planning and service delivery from the perspective of frontline workers.

### 34

#### **A gluten-free casein-free diet can be beneficial for persons with FASD**

Diane Black

FAS Foundation of the Netherlands, European FASD Alliance

**Objectives:** Gluten, the major protein found in wheat, rye, oats, and barley, is increasingly being linked with various neurological and psychiatric disorders. Research reports have shown a relation with ataxia, epilepsy, autism, schizophrenia and elderly dementia, and various trials have shown that a diet free of both gluten and casein, the major milk protein, is beneficial in many cases. A number of parents of children with a FASD have found that the gluten-free casein-free diet improves physical health, behavior, and development of their children. However, no properly designed studies have been carried out to test the wider applicability of this diet for persons with FASD. Here, I report a small pilot study, based on parental reports before and after stabilization on the GFCF diet.

**Materials & Methods:** Parents were asked to fill in the FASQ based on the child's behavior before beginning the diet, and after a period of stabilization on

the diet. The FASQ is a questionnaire developed by Reinhold Feldmann of the University Hospital of Muenster to define the behavioral phenotype of FASD.

**Results:** Scores on the FASQ diminished significantly when the child was on the GFCF diet, showing an improvement in behavior and learning.

**Conclusions:** The GFCF diet appeared to be beneficial for the children in the study group. It should, however, be recognized that the small study group were self-designated, and that the evaluation of behavior before going on diet was based on recall, in some cases, of the situation years previously. Based on the promising results of this small study, it would be desirable to implement such a study in a larger, randomly assigned group of children with FASD, to see if the results can be generalized.

## WHAT IS HAPPENING IN MY COUNTRY? II

### CHAIR: KATARINA WITGARD

### 35

#### **What is happening in my country? Germany**

Gisela Michalowski

FASD Deutschland e.V.

**Background:** In September 2011, FASworld changed its name and became FASD Deutschland e.V. We now have our own logo and our own name. FASD Germany e.V is a non-profit parent support group. We help educate people about FASD - the causes, how it could be eliminated and how to deal with people who have FASD. A wealth of information can be found on our web site which is well-visited. We give lectures, organize workshops and pass on expert knowledge e.g. the latest scientific findings from around the world as well as our own experience. In addition, we run a closed online support group where members really can find support - here they find answers to specific questions and problems relating to FASD and of course moral support - there is always someone ready to listen and who is willing and able to help. This group has in turn led to the formation of regional support groups throughout Germany in which people really help one another - it's not just about moral support, practical help plays an important role too. The Federal Ministry of Health - in particular, the Federal Drug Commission - has supported us since 2011. This is a great help and contributed to the success of the last two symposia. 2011 was the first year in which we were able to publish symposium proceedings: FASD 2011 facets of a syndrome. Many professionals, including members of FASD Germany, are working on guidelines to be implemented for making the diagnosis of FASD. Here

too it was Mrs. Dyckmans, the Federal Drug Commissioner, who initiated this commission. Members of the executive board of FASD wrote a guide on how to deal with people with FASD. Far too few people are knowledgeable about FASD and so there is a great need to educate people in Germany and promote awareness about FASD among professionals and the general public alike. Schools must also take action and inform pupils about the life-long consequences caused by alcohol abuse during pregnancy. In Germany there are numerous problems related to young people and adults with FASD in the field of education and when seeking employment. The problems of children affected by FASD become obvious at school. As these youngsters become adults they want to be independent, they want to have a job and yet desperately need help and support in shaping their daily lives. Unfortunately, they are too often deprived of this help because they are judged purely by appearance and without knowledge of FASD their handicap is simply not recognized.

### 36

#### What is happening in my country? -Israel

Yehuda Senecky

Child Development and Rehabilitation Institute, Schneider Children's Hospital of Israel, Kaplan 14 St', Petah Tikva, Israel

**Objectives:** In our previous searches we revealed that alcohol consumption is frequent among pregnant Israeli women. We found that lack of knowledge regarding alcohol damage and risk and about FASD extends to physicians and other medical staff who attend women during the pregnancy.

**Materials & Methods:** Over the last two years, we concentrated a lot of effort to stimulate interest and spread knowledge among print and electronic media. We have written articles in professional magazines and we held the first conference of its kind in Israel on the topic of FASD.

**Results:** Information and knowledge about the risk of alcohol consumption during pregnancy and the potential damage caused to the future newborn are spreading slowly but steadily.

**Conclusion:** In Israel improved educational programs on the risk of alcohol consumption during pregnancy are needed for both professionals and the general public in conjunction with legislations steps. We work in close cooperation with the Anti-Drug and Alcohol Authority of Israel and get great support.

### 37

#### What is going on in Finland?

Ilona Autti-Rämö

Research Professor, Chief of Health Research, The Social Insurance Institution, Finland

**Objectives:** The focus of this presentation is to summarize the current attempts in Finland to minimize.

**Materials & Methods:** New initiatives to change legislation that could have an effect on

1) Alcohol availability,

2) Alcohol advertising, and,

3) Treatment of pregnant women with alcohol abuse are currently in progress and under debate. The initiatives were started by the Ministry of Social and Health Affairs and will be presented shortly.

**Results:** The moral values of society and its responsibilities to protect the unborn and the offspring are emphasized by the health and social services authorities. The public debate is centered both on securing the health of the unborn baby and children in general and on ensuring the rights of the public to make lifestyle choices. However, a gradual change towards a more favourable attitude to restrictions can be observed among the public, especially with regard to the content of alcohol advertising and partly also to alcohol availability. Commercial and industrial organizations, however, oppose the changes in legislation. They also see themselves as having an important economic impact on society and underestimate alcohol related health problems. The proposed law on the forced treatment of pregnant women with alcohol problems has raised a lot of criticism, mainly due to the lack of voluntary treatment options. The updated situation as of October 2012 will be summarized at the conference.

**Conclusion:** In Finland, several initiatives are currently in progress that could have a marked effect on alcohol availability and consumption especially in young adults. Their potential to lead to statutory restrictions remains to be seen.

### 38

#### Canadian FASD prevention programs: results of a national environmental scan

Jessica Moffatt, Egon Jonsson

Institute of Health Economics and Department of Medicine, University of Alberta

**Objectives:** Considerable progress has been made to understand Fetal Alcohol Spectrum Disorder(FASD) in

Canada; however, much work is needed in regards to prevention.

The objective of this study:

1) document what initiatives are occurring in across Canada to prevent FASD; and 2) document the level of formal evaluation occurring within preventative initiatives.

**Materials & Methods:** An environmental scan was conducted to capture the FASD preventative programs occurring across Canada. Three online directories were searched to establish an initial list of stakeholders, with snowball sampling used to connect to any additional stakeholders not captured within these databases. Each stakeholder was sent a brief email questionnaire, and stakeholders from each provincial government received a follow-up telephone call to verify information captured through these surveys.

**Results:** Provinces and territories of Canada differ greatly in their level of activity in FASD prevention. In particular, gaps were identified in Québec and the Atlantic provinces, where there are few programs that specifically address FASD. Programs also vary widely in their approach, target audience, scale and scope. Most prevention initiatives are aimed solely at women and do not address the supportive role that male partners, family members and the wider community may play in preventing FASD. Few, if any, programs address the specific needs of immigrants, particularly women from countries in which public awareness of FASD is low. The environmental scan showed that an overwhelming majority of the FASD-prevention programs currently practiced in Canada have never undergone formal evaluation.

**Conclusion:** Many innovative initiatives are occurring across Canada to prevent FASD; however there remains wide variation in the scope, size, and organization of prevention programs across the country.

## 39

### Developing policy for FASD in Scotland

Maggie Watts

FASD Co-ordinator for Scotland, Child and Maternal Health Division, Children and Families Directorate, The Scottish Government, Edinburgh, UK

**Objectives:** The appointment of a national coordinator for FASD was made by the Scottish Government in January 2010. The stated aim of the post is to lead on the development of the FASD strategy in Scotland. Its objectives include working across government and other agencies to embed FASD in emerging and existing policies, driving forward improvements in the

prevention of FASD, encouraging surveillance and supporting screening approaches, promoting the treatment of FASD and working with the voluntary sector to enhance support for families.

**Materials & Methods:** The post is part-time and is supported by a Policy Officer in the Scottish Government. A governmental working group, incorporating officers from teams for alcohol, drugs, justice, children and young people and communications, and including the national agencies for health promotion and health information has been established. This group has developed an action plan which it is now implementing.

**Results:** After eighteen months we are beginning to see some success. Awareness raising events have been supported across the Government departments and at a range of events across Scotland. These events have been developed by local groups including alcohol and drug partnerships, child protection committees, voluntary sector agencies for children and for alcohol related harm, and adoption and fostering groups. There are the beginnings of a greater understanding of the harm associated with maternal drinking and that efforts on prevention must be increased.

**Conclusion:** Developing a strategy to address fetal alcohol harm has presented huge challenges. Working across so many different sectors both within and outside of Government requires considerable time, effort and patience. Whilst there has been funding allocated to the co-ordinator post and to support a voluntary surveillance programme within paediatric services, there is no specific funding stream for wider FASD work, so the challenge of working within existing resources has been ever-present. The next steps will include engagement across social care and education sectors to raise awareness, review practice and endeavour to incorporate prevention of fetal alcohol harm and the management of disability associated with FASD into everyday practice.

## 40

### What is happening in my country?

Magdalena Borkowska

The State Agency for Prevention of Alcohol Related Problems, Warsaw, Poland

**Objectives:** Prenatal exposure to alcohol is a leading preventable cause of the birth defects, which can include physical, mental, behavioral and or learning disabilities with possible lifelong complications. Unfortunately many of Polish women are not aware of that and according to data from 2009, 14% of all young women and 29% of those who have been drinking in

the past 12 months, have been drinking alcohol during pregnancy. The goal of PARPA is to increase social awareness in the issue of FASD.

**Materials & Methods:** The ways of sharing the information of FASD by social events, campaigns, educational programs or publications, and also by giving the assistance of experts to all the groups involved in the topic. PARPA is expanding the knowledge by conducting and participating in the international projects.

**Results:** Research on FASD issue will increase the knowledge, the social awareness and will lead to better prevention. During the current year, the Training and Diagnosing Center will start its work in The Child St. Louis Hospital in Cracow.

**Conclusion:** What PARPA is planning to obtain is the information about the prevalence of FASD in Poland among children (7-9 years old) and gain the most productive tool for diagnosing children with FASD. Moreover, we are planning to conduct second edition of nationwide education campaign “Pregnancy With No Alcohol”.

#### 41

**Case report of a woman consuming alcohol during pregnancy and the support given by the Stockholm County and Health Services: lessons of failures and success!**

Ihsan Sarman<sup>1</sup>, Asa Magnusson<sup>2</sup>, Hanna Eklund<sup>2</sup>

<sup>1</sup>Sachsska Children Hospital in Stockholm; <sup>2</sup>Antenatal Care Unit for drug dependent women in Stockholm

**Background:** A 26 year old women, encounters the delivery unit, for premature rupture of membranes (PROM). She admits drinking issues and use of drugs. She has not attended the regular antenatal care. Ultrasonic examination reveals a foetus corresponding to 25<sup>th</sup> weeks of gestation in accordance with the menstrual date. No PROM is diagnosed. Despite the attempt to make her stay, the woman leaves the hospital. Social worker comes in contact with her a week later. The woman explains that she is not using drugs regularly, but that she had a relapse with an intake of “some glass of wine”. She intended to go through with an abortion at 16<sup>th</sup> weeks but regret to undergo a late abortion. She already had a child in foster care. First antenatal visit a month later, at a specialist antenatal care for pregnant women with addiction problems in Stockholm County is arranged. She describes problems with lack of energy since long time. She has difficult to remember how much alcohol she consumed.

**Materials & Methods:** AUDIT reveals 25 points and Time Line Follow Back shows consumption of over 10

drinks on the same occasion at least once last month. She admits previous treatment with Disulfiram. The work at the unit focuses on weekly contact with the midwife, drug tests, treatment with B-vitamin injections, and contact with social welfare authorities, (SWA). The drug tests showed that she had continued to consume alcohol. The antenatal care unit applied for coercion care in SWA for treatment, resulting in daily alcohol test (breathalyse) at the SWA, which all were negative. However, the blood tests at the antenatal clinic show positive results on Phosphatidyl Ethanol (PETH). The patient and SWA decide that the child should be taken care off by a foster family after the delivery.

**Results:** The delivery is uneventful at full time with normal somatic proportions. The birth and the foster mother both stay at the maternity the first two days taking care for the baby. The girl has no external traits of FAS but shows difficulties in self regulation after a week. The birth mother is given contraceptive implant for the next 3 years.

**Conclusion:** Based on a real life story we illustrate different problems in our country when treating women with alcohol dependency during pregnancy. Questions concerning diagnostic, legislation and health care are central issues to face. Moreover it is important to understand specific neuropsychological problems alcohol dependent woman may bear.

## PLENARY SESSION IV

### BIOCHEMISTRY AND ANIMAL STUDIES

CHAIRS: RAFAEL DE LA TORRE AND AURELIO LUNA

#### 42

**Determination of maternal-fetal biomarkers of prenatal exposure to ethanol**

O Garcia-Algar<sup>1</sup>, X Joya<sup>1</sup>, S Pichini<sup>2</sup>

<sup>1</sup>URIE Group, Hospital del Mar Research Institute-IMIM-Parc de Salut Mar, Barcelona, Spain; <sup>2</sup>Drug Research and Evaluation Department, Istituto Superiore di Sanità, Rome, Italy

**Background:** The deleterious effects exerted by prenatal ethanol exposure include physical, mental, behavioural and/or learning disabilities that are included in the term fetal alcohol spectrum disorder (FASD).

**Objectives:** Assessment of exposure to ethanol at both prenatal and postnatal stages is essential for early prevention and intervention. Since pregnant women

tend to underreport alcohol drinking by questionnaires, a number of biological markers have been proposed and evaluated for their capability to highlight gestational drinking behaviour.

**Materials & Methods:** These biomarkers include classical biomarkers (albeit indirect) of alcohol-induced pathology (mean corpuscular volume (MCV), gamma glutamyltransferase (GGT), aspartate aminotransferase (AST) and alanine aminotransferase (ALT)) acetaldehyde-derived conjugates, and finally derivatives of nonoxidative ethanol metabolism (fatty acid ethyl esters (FAEEs), ethyl glucuronide (EtG), ethyl sulphate (EtS) and phosphatidylethanol (PEth)). Since ethanol itself and acetaldehyde are only measured few hours after ethanol intake in conventional matrices such as blood, urine and sweat, they are only useful to detect recent ethanol exposure. In the past few years, the non-oxidative ethanol metabolites have received increasing attention because of their specificity and in some case wide time-window of detection in non-conventional matrices from the pregnant mother (oral fluid and hair) and fetus-newborn (neonatal hair, meconium, placenta and umbilical cord).

**Conclusions:** This presentation reviews the markers of ethanol consumption during pregnancy and related prenatal exposure. In addition, clinical toxicological applications of these procedures are presented and discussed.

### 43

#### The use of animal models for study Fetal Alcohol Spectrum Disorders (FASD) and the neuroteratogenic effects of alcohol

Consuelo Guerri

Prince Felipe Research Center, Avda Eduardo Primo Valencia, Spain

**Objectives:** Although studies in humans have been very important in identifying the spectrum of disorders which cause the consumption of alcohol during pregnancy, the use of animal models have been critical for addressing the mechanisms of the actions of ethanol during fetal development and to demonstrate the teratogenic effects of ethanol.

**Results:** Neurodevelopmental damage, as a result of prenatal alcohol exposure is a significant health problem. Studies in animal and in neural cell culture have also provided evidence of the vulnerability of the central nervous system to the effects of ethanol. These studies revealed that ethanol interferes with important ontogenetic stages of the mammalian brain, and that the levels of ethanol reaching the foetal brain, and the developmental timing of ethanol exposure are

important determinants of the specific brain structures affected and the resulting degree of damage. The *in vitro* generation of neural cells from human embryonic stem cells has provided new insights into the effects of ethanol on early human embryogenesis and the generation of neuroprogenitors. These findings support the conclusion that alcohol acts by different mechanisms depending on the dose, pattern of exposure, and timing of exposure relative to fetal development. Experimental models have been also used to identify structural damage to specific brain regions and the neural pathways that are responsible for many of these functional/behavioral deficits. Most of the neurobehavioral deficits identified in children with FASD have been documented in animal studies with a variety of models. Researchers now are exploiting this knowledge to develop screening tools for prenatal alcohol exposure injury by testing for specific functional deficits. Finally, a number of promising approaches to achieve neuroprotection are now under investigation, including the use of retinoids, antioxidants, neuromodulatory compounds, peptides and nutritional/nutriceutical interventions. Environmental enrichment and voluntary exercise have also been shown to ameliorate some of alcohol's impact during development.

**Conclusions:** Animal models of FASD have been used to demonstrate the specificity of alcohol's teratogenic effects and some of the underlying changes in the central nervous system (CNS) and, more recently, to explore treatments that could ameliorate the effects of alcohol. Animal models will continue to be invaluable for the development of protective and treatment strategies, and for providing a greater understanding of FASD.

### 44

#### Maternal ethanol consumption alters the epigenotype and the phenotype of offspring in a mouse model

A Nyman<sup>1</sup>, H Marjonen<sup>1</sup>, A Ahola<sup>2</sup>, E Whitelaw<sup>3</sup>, S Chong<sup>4</sup>, V Rogojin<sup>5</sup>, S Hautaniemi<sup>5</sup>, N Kaminen-Ahola<sup>1</sup>

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**Objectives:** Recent studies indicate that environmental factors like nutrition and toxic agents affect the epigenome of the developing embryo. In our study we

are investigating how alcohol, by modifying the epigenetic reprogramming, would lead to a compromised epigenetic state, altered fetal development and adult disease. Because adverse brain and behavioural outcomes are the most devastating consequences of prenatal alcohol exposure, we are focusing on the brain tissue.

**Materials & Methods:** We have developed a model of gestational ethanol exposure in the mouse based on maternal ingestion of 10% ethanol for eight days after fertilization. We have also investigated the effects of ethanol exposure before fertilization. Female mice were given 10% ethanol for four days per week for ten weeks prior to fertilization. In both studies, we used the epigenetically sensitive *Agouti viable yellow* ( $A^{vy}$ ) allele as a biomarker: the methylation level of this allele correlates with gene expression, resulting in mice with a range of coat colours.

**Results:** We observed expression changes in the  $A^{vy}$  allele in offspring, resulting in changes in coat colour in both experiments. Our model of gestational ethanol exposure produces offspring with postnatal growth restriction and craniofacial changes that are reminiscent of fetal alcohol syndrome (FAS) in humans. These findings and our preliminary results from gene expression arrays of hippocampus suggest that moderate ethanol exposure *in utero* is capable of inducing changes in the expression of genes other than  $A^{vy}$ .

**Conclusion:** Our data suggest that ethanol modifies the establishment of epigenetic marks in the preovulatory oocyte and in the embryo, and that this can alter adult phenotype. After the mouse studies we will proceed with human samples. We have already established collaboration with Finnish clinical specialists who enable the collection of tissue samples from affected individuals. In this way, we hope to gain a better understanding of the molecular processes underlying this syndrome. Our aim is to find biomarkers for estimating the severity of damage and enable early intervention and appropriate therapy.

## PLENARY SESSION V

### MANAGEMENT OF FASD

CHAIR: LEOPOLD CURFS

45

**The utilization of various health care services by Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder-affected individuals and the associated costs**

Svetlana Popova<sup>1,2,3</sup>, Shannon Lange<sup>1,2</sup>, Larry Burd<sup>4</sup>, Jürgen Rehm<sup>1,2,5</sup>

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**Objectives:** To examine the utilization rates of various health care services among individuals with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) and compare these rates with those of the general population of Canada, as well as with the rates observed in other countries. Also, to estimate the associated costs attributable to the health care utilization of FAS and FASD-affected individuals.

**Materials & Methods:** The utilization rates of health care services (number of admissions and length of stay) in Canada were obtained from various official databases, including: Canadian Institute of Health Information (CIHI), provincial ministerial officials, and drug addiction program coordinators. Quantification methods were used to calculate the economic impact that FAS and FASD have on the Canadian health care system. For comparison purposes, the burden and cost of health care associated with FAS and FASD in other countries were obtained from the available literature.

**Results:** Health care utilization rates (number of hospitalizations and days in acute inpatient and psychiatric care; number of emergency department and day surgery visits and hours of care; and substance-attributable specialized inpatient and outpatient admissions and days of treatment) and the associated costs were estimated. The official data (from CIHI) pertaining to the utilization of health care services by individuals diagnosed with FAS are likely to be underreported. It was found that the rate of acute care hospitalizations among individuals with FAS is 3.6 times lower than that of the general population of Canada. This is very unlikely, given that FAS is associated with a much higher rate of morbidity than the general population.

**Conclusion:** The quantification of the health care costs associated with FAS and FASD is crucial for policy developers and decision makers alike, to understand of the impact of prenatal alcohol exposure. The ultimate goal of such research is to initiate preventive interventions. The challenges of estimating the burden

and health care cost associated with FASD will be discussed.

**Acknowledgement:** *This work was supported by the Public Health Agency of Canada.*

#### 46

##### **The importance of expert physical diagnosis in FASD**

Miguel del Campo

Genetics Unit, Hospital Vall d'Hebron, Department of Life Science, Universidad Pompeu Fabra, Barcelona, Spain; Department of Obstetrics, Gynecology and Reproduction, Institut Univ Dexeus, Barcelona, Spain.

**Background:** FASD is the term used to describe different categories of consequences of prenatal alcohol exposure. Abnormal growth and characteristic physical features can be present in FASD, and then the diagnostic term is the fetal alcohol syndrome with complete or partial features.

**Materials & Methods:** All systems used to establish diagnostic criteria for FASD (Institute of Medicine, Canadian guidelines, 4 digit coding system), assess the presence or absence of the 3 major physical features (short palpebral features, smooth philtrum and upper lip) growth deficits (height and weight <10%) and physical evidence of central nervous system involvement (microcephaly) to identify the different diagnostic categories. In order to identify the physical features associated with FAS, several important facts should be taken into account: **1).** Expert physical diagnosis can be necessary. FAS is a dysmorphic syndrome with similar features to several genetic or other teratogenic syndromes with intellectual disability and behavioral problems. A differential diagnosis with other conditions should always be made, especially when the full pattern of malformation characteristic of FAS is not present. Genetic tests may be needed to rule out other causes. **2).** Several studies have proven that additional facial features such as abnormal ears (railroad track ears), ptosis of the eyelids, midface hypoplasia and a long philtrum, are all characteristic features of FAS. Other characteristic non-facial features include contractures of one or multiple joints (camptodactyly and others), limitation of pronation and supination of the elbow, clinodactyly of the 5<sup>th</sup> finger of the hands, and most importantly, abnormal hand creases (hockey stick crease and others) are also very specific to FASD and should be taken into account for this diagnosis. **3)** It has been proven that all these physical features together in a pattern are very specific to FAS, and their presence should be a firm indicator that the etiology of learning or behavioral problems is in fact prenatal exposure to alcohol. In the absence of physical findings, firm recognition of exposure or the

presence of a very characteristic neurobehavioral profile are necessary in order to make a diagnosis of FASD. **4)** Many of these features are predictors of more severe neurobehavioral involvement, and lower IQs are seen in patients with the most prominent physical features. They can be predictors of outcome, according to the number (dysmorphology scores) and severity of the growth deficits and the dysmorphic features.

**Conclusions:** We believe the identification of these physical features should be part of the knowledge of any pediatrician or other professional dealing with children at risk for FASD, but only expert physical diagnosis can assess some difficult cases and make sure no other condition is present, especially in the absence of known prenatal exposure to alcohol.

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##### **UK Consensus statement on the clinical management of FASD in the UK: Clinical pathways**

Raja Mukherjee<sup>1,2</sup>

<sup>1</sup>National FASD Specialist Behaviour Clinic, Surrey and Border's Partnership NHS Foundation Trust; <sup>2</sup>UK FASD Professionals Network

**Objectives:** To present developed and proposed clinical pathways to stimulate discussion in other areas re clinical interventions for people with FASD

**Materials & Methods:** Over two days on the 12<sup>th</sup> and 13<sup>th</sup> of October 2011 70 Doctors from around the UK attended a residential conference to educate each other and develop a consensus statement regarding how to recognise FASD at different stages from birth to adulthood. (5 stages Peri natal 0-0.5, Early years 0.5- 4, Primary school 4-11, Secondary School 11-18 and Adulthood 18+)The groups covered areas related to the above age groups based on semi structured questions before the feedback was analysed thematically to extract recommendations. Preliminary findings were commented on by the membership as part of a consultation before the final document was finished.

**Results:** Recommendations about the following were established, and these will hopefully be discussed as well as clinical pathways proposed will be presented.

**Conclusions:** Other countries have developed similar statements, however the needs of each country require these to be modified to be relevant to each setting and healthcare system. These findings offer a practical approach to FASD in the UK at different ages meeting a direct clinical need. The aim is to share clinical pathways to facilitate similar debates across Europe



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**The 1st Canadian FASD & sleep consensus paper**

Osman Ipsiroglu<sup>1</sup>, Gail Andrew<sup>2</sup>, Heather Carmichael-Olson<sup>3</sup>, Maria Chen<sup>4</sup>, Jean-Paul Collet<sup>5</sup>, Jacqueline Pei<sup>6</sup>, Jennifer Garden<sup>1</sup>, Ana Hanlon-Deerman<sup>7</sup>, Roderick Houben<sup>8</sup>, James Jan<sup>1</sup>, Kathy Keivers<sup>9</sup>, Dorothy McNaughton<sup>10</sup>, Christine Looock<sup>11</sup>, Lori Vitale-Cox<sup>12</sup>, Wayne Yo<sup>13</sup>, Dorothee Veer<sup>1</sup>, Joanne Weinberg<sup>13</sup>, Manisha Witmans<sup>14</sup>

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**Objectives:** Although up to 85% of children with FASD experience SP which significantly impact functioning and quality-of-life (QoL), sleep problems (SP) are rarely addressed by health care providers (HCP). In order to develop a framework for a structured approach to SP and to determine skills and knowledge necessary to diagnose and treat children with SP and/or disorders, an interdisciplinary consensus meeting was organized prior to the 4th International FASD Conference in Vancouver (2011).

**Materials & Methods:** Existing published/submitted clinical research exploring the problem and trends of medical treatment (medication) were reviewed. Based on the Canadian Health Care Systems' universal services philosophy, a 3-Level-Curriculum was proposed and the needs for future research and knowledge dissemination were discussed as a guideline for screening/assessing SP.

**Results:** Level I includes screening with a focus on behaviour, day- and night time situations and a simple measure for quality-of-life. All HCPs should be

“empowered to close the screening based sleep-service-related gaps at the level of care they offer”. Level II includes assessments by HCPs (e.g. occupational/behavioural therapist or community paediatrician) using sleep-logs/-diaries as clinical monitoring/evaluation tools and validated sleep questionnaires, thus requires a formal training. Level III represents regional health care services and is the highest level of the curriculum in regards to structured knowledge dissemination.

**Conclusion:** Knowledge dissemination is needed to enable this proposed approach and will be provided through the collaboration of the Consensus Group with the Intervention Team of the Canada Northwest FASD Research Network. Evaluation of activities will guide and coordinate future research needs.

**Source of Funding:** Victoria Foundation FASD-Action-Fund

**PARALLEL SESSION II.A.****PSYCHOSOCIAL DEVELOPMENT****CHAIR: RAJA MUKHERJEE**

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**Fetal Alcohol Spectrum Disorders in children adopted from Poland: Neurobehavioral functioning and early detection**

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<sup>1</sup>Utrecht Centre for Child and Adolescent Studies, Utrecht University, Utrecht, The Netherlands; <sup>2</sup>Department of Developmental and Clinical Psychology, Tilburg University, Tilburg, The Netherlands; <sup>3</sup>Adoption Department, Faculty Social Sciences, Utrecht University, Utrecht, The Netherlands

**Objectives:** In some populations, an increased prevalence of Fetal Alcohol Spectrum Disorders (FASD) exists, for example in children adopted from Central Eastern European countries. This study investigates the prevalence of possible neurobehavioral indicators for FASD in a group of children adopted from Poland to the Netherlands, and to what degree these indicators can detect children with FASD.

**Materials & Methods:** Participants were Dutch families with 121 children (63 boys; response rate 67%) adopted from Poland between 1999 and 2006. On average the children were 3.0 years old (SD = 1.6) at adoption, and 10.9 years old (SD = 2.7) at the time of study. Adoptive parents completed a questionnaire concerning background variables of the child, the

Behavior Rating Inventory of Executive Function (Gioia et al., 2000) and the Fetal Alcohol Syndrome Questionnaire, developed by Feldmann (Scheffner, 2012), measuring FASD related behavioral problems. Parents of three children did not know what FASD is and were excluded from analyses.

**Results:** Three groups were distinguished: children with a diagnosis in the FASD spectrum (n = 36; 31%), children whose parents suspected FASD (n = 26; 22%), and children without a FASD diagnosis or suspicion for FASD (n = 56; 47%). The three groups differed significantly on the eight combined clinical scales for executive functioning (partial  $\eta^2 = .136$ ) and on FASD related behavior problems ( $\eta^2 = .086$ ). Post Hoc comparison of the subscales on executive functioning indicated that children with a FASD diagnosis had more problems with Inhibition and Emotional Control than children without FASD. For FASD related behavior problems Post Hoc analyses indicated that FASD group scored significantly higher than children without FASD. On both behavioral measures the suspected group scored between the other two groups and did not differ significantly from either group.

**Conclusion:** FASD is prevalent in children adopted from Poland. Children diagnosed with FASD show more difficulties in neurobehavioral functioning than children without this diagnosis. Because of the importance of early diagnosis of FASD, children from high risk populations need to be screened for FASD. In adopted children multiple confounders might be present that complicate screening with a behavioral measure. Even though not all children with FASD can be detected solely based on their neurobehavioral profile, screening based on behavior might be a helpful tool.

## 50

### Very early pregnancy binge exposure may affect child behavior

Astrid Alvik

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**Objectives:** In a population-based study, representative of pregnant women in Oslo, the alcohol consumption before and during pregnancy are described. In addition, a potential association between binge drinking mainly before recognition of pregnancy and child development and behavioral symptom scores has been explored.

**Materials & Methods:** Questionnaires Q1-Q4 were answered at 17 (N=1749) and 30 weeks of pregnancy, 6 months after term and at child age 5 ½ year, with relatively high response rate. In addition to birth data and child development and behaviour, maternal alcohol

use, smoking and demographic and mental health variables were included.

**Results:** In this sample, little alcohol use and little binge drinking was reported after pregnancy recognition. Change in alcohol use occurred mostly at recognition of pregnancy, also for those with planned pregnancy. Approximately one fourth of the sample reported very early binge drinking ( $\geq 5$  drinks). In adjusted analyses, frequent very early binge drinking predicted more behavioural problems, and was the strongest predictor of such problems. However, binge fetal exposure did not predict motor development.

**Conclusion:** Behavioral problems may be sensitive measures of early binge exposure. Women should be advised to avoid binge drinking when planning pregnancy.

## 51

### Profile of executive and attention functions in a sample of 31 Russian adopted ADHD children compared with 31 probable genetic ADHD children

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<sup>1</sup>Neurology Service. Sant Joan de Déu's Hospital. Barcelona

**Objective:** In recent years there has been a significant increase in the rates of international adoption in our country. Children from the Russian Federation between 1997 and 2007 accounted for 60% of all adoptions (Callejón- Poo et al 2011). Several authors (Gray et al 2006, Miller et al 2009) have reported that ADHD is the cognitive-behavioural disorder diagnosed more frequently in this population. ADHD is a neurodevelopmental disorder that impairs executive function as a primary neuropsychological deficit. During the past decade the incidence of alcoholism among Russian childbearing age women has increased by 48% (Gonzalvo- Oliván 2004), so that these children represent a risk factor, along with the institutionalization time prior to adoption. Our goal is to compare the profile of executive and attention functions in a sample of children adopted from Russia with a diagnosis of ADHD, with probable genetic ADHD children.

**Materials & Methods:** Thirty one adopted children who consult the Learning Disabilities Unit (UTAE) of the Neurology's Department of Sant Joan de Deu's Hospital (Barcelona), diagnosed of ADHD according to DSM-IV, age ranged between 6 and 10 years, were compared with 31 probable genetic ADHD children who consult in the same unit. We analyze the Intelligence Quotient (IQ), the executive and attention functions and the results of Achenbach's

questionnaires and ADHD's ratings scales both for parents and teachers.

**Results:** Preliminary data suggests that ADHD Russian adopted children have higher internalizing and externalizing problems (according to Achenbach's Questionnaire), lower IQ scores and higher difficulties in executive and attention functions than the sample of probable genetic ADHD children.

**Conclusions:** Russian adopted children tend to have more cognitive and behavioural problems compared to probable genetic ADHD children. This profile is the one described in the Fetal Alcohol Spectrum Disorders. Given the importance of cognitive and behavioural aspects within the family environment, school and sociability, we recommend a routine monitoring of Russian adopted children to implement therapeutic interventions as early as possible.

## 52

### Sensory processing disorder in children with Fetal Alcohol Syndrome Disorders

Bàrbara Viader Vidal

Centre d'Estimulació Infantil de Barcelona (CEIB),  
Barcelona, Spain

**Objectives:** The aim of this communication is to describe Sensory Integration Disorder in children affected by FASD. The main goal is to analyze the effects of FASD and sensory deprivation in the process of sensory integration. Taking in account that one of the main needs for proper neurological development are sensory stimuli: what happens when a child does not receive the necessary sensory stimuli because he/she is living in an orphanage? Moreover, what about if this child also is affected by FASD?

**Materials & Methods:** We use the data obtained with *Sensory Profile Test* by *Winnie Dunn*, administered to 500 adopted children, who lived in orphanages. The analysis took place in the *Centre d'Estimulació Infantil de Barcelona*. The recollection date began January 2006, and ended June 2012. The children were aged from 3 to 12 years old.

**Results:** The lack of sensory stimulation of a child living in an orphanage has a severe impact on development. The impact is more severe if the child is affected by FASD. The sensory processing disorder observed in adopted children with FASD, affects behavior, motor maturity, learning ability, interaction and communication skills.

**Conclusion:** After the data analysis of the *Sensory Profile Test*, we get different profiles that indicate that sensory processing disorder is severe in adopted children, and even more severe in children affected by FASD. Both sensory deprivation and FASD have

negative impacts in sensory integration neurological development.

The most common sensory processing disorders are:

- 1) Sensory seeker behavior
- 2) Disorganized and disruptive behavior
- 3) Disorders in level of arousal
- 4) Sensory hypersensitivity
- 5) Coordination and praxis disorder

**Conclusion:** Children adopted from Bulgaria and Romania were the most affected group. Children adopted from Russia and Ukraine were the next affected group.

## 53

### Fetal alcohol exposures and psychiatric symptoms in Brazilian school age children

Maria Luiza Zamboni, Sarah Teófilo de Sá Roriz,  
Matheus Andrea Angelucci, Erikson Felipe Furtado

School of Medicine of Ribeirao Preto, University of  
Sao Paulo, Ribeirao Preto, Brazil

**Objectives:** Children with FASD are at risk for behavioral and mental health problems. Research in the last decade describes associations between prenatal alcohol exposure and psychiatric symptoms in childhood. As far as we know, there was no study about this subject for Brazilian children. Therefore, our main goal was to investigate in a Brazilian community sample the relationship between maternal alcohol consumption in pregnancy and psychopathology in the school-age offspring.

**Materials & Methods:** The study design was of a longitudinal study, which, started at the third trimester of pregnancy with the assessment of alcohol consumption in 449 pregnant women and that continues till to the present with the follow-up of the children. This sample had 22.1% of women identified as risky alcohol drinkers by means of screening using the short questionnaire T-ACE. From the original sample we have evaluated 59 children of the cohort. Child mental health problems were assessed with the Achenbach Child Behavior Checklist (CBCL) and through semi-structured psychiatric interview (K-SADS-PL).

**Results:** We found a statistically significant ( $p < 0.05$ ) difference for the average total CBCL score when comparing children of mothers who did not consume alcohol in pregnancy ( $M = 41 \pm 24.3$ ) compared to children of mothers with at least once per week consumption of alcohol ( $M = 60.7 \pm 36.0$ ), as well a statistically significant difference for the prevalence of psychiatric diagnoses (K-SADS-PL) among groups (34.8% x 77.8%;  $p = 0.017$ ).

**Conclusion:** These results suggest an association between regular consumption of alcohol in at least once per week pattern during pregnancy with psychiatric symptoms and diagnoses in the school age offspring. This study is most probably the first for a Brazilian sample. The research project will continue forward aiming to expand the assessment of this Brazilian sample with the inclusion of biochemical, neuroimaging and neuropsychological methods.

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**An environmental adaption, a school success guarantee for children with FASD?: the case of the Reunion Island**

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**Objectives:** This communication aims at showing the social, demographic and academic characteristics of a cohort of 30 children from the Reunion Island, between 4 and 15 years old, all diagnosed as FASD. Then, the criteria for diagnosis used to classify the children are studied. Last, the characteristics enabling better school integration for these children are identified.

**Materials & Methods:** A retrospective cohort of 30 children with FASD was constituted using the data of the CAMSP (Centre d'action medico-social précoce, Medico Social Center for diagnosis, rehabilitation and support for disabled children from 0 to 6 years old and their parents) of Saint-Louis. A questionnaire for each child has been filled in information from the data base. The pediatrician met with every child to complete the criteria for diagnosis and the tests required to characterize the syndrome.

**Results:** Three children's profiles emerge from a factorial analysis.

**Conclusion:** A large part of FASD children is enrolled in mainstream classes according to their age but not to their school level. This gap between schooling class and school level increases as they grow up. The syndrome's invisibility explains FASD children presence in mainstream classes as teachers are lured by their "deceiving appearance". Their IQ interpretation is often misguided, and therefore prevents them from their handicap acknowledgement, and from special educational classes integration. And last, their - relative - school success is also better with foster families but with their biological mother's approval.

**PARALLEL SESSION II.B.**

**TARGETED PREVENTION**

**CHAIR: THIERRY MAILLARD**

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**Cross-disciplinary specialist care for substance-abusing pregnant women and their infants in Gothenburg, Sweden, and what the women tell us about their experience of the care**

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Maternity-Child Healthcare Team in Haga, Primary Health Care, Region Västra Götaland, Department of Health Care, Sweden

**Objectives:** Sweden's comprehensive, free-of-charge antenatal and paediatric health care services have almost 100% attendance and high credibility among women and families. Local antenatal care routines in western Sweden now entail a first visit to a midwife one week after positive pregnancy test and very early AUDIT screening and narcotics/nicotine/medication counselling for all pregnant women. The specialist team serves Greater Gothenburg's substance-abusing pregnant women and their infants with specialist antenatal and paediatric care. The aim of the study was to evaluate this specialist care.

**Materials & Methods:** Women are referred by antenatal care centres, substance abuse facilities, social services or the criminal justice system and some come on their own initiative. During pregnancy, women see midwives weekly and most are tested for narcotic/alcohol regularly. Team members are midwives, paediatric nurse, social worker, psychiatric nurse, gynaecologist, paediatrician, psychiatrist, assistant nurse. Team conferences determine individualised care and support for each woman and the follow-up for infants/women. Extensive collaboration with social services, psychiatry and the paediatric health care system is essential. Long-term follow-up is often required.

A quality study will be performed including semi-structured interviews with women that have attended the specialist unit, focusing on their experience of the care.

**Results:** A majority of the patients stay substance-free during pregnancy, and no cases of FASD (fetal alcohol syndrome) or other serious neonatal effects of substance abuse have been diagnosed so far. Further results will be presented.

**Conclusion:** The evaluation shows the benefits of the multidisciplinary team, continuity, treatment and the individualised, structured but at the same time flexible

support for the women. The women narrated about the reception, not being stigmatized and they did not feel belittle.

## 56

### Evaluation of Fetal Alcohol Spectrum Disorder(s) training & education events in three European sites

Liam Curran

Certified Fetal Alcohol Spectrum Disorder Educator/Senior Supervising Social Worker, Fostering People (Ireland)

**Objectives:** Fetal alcohol spectrum disorders (FASDs) are preventable birth defects directly linked to consumption of alcohol during pregnancy, resulting in a significant public health cost burden. Current estimates suggest that 1% or 5 million people are living with fetal alcohol brain injury in Europe. Many medical and allied health professionals are key to (1) primary prevention of FASDs through working with women of childbearing age and (2) secondary prevention through working with affected individuals whose lives can be greatly improved with knowledge based interventions. The aim of this work was to demonstrate the pressing and urgent need for European health and allied health service providers to upskill their employees with the knowledge and ability to deal and manage FASD affected children & adults.

**Materials & Methods:** Participants were drawn from Social Work, Psychology and Foster & Adoptive Parents who participated in FASD training in three different European sites (Ireland, United Kingdom, and Poland) during 2011. Training was delivered using core material from Fetal Alcohol Spectrum Disorder(s) Competency – using Curriculum Development Guide for Medical and Allied Health Education and Practice (CDC) alongside relevant local data of prevalence rates of FASD and drinking rates in pregnancy as applicable to the site of the training. Data was collated using structured evaluation questionnaires along with themed group work within the training events.

**Results:** Evaluations from these multi-site training events suggest that Training, Education and Policy development concerning FASD is sought by allied health professionals, Foster & Adoptive Parents in order to properly respond to the needs of individuals living with FASD. The data suggests that there is an increased need for awareness of the life long disability of FASD and the complex problems faced by professionals to respond in a professionally competent manner.

**Conclusion:** The evaluation of three European training events suggest that competence, especially when viewed separately in terms of knowledge versus capacity for application of information, in the area of FASDs is

lacking in both the provider and caring professionals. Addressing this may be best achieved through the undertaking of a structured 'Training Needs Analysis' in multiple sites throughout the EU.

## 57

### Preventing prenatal alcohol use via health counseling by midwives and Internet-based computer tailored feedback: a randomized controlled trial

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<sup>1</sup>Dutch Institute for Alcohol Policy (STAP), Utrecht, The Netherlands; <sup>2</sup>Maastricht University/CAPHRI/Department of Health Promotion, Maastricht, The Netherlands

**Objective:** It is estimated that 35 to 50% of the Dutch pregnant women continue to consume alcohol in pregnancy despite the accumulating evidence that even low levels of prenatal alcohol exposure can cause adverse neurobehavioral effects in children. We used an RCT to test the effectiveness of a health counselling method by midwives (HC) and an Internet-based computer tailored method (CT) in reducing prenatal alcohol use.

**Materials & Methods:** Sixty midwife practices recruited 400 pregnant women who had consumed alcohol since they knew they were pregnant. Nineteen practices (138 respondents) were assigned to the HC condition and provided brief health counseling and self-help materials to stop drinking alcohol. Twenty-one practices (118 respondents) were assigned to the CT condition. Pregnant women of these practices received personalized tailored feedback via the Internet. Twenty practices (144 respondents) were assigned to the control group (CG); respondents of these practices received routine alcohol advice. The main outcome measures were alcohol abstinence and alcohol use three months after baseline. Multilevel multivariate logistic and linear regression analyses were conducted to investigate whether HC and CT in addition to potential confounding and moderating variables had an effect on the outcome variables.

**Results:** Multilevel logistic analyses with alcohol abstinence at T1 as outcome variable showed significant differences between CT and CG. CT significantly decreased alcohol use at T1 (odds ratio 0.379, 95% confidence interval 0.145 – 0.990) compared to CG. Differences between HC and CG with regard to alcohol abstinence at T1 were not significant. Multilevel linear analyses with average alcohol consumption at T1 showed a significant interaction effect between condition and alcohol use

before pregnancy. HC was more effective for respondents with a lower alcohol use before pregnancy compared to respondents with a higher alcohol use before pregnancy (regression coefficient B 0.027, 95% confidence interval 0.014 – 0.041).

**Conclusions:** More research is needed to understand why HC interacts with alcohol use before pregnancy. This significant interaction may imply that midwives provide different educational messages on alcohol in pregnancy to different clients. Another explanation may be that the effectiveness of HC for pregnant women who used a small amount of alcohol before pregnancy is due to the content of the intervention. Nevertheless, this research has shown that CT is an effective intervention to increase alcohol abstinence of pregnant women. A nationwide launching of this relatively inexpensive method has high potential to decrease the number of Dutch pregnant women using alcohol.

## 58

### **A randomized trial: telephone vs. in-person brief intervention to reduce the risk of an alcohol-exposed pregnancy**

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**Objectives:** The adverse effects of alcohol consumption during pregnancy have been widely reported, and represent a leading preventable cause of physical and cognitive birth defects in the United States (Bertrand, 2009; Hoyme et al., 2005; Wilton and Plane, 2006). Brief, effective interventions are needed to reduce the risk of an alcohol-exposed pregnancy in sexually active women who drink and do not use effective contraception.

**Materials & Methods:** The Healthy Choices study compared the efficacy of a brief intervention delivered either over the telephone or in-person. In addition to indicators of alcohol use, contraception methods and compliance were examined, along with measures of mood and domestic violence. Women between the ages of 18 and 44 who were drinking above recommended levels and not using effective contraception were randomly assigned to either a telephone intervention group (n=68) or in-person intervention group (n=63).

**Results:** Overall, participants showed significant reductions in alcohol use, and increases in effective use of contraception (thus reducing their risk of an alcohol-exposed pregnancy). There was no significant

difference in success of the intervention between the two conditions (telephone vs. in-person).

**Conclusion:** Telephone-based brief intervention can be successful and cost-effective in reducing the risk of an alcohol-exposed pregnancy and the incidence of fetal alcohol spectrum disorders.

## 59

### **Preventing FASD by supporting pregnant, substance using women with FASD: new evidence-based promising practices from Canada**

Lynda Dechief<sup>1,2</sup>, Deborah Rutman<sup>2,3,4</sup>

<sup>1</sup>Equality Research & Consulting, Nelson, Canada; <sup>2</sup>Canada Northwest FASD Research Network, Preventing FASD from a Women's Social Determinants of Health Perspective Network Action Team; <sup>3</sup>Faculty of Human and Social Development, & Senior Research Associate, School of Social Work, University of Victoria, Canada; <sup>4</sup>*Substance Using Women with FASD and FASD Prevention Project*

**Objectives:** Participants will leave the workshop with:

- 1) Increased knowledge regarding emerging/promising practices in supporting substance using women with FASD
- 2) Enhanced understanding of what women with FASD find helpful when accessing health and social care, including substance use treatment
- 3) Improved understanding of what are FASD-informed approaches and accommodations to practice and programming
- 4) Improved capacity to make FASD-informed accommodations to their own communication and practice and in their own programs/organizations/research.

**Materials & Methods:** Participants will actively engage with the workshop material through a variety of formats and media, including:

- 1) Small and large group discussion/interaction,
- 2) Presentation and discussion of video clips profiling the experiences of women with FASD in accessing support and services,
- 3) An interactive 'case scenario' activity,
- 4) An exercise on applying the workshop learnings in their own service or program,
- 5) As well, handouts and resources materials will be provided so that participants are able to take key information away with them.

**Results:** This skill building workshop will engage participants in interactive knowledge transfer of the findings from the *Substance Using Women with FASD*

and *FASD Prevention Project*, a three-year community-based research project which involved a comprehensive literature review, interviews with service providers regarding their perspectives on promising approaches in working with women with FASD, and voices of women with FASD regarding what had worked for them in addressing their substance use problems.

**Conclusion:** Through engaging in this workshop, participants will learn to put promising approaches into practice in their own service or program.

## 60

### **Results for babies of mothers who were involuntarily hospitalized during pregnancy because of alcohol and substance abuse**

Egil Nordlie

Borgestadklinikken, Skien, Norway

**Objectives:** Norwegian legislation gives the opportunity to hospitalize substance abusing pregnant women against their own will if there is a high probability that the substance abuse will cause damage to the child. Reducing the risk of FASD is one of the intentions of this legislation. The former Norwegian Social Services Act, section 6.2a – from January 2012 incorporated in a new Community Health Care Act, Section 10.3 – was carried into effect in 1996 and Norway is probably the only country in the world having an act like this. Borgestadklinikken, located in Skien, Norway, has a special treatment unit for these women.

**Materials & Methods:** Birth weights, lengths and head circumferences of the babies of 54 voluntarily and 110 involuntarily hospitalized mothers were compared and both categories were compared to the national average. Alcohol and substance abuse of their mothers were charted. Birth weight is a significant indication related to health conditions for the child during pregnancy, including alcohol exposition. Birth weights were also correlated to the duration of the hospitalization.

**Results:** The progress of the coercion is described. The treatment of the women and the women's health factors are described. Exclusively alcohol abuse was the reason for compulsory treatment in five cases and twenty-five women had been drinking alcohol as a supplement to other drugs in their pregnancies. Birth weight of the babies of involuntarily hospitalized mothers was in average 3165g and 3362g for babies of voluntarily hospitalized women. When involuntarily hospitalized mothers stayed in the clinic for more than 140 days, the average birth weight of their children was 3512g. When their stays were shorter, the average birth

weight was 483g lower. During the last years the duration of the stays increased and deliveries occurred closer to expected birth.

**Conclusions:** If necessary to use this act, it will have positive effect on the child when sanctions are made as early as possible during pregnancy, which will consequently reduce the risk of developing FASD. However, fewer pregnant women with alcohol abuse than expected have been hospitalized at Borgestadklinikken – considering alcohol being a legal and the most common substance, and despite the fact that alcohol is the most toxic substance for the fetus. The reasons why relatively few pregnant women with alcohol abuse are hospitalized against their own will, compared with the number of women with other substance abuse, will be discussed. Attitudes among health staff is an important factor.

## PARALLEL SESSION II.C

### PREVALENCE OF FASD

CHAIR: MAURO CECCANTI

## 61

### **Prevalence of FAS in Germany**

Reinhold Feldmann

Department of Pediatrics, University Hospital Muenster, Germany

**Background:** In several studies, the prevalence of the Fetal Alcohol Syndrome (FAS) is reported to be 1:300 in the western countries. No data for the prevalence of FAS in Germany, however, have been published yet.

**Materials & Methods:** We assessed the prevalence of FAS in 267 German foster children using the Fetal Alcohol Syndrome Questionnaire (FASQ).

**Results:** FAS was found in 23.4% of the assessed foster children. Eighty percent of children with FAS are living in foster or adoptive families or in orphanages/special care. Assuming that the percentage of FAS is the same for all these forms of care, the number of children with FAS in Germany is 47.000. This is one in 282 newborn children.

**Conclusion:** The prevalence study, although performed on a sample of foster children only, is yielding some evidence for a prevalence of FAS in Germany that is comparable to those reported for other western countries.

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### **Fetal Alcohol Spectrum Disorder in a preadoption clinic in Israel – the tip of the iceberg?**

Ariel Tenenbaum, Pnina Hertz, Talia Dor, Yael Castiel Alon Sapir, Isaiah D Wexler

Medical Unit for Adoption and Foster Care, Department of Pediatrics, Hadassah University Medical Center, Mount Scopus Campus, Jerusalem, Israel

**Objectives:** To determine the number of children with FASD or at risk for FASD in a select population of high risk patients seen at a clinic evaluating foster and adopted children in Israel. Israel is a country in which relatively few cases of FASD have been formally diagnosed and the prevalence has not been systematically evaluated.

**Materials & Methods:** Israeli children under 2 years old who were candidates for domestic adoption or in foster care were prospectively evaluated for clinical manifestations of FASD based on modified Institute of Medicine criteria, and information was obtained regarding parental use of alcohol or other illicit drugs.

**Results:** Of the 100 patients prospectively evaluated, 8 had mothers with a known history of alcohol consumption during pregnancy. Two of the children had fetal alcohol syndrome (FAS) without known maternal exposure to alcohol and two had partial FAS. Eleven other children were at risk for development of one of the diagnostic categories of FASD.

**Conclusions:** In a population of pre-adoption and foster children, 15% either had manifestations of FASD or were at risk for developing FASD. Although this is a select high risk population, the data from this study strongly suggest a greater prevalence of FASD in Israel than previously assumed. This increase may be related to the increasing consumption of alcohol among adolescents and young adults living in Israel. Under-diagnosis of FASD is detrimental to affected children who could benefit from early and targeted interventions especially designed for FASD. Implementation of public health educational programs for the population as well as formal updates for the medical personnel may reduce the prevalence of FASD and prevent its detrimental affects.

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### **FASD diagnostic detection rate in Germany**

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**Objectives:** Systematic epidemiological data for FAS(D) from Germany are not yet available (Spohr, 2008). We were interested in determining what number of patients should be assumed to exist in Germany, based on international incidence data, and what proportion of patients with FAS(D) has already been diagnosed.

#### **Materials & Methods:**

**1)** Analysis of the number of patients per year officially determined in Germany in the context of Diagnosis Q86.0 ([www.gbe-bund.de](http://www.gbe-bund.de)).

**2)** Additional determination of the number of live births per year in Germany as well as the number and age distribution of deaths with Q 86.0.

**3)** Analysis of previously published case series and case reports from Germany (PubMed etc.). In the presence of case series of a study group published several times under different aspects, the publication with the highest case number was considered.

#### **Results:**

**1)** In the years 2001 to 2010, in the hospitals of Germany 11-62 cases per year were registered with the Diagnosis Q 86.0. Assuming a FAS(D) frequency of 0.5/1,000 live births for FAS and of 2.0 and 5.0 for FASD, in Germany one can assume an incidence of 367 FAS and up to 3,672 FAS(D) cases per year. With a year-by-year observation, therefore, in Germany only 0.3-16.4% of all assumed FAS (D) cases per year among inpatient conditions were diagnosed (detection rate regarding FAS 3.3 to 16.9%, regarding FASD including FAS 0.3-4.2% per year).

**2)** The mortality rates that can also be determined in Germany, with 4.71% per year for children 0-10 years with Q 86.0, reflect international data. From the incidence and mortality figures for Germany, a prevalence of 3,298 cases with FAS at the age of 0-10 years can be determined; for FASD there were 33,037 cases.

**3)** Between 1974 and 2012, in case series and case contributions from Germany (including East Germany, former GDR) reports on 628 patients with FAS(D) were published. This corresponds to 16-17 patients/year.

**Conclusion:** In Germany since 1974, particularly through the work of Spohr, Majewski, Löser and Steinhausen, a considerable amount of medical knowledge about FASD has been accumulated. In hospitals, only 0.3 to 16.4% of all assumed FAS(D) cases were registered under the ICD 10 No. Q 86.0. This suggests that the attention of physicians must be more intensively drawn to the issue. On an international level it is necessary that the ICD 10 be updated with respect to FAS (D), because with the



diagnosis No. Q 86.0 the diagnosis FAS(D) is not adequately covered.

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##### **The prevalence of fetal alcohol spectrum disorders and concomitant disorders among orphanage children in Lithuania**

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**Objectives:** According to the WHO, Lithuania is in a 12<sup>th</sup> position of adult (15+) per capita alcohol consumption in the world. There is no data on the prevalence of fetal alcohol spectrum disorders (FASD) and concomitant disorders in the country. The purpose of this study were to determine the actual prevalence of FASD and concomitant somatic disorders among the pre-school age children living in orphanages in Lithuania, and to assess the prevalence of pre-study diagnosed cases.

**Materials & Methods:** A cross-sectional study was performed in 5 orphanages (Babies' homes) where 337 children were examined. The pediatric examination included anthropometric measurements (height, weight, occipito-frontal circumference) and phenotypic screening. Perinatal and postnatal clinical and developmental history, also cognitive/behavioural aspects were assessed from medical documentation, interviews with caretakers and nurses. Revised IOM criteria for the diagnosis of FASD were used (Hoyme et al., 2005). In addition, 16 children diagnosed with fetal alcohol syndrome (FAS-16 group) underwent more detailed investigation: cranial CT scan, audiometry, auditory brainstem response (ABR), abdominal ultrasound, ophthalmoscopy, sleep EEG, evaluation by endocrinologist.

**Results:** FASD was identified in 40% (134) of children; FAS was found in 22%, partial FAS in 7%, and alcohol-related neurodevelopmental disorders in 11%. FASD diagnoses prior to the study have been suspected in 29.9% of these children. In the FAS-16 group, the following findings have been recorded: cerebral dysmorphism in 7/16 (43.8%); hearing disorders confirmed by audiography in 9/14 (64.3%), with a medium or severe hearing disorder in five children; abnormal ABR in 7/13 (53.8%); retinal changes in 5/16 (31.2%); nonspecific changes on sleep EEG in 9/16 (56.3%); one child was diagnosed with hepatomegaly and one with hypopituitarism.

**Conclusion:** This study, being the first one in

Lithuania focused on FASD, has shown that FASD is highly prevalent in children at orphanages, however, underdiagnosed. Also, awareness and knowledge of specialists in the topic seems to be insufficient. Hearing disorder is worthy of note for its high prevalence in FASD population and for its possible impact on neurodevelopment.

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##### **Anthropometric birth data, sex, and fetal alcohol exposure in a Brazilian community sample**

Fabiana Spinetti dos Santos<sup>1,2</sup>, Poliana Patrício Aliane<sup>2</sup>, Patrícia Maria dos Santos D'Andrea Parpinelli<sup>2</sup>, Larissa Horta Esper<sup>2</sup>, Erikson Felipe Furtado<sup>2</sup>

<sup>1</sup>Faculdade de Ciências Farmacêuticas de Ribeirão Preto, Ribeirão Preto, Brazil; <sup>2</sup>Faculdade de Medicina de Ribeirão Preto, Ribeirão Preto, Brazil

**Objectives:** Alcohol consumption by pregnant women is related to fetal damage resulting in a large spectrum of physical and behavioral problems in the offspring. This study aimed to assess fetal exposure to alcohol in pregnant women through questionnaires, interviews and postpartum data in a Brazilian sample of pregnant women.

**Materials & Methods:** Data were collected longitudinally from 66 pregnant women since the first trimester of pregnancy as well from their newborns. All participants are living in the region of Ribeirão Preto, State of São Paulo, Brazil. The questionnaires T-ACE (*Tolerance, Annoyed, Cut down, Eye-Opener*) and AUDIT (Alcohol Use Disorders Identification Test) were employed as screening instruments for alcohol use. Postpartum information was collected such as: birth weight and length, childbirth delivery type and newborn gender.

**Results:** T-ACE positive pregnant women scored  $2.69 \pm 0.79$  and  $9.2 \pm 4.1$  in the questionnaires T-ACE and AUDIT (N = 36), respectively. The average number of drinks in the first, second and third trimester was 50.4, 12.6 and 15.7, respectively for the T-ACE positive group. Two thirds (66.67%) of the sample of pregnant women were found as AUDIT positive (cut-off  $\geq 7.0$ ). A statistically significant inverse Spearman correlation was found only for newborns of female sex for birth length and AUDIT total score (N = 16,  $\rho = -0.556$ ,  $p = 0.025$ ). No newborn was found as a clinical FAS case, and all other birth parameters were found in the normal range.

**Conclusion:** No statistical differences were observed in relation to anthropometric variables except for birth length in the female newborn. Meconium samples have been collected and will help to complement this study, allowing comparison of these values with the information provided by pregnant women and

providing an objective measure in order to validate the findings.

### PARALLEL SESSION III.A

#### 4-DIGIT CODE

CHAIR: RUDI KOHL

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#### The diagnosis of FASD using the 4-digit code

Rudi Kohl

FASD clinic, Jonx/Lentis, Winschoten, Netherland

**Objectives:** The only biographic study performed in Europe (Italy) to date suggests that FASD has a much higher prevalence than previously suspected. FASD remains difficult to diagnose and requires a multi disciplinary approach. Since 2004 at the 1<sup>st</sup> FAS clinic, Zutphen, Netherland; and subsequently since 2008 at the 2<sup>nd</sup> FASD clinic, Winschoten, Netherland; we have used the 4-digit code as diagnostic basis. The main goal is to share our experience and demonstrate the practical application of the 4-digit code in a workshop approach.

**Materials & Methods:** The workshop will cover a discussion of teratogens, embryology, and toxicology of alcohol to better understand the application of the 4-digit code. The tools and application of the 4-digit code will be demonstrated. The incidence with reference to possible genetic preventive factors and social consequences with guidelines to further management will be discussed.

**Results:** The participants will be able to establish the diagnosis with greater confidence.

**Conclusion:** The 4-digit code is a practical and useful tool in establishing the diagnosis of FASD

### PLENARY SESSION VI

#### THE FUTURE OF FASD

CHAIR: DIANE BLACK

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#### Fetal Alcohol Spectrum Disorders: Past, present, future

Kenneth R Warren

National Institute on Alcohol Abuse and Alcoholism, NIH, USA

**Background:** In a worldwide context, attitudes towards the alcohol consumption in general, and more specifically the use of alcohol in pregnancy, has been influenced by the events surrounding temperance movements arising in the late 19th and early 20th century. These movements resulted in the implementation of temperance policies in many European countries and total alcohol sale or consumption prohibition in some European countries as well as in Canada and the United States. The societal rejection of prohibition and some of the more restrictive aspects of temperance lead to changes in public attitudes on alcohol including the unwarranted rejection of existing research findings on alcohol's effects in pregnancy. The unjustified acceptance of alcohol as an agent totally devoid of any potential risk to fetus in the mid-twentieth century has created a significant public health dilemma that those who are today involved in education and clinical care still strive to overcome. There are challenges that researchers must face as well for these historical events.

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#### The Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD): an update

Edward P. Riley

Center for Behavioral Teratology and Department of Psychology, San Diego State University, San Diego, CA, USA

**Objectives:** The Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) was established by the National Institute on Alcohol Abuse and Alcohol (NIAAA) in 2003 with the overall goal of improving the diagnoses of fetal alcohol spectrum disorders (FASD). It is a multidisciplinary, multisite, international project combining both clinical and basic science projects. To date, CIFASD it has involved projects in seven different countries, including four in Europe. The major objective is to provide an overview and update on CIFASD, highlighting major accomplishments to date

**Materials & Methods:** CIFASD utilizes a comprehensive approach to many of the critical questions in FASD research including improved diagnosis and enhanced understanding of the dysmorphology, neurobehavioral phenotypes, and neuropathology associated with prenatal alcohol exposure. One goal of CIFASD is to integrate information from three modalities (brain, face, and behavior) at a variety of ages, to guide early recognition of FASD with greater sensitivity. Our research projects utilize state-of-the-art techniques in

brain imaging, craniofacial image analysis, behavioral phenotyping, and genetics.

**Results:** Our brain imaging project is examining data longitudinally, as preliminary data suggest a difference in the trajectory of brain developmental between alcohol-exposed and control children. Our behavioral projects are refining the profiles of cognitive deficits following prenatal alcohol exposure, and showing similarities and differences between behaviors of children with an FASD compared to those with ADHD. Our work on facial imaging may better identify not only individuals with FAS, but also those with subclinical features. We are examining potential biomarkers of alcohol exposure, and how genetic and nutritional variables modify FASD to better identify individuals with, or at risk for FASD.

**Conclusion:** Our efforts are accelerating progress in identifying children with prenatal alcohol exposure, which we envision will lead to earlier and improved interventions. This work should inform promising practices in the identification and treatment of individuals exposed to alcohol prenatally.

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### **FASD as an important topic in Europe wide alcohol policy**

Lauri Beekmann

Eurocare, NordAN, Estonian Temperance Union, Estonia

**Background:** This presentation will introduce the current situation of European alcohol policy from the point of a Europe-wide alliance of NGOs. As the European alcohol strategy, which has protection of unborn children as one of the priority themes, is ending this year, the presentation will explore the future outlook for the next strategy and how it could influence the FASD situation in EU States.

**Methods:** The presentation will also focus on Eurocare, which is the leading alcohol policy oriented NGO alliance in Europe and has been focused on FASD for several years. It will introduce the ways how this wider network could help to decrease alcohol related harm, including the prevalence of FASD.

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### **Reducing alcohol related harm – the role of midwives**

Susanne Simon,

European Midwives Association (EMA)

**Background:** The European Midwives association (EMA) is a non-governmental organization of midwives, representing midwifery associations from all member states across Europe. EMA is an active member of the European Alcohol and Health Forum. To reduce alcohol related harm midwives are gate keepers and can play an essential health promotion and disease prevention role in the provision of preconception and antenatal care. Results of a survey undertaken by EMA showed that discussion about alcohol related harm with women and their partners is a common practice undertaken by midwives sometimes already pre-conceptually but mainly during pregnancy. Midwives are ideally placed to educate and inform women and their partners about the harmful effects of hazardous alcohol consumption preconception, during pregnancy and the whole childbearing period.

## POSTERS

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### **Berliner EvAS - A new tool for detection and categorization of alcohol consumption in pregnancy**

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<sup>1</sup>Infektionsambulanz, Klinik für Geburtsmedizin, Campus Virchow-Klinikum, Charité – Universitätsmedizin Berlin, Berlin, Germany; Klinik für Neonatologie, Campus Virchow-Klinikum, Charité – Universitätsmedizin Berlin, Berlin, Germany

**Objectives:** Early detection of maternal alcohol consumption in pregnancy is the crucial point in prevention and/or early diagnosis of FAS and FASD. The tools currently in use for patient interrogation are the same tools used for detection of alcohol use disorders in non-pregnant subjects. Questionnaires like the CAGE, T-ACE, AUDIT and TWEAK are well established to detect a high and/or regular consumption of alcohol, whereas they can cause denial in subjects with low alcohol consumption leading to false negative screening results. Our aim was to develop a new questionnaire with reduced risk for false negative results.

**Materials & Methods:** We developed a questionnaire that includes an evaluation system for immediate risk stratification. In retrospective testing using patient files as well as a prospective study applicability of the “Berliner EvAS”-questionnaire has been tested.

**Results:** “Berliner EvAS”-questionnaire is an easy to use, non-stigmatizing tool to detect alcohol consumption in pregnancy. In our retrospective

analysis, risk stratification by “Berliner EvAS” shows good consistency with data from biochemical screening results for alcohol.

**Conclusion:** Early detection of FAS and FASD relies on diagnosis of maternal alcohol consumption. With the risk stratification of “Berliner EvAS”, pregnancy counseling can focus on patients at risk for alcohol related birth defects. At the second European Conference on FASD, we present an English translation of our tool.

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### **Learning how to live one’s own life: growing up is still a major challenge for young adults with FASD**

Heike Hoff-Emden

KMG Rehabilitation Center, Ellrich/OT Sülzhayn, Germany

**Objectives:** Growing up is for FASD patients very difficult because they lack autonomy and professional training, which are a precondition for leading an independent life. Reasons are deficits in executive functions (for example working memory, concentration, alertness) and permanent high stress level/stress intolerance caused by the alcohol-harmed brain during pregnancy and harmful postnatal family situation.

**Materials & Methods:** We developed an anti-stress training for young adults, who live in a high-frequently served care group. First, the social caregiver filled out the SDQ-questionnaire in order to be informed about social, emotional, health problems. Initially, three female and three male FASD-adults, aged between 19 and 24, were supposed to join a single training once a week for 5 times in their own premises. As explicitly wished by the subjects, one social caregiver was always present at the training. In order to learn how to relax, we asked the participants to describe their feelings and to acquire certain methods for reduce their stress level.

**Results:** Only one or two of the FASD-residents took part in this training. The result showed that only one well prepared activity at a time is possible. Moreover, FASD adults constantly need someone to support them throughout the day. Finally, to be sustainable the training needs to be repeated every day.

**Conclusion:** Adults suffering of FASD need a long time before becoming 18, a concept of transition to their adult life that includes autonomous living, acquiring professional skills and accepting their disability. As a consequence, it is very important to introduce objectivities to carry out certain functions and disabilities, for example supported by ICF-CY

(independent from IQ). National authorities have to be informed and have to accept this fact. Social rights need to be adapted and practiced well enough to make young FASD adults benefit most. These ideas can be found in one of our papers for the German ministry of health. Additionally, a fully functioning network needs to be installed. National guidelines are in progress. In summary, the ideas mentioned above seem to be the only possible way to support young adults with FASD in the process of growing up.

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### **Creating a circle of hope: supporting birth mothers to prevent FASD**

Kathleen Tavenner Mitchell

**Objectives:** Women who have used alcohol or other drugs while pregnant are likely to drink in their next pregnancy without support. Women need a safe environment to discuss and share their feelings regarding their use while pregnant. Mothers that discover that their drinking has caused problems for their children will experience tremendous guilt and shame, and a long process of grief.

Participants will be able to describe the model of the National Organization on Fetal Alcohol Syndrome (NOFAS) Circle of Hope (COH), birth mothers network. The attendees will be able to discuss many of the successes of the program including the peer mentorship component, the Women in Recovery Summits, the COH annual meeting, and the COH national speaker’s bureau.

**Materials & Methods:** The speaker will use a Power Point presentation, photos and graphics, and a DVD *Recovering Hope*. The audience be provided with an overview of the history of the network, the components of the program and will learn from the many stories of the members of the COH. Participants will receive free NOFAS COH FASD prevention materials and materials from the Centers for Disease Control (Fact Sheets, brochures, FASD Diagnostic publications, posters, and *Recovering Hope* DVD’s).

**Results:** Conference participants will be introduced to the steps that NOFAS and a U.S. government agency took to educate the highest risk group for having a child with FASD, women with alcohol dependencies, about FASD. They will learn how NOFAS organized their peer mentoring program for birth mothers and taught them how to speak in open forums about their prenatal alcohol use.

**Conclusion:** The audience will discover the importance of developing programs that support birth mothers and address the stigma associated with drinking while pregnant. Reaching birth mothers has

global reach and countries from across the seas can be connected to work together to support women to prevent FASD.

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### **Towards an evaluation framework for community-based FASD prevention and FASD support programs**

Deborah Rutman<sup>1,2</sup>, Nancy Poole<sup>2,3</sup>, Sharon Hume<sup>1</sup>, Marilyn Van Bibber<sup>1,2</sup>, Carol Hubberstey<sup>1</sup>

<sup>1</sup>Principal, Nota Bene Consulting Group, Victoria, Canada; <sup>2</sup>Canada FASD Research Network, Preventing FASD from a Women's Social Determinants of Health Perspective Network Action Team; <sup>3</sup>British Columbia Centre of Excellence for Women's Health, Vancouver Canada

**Objectives:** This presentation will share findings arising from a project in Canada that aims to identify promising evaluation methods and create common evaluation frameworks and tools for FASD prevention programs serving pregnant women and mothers, and supportive intervention programs for youth and adults living with FASD.

In this conference session, participants will have the opportunity to:

- 1) Enhance their knowledge about evaluation practices and frameworks, particularly in relation to FASD prevention and support programs
- 2) Discuss and provide feedback on this project's emerging conceptual 'maps' and web-based 'toolkit' for FASD-related programming and initiatives
- 3) Be linked to web based resources related to the project.

**Methods & Materials:** Following an extensive review of existing frameworks, methods and indicators of success being used by FASD programs, in the fall of 2011 the project team facilitated day-long consultations with program providers and researchers in three regions of Canada. We received input on key outcomes, indicators, and respectful and effective approaches and tools for collecting evaluation and outcome data. The team then created three Conceptual Maps, which may be used as tools for conceptualizing evaluation and describing the connection between program philosophy and program activities, formative outcomes, and client, community, and systemic outcomes.

**Results:** In this conference session, we will present the Conceptual Maps, and session participants will be invited to provide feedback and discuss their experiences of promising practices in evaluation, as

well as policy and ethical implications for FASD program development, delivery and evaluation.

**Conclusion:** The importance of strong evaluation in the development and delivery of FASD-related programs and services cannot be overstated. Through participation in this workshop, participants will learn about FASD prevention and intervention programming, and will build understanding about useful and use-able approaches to evaluation practices – i.e., what works, for whom and in what context.

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### **Morbidity in children of mothers who have received in-patient health or social care due to an alcohol or drug related diagnosis**

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<sup>1</sup>Research Professor, Chief of Health Research, The Social Insurance Institution, Research Department, Helsinki, Finland; <sup>2</sup>Researcher, PhD, National Institute of Health and Welfare, Alcohol and Drugs; <sup>3</sup>Research Professor, National Institute of Health and Welfare, Alcohol and Drugs

**Objectives:** The focus of this study is to analyze whether maternal alcohol or drug related diagnoses leading to in-patient health or institutional social care were related with higher prevalence of diagnoses suggestive of abnormalities in neurological, neurobehavioral or visual development in the offspring during their first 7 years of life.

**Materials & Methods:** The data of this study consists of the entire cohort of children born in Finland in 2002 (n=55547) and their biological mothers (n=54686). The following register based data covering the years 1998-2009 for the mothers and 2002-2009 for the children were used in this study: **1)** Information on in-patient medical treatment of the mother due to an alcohol or drug related diagnosis, **2)** mother's use of institutional social care due to substance use problems and related diagnoses, and **3)** children's predefined diagnostic groups (F70-79, F80-89, F90-99, G40, G80 and Q86) requiring in-patient care.

**Results:** 856 (1.56%) of mothers had been treated for alcohol or drug related diagnoses either in a health or social care setting. Their children had a significantly higher frequency of diagnoses in the ICD-10 diagnostic categories F 80-89 (pervasive and specific developmental disorders, 9.93% vs. 4.48%, p<0.001), F 90-99 (behavioral and emotional disorders, 9.00% vs. 3.15%, p< 0.001), G80 (cerebral palsy and other paralytic syndromes, 0.82% vs. 0.2%, p=0.001), and Q86 (teratogenic dysmorphic syndromes, 1.87% vs. 0.02% p<0.0001). No significant differences were

observed for the diagnostic groups F70-79 (mental retardation, 0.23% vs. 0.35%) or G40 (epilepsy, 0.9% vs. 0.7%)

**Conclusion:** Maternal alcohol and/or drug abuse requiring in-patient health or social care was connected with a substantial increase in offspring morbidity both in neurological and neurobehavioral disorders as well as dysmorphic syndromes caused by teratogenic agents.

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**Choices are simple...there's no safe time for liquor; not with a baby in the picture**

Alaina Thursby<sup>1</sup>

<sup>1</sup>Fetal Alcohol Spectrum of Services, Bissell Centre, Edmonton, Canada

**Objectives:** Awareness, education, and prevention are key to eliminating Fetal Alcohol Spectrum Disorder (FASD), which is a 100% preventable lifelong disability. The aim of this presentation is to share resources and ways that the community is being engaged in Edmonton, Canada. The main goals are to raise awareness, provide new resources, and to get conversations started so that we can put forth a clear message that no alcohol is best during pregnancy. A music video and cell phone ringtone have just been created and released in order to target youth and young adults. This video is a unique resource that is being used in various settings and has received extensive positive feedback. Prevention initiatives and a public health message will be at the forefront of this interactive presentation.

**Materials & Methods:** A power point presentation will be used. Also, print materials will be handed out, the music video 'You Can Choose' will be shown that has been created in partnership with the Fetal Alcohol Spectrum of Services (FASS) and the Edmonton Fetal Alcohol Network (EFAN), and information will be provided on how to access the free ringtone.

**Results:** The presentation shared resources and provided information on what new and unique tactics are being used in the Edmonton community to raise awareness about this invisible, preventable disability.

**Conclusion:** As a community it is our responsibility to work together to raise awareness and to educate on FASD. By providing information and having an open discussion we can help to start these much needed conversations and begin to break down the stereotypes, misconceptions, and stigma associated with alcohol, pregnancy, and FASD.

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**Whole body composition analysis using air-displacement plethysmography in children with prenatal alcohol exposure**

Nora Dörrie<sup>1</sup>, Inga Freunsch<sup>1</sup>, Manuel Föcker<sup>1</sup>, Michelle Margold<sup>1</sup>, Lena Janssen<sup>1</sup>, Sebastian Wölfle<sup>1</sup>, Özgür Albayrak<sup>1</sup>, Johannes Hebebrand<sup>1</sup>

<sup>1</sup>Department of Child and Adolescent Psychiatry and Psychotherapy, University of Duisburg-Essen, Germany

**Objectives:** Numerous studies indicate that a significant number of patients exposed to alcohol prenatally suffer from deficits in weight and/or in height from birth into adulthood. However, especially in animal studies, prenatal alcohol exposure was shown to cause alterations in glucose and lipid metabolism similar to those observed in obese patients developing a metabolic syndrome. We hypothesize disturbances in body composition in children with prenatal alcohol exposure and set out to measure fat free and fat mass in children and adolescents with Fetal Alcohol Syndrome (FAS).

**Materials & Methods:** We measured body composition in 18 patients with full or partial FAS according to the 4-Digit Diagnostic Code (Astley, 2004) using whole body air-displacement plethysmography (BOD POD method, COSMED USA, Inc.). 23 patients were recruited from our outpatients' clinic. In five cases, it was not possible to complete body composition analysis due to excessive motor restlessness during the measuring process. Additionally, body composition was measured in 142 children and adolescents without FAS. As control group and study group differed significantly in age and body mass index (BMI), a matched-pair analysis was performed, matching for BMI, sex and age.

**Results:** No statistically significant difference in body composition was found between children with partial or full FAS and controls. In accordance with previous research, BMI-for-Age percentiles in the study group were significantly lower than in the control group.

**Conclusion:** Our findings show that growth deficiency in FAS or partial FAS affects body fat mass and fat-free mass to a similar extent. We cannot exclude that significant differences in body composition will appear upon enlargement of the sample size.

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**FASD multidisciplinary diagnostic clinic model in a rural Canadian setting and the use of "MAP" (Multi-Action Plan) for assigning responsibility and monitoring follow up of recommendations and utilization of resources**

*From FASD clinic recommendations to results: a “MAP” of our path*

Hasmukhlal Rajani<sup>1,2</sup>, Teresa O’Riordan<sup>1</sup>, Kelly Cameron<sup>1</sup>

<sup>1</sup>Northwest Central FASD Services Network, Barrhead, Alberta, Canada; Department Of Pediatrics, University Of Alberta, Alberta, Canada

**Objectives:** Accessing multidisciplinary FASD assessment and diagnostic services in Canada, given our large geography and sparse population creates unique challenges that require innovation. Follow up of clinic recommendations and assigning responsibility and resources depend on location and availability. We have used the “MAP” (Multi-Action Plan) to facilitate a community response to the client’s needs and to track the follow up of recommendations and access to resources.

**Materials & Methods:** Members of the multidisciplinary diagnostic clinic, Report templates including the “MAP”. The NWC FASD network has been diagnosing children with prenatal exposure to alcohol for three years, and using the MAP template to follow up and coordinate services. FASD is now recognized as one of the leading causes of developmental disability. The prevalence rate of “FAS” is quoted from 1-3/1000 with “FASD” being estimated to be 3-9 times greater. Arriving at a FASD diagnosis is a complex process. It is recognized that a diagnosis is not only important to better determine prevalence rates but also crucial for clients to be able to access needed and eligible services. Similarly, multidisciplinary assessments are necessary for an accurate diagnosis and are equally important for informing interventions. Accessing multidisciplinary FASD assessment and diagnostic services in Canada, given our large geography and sparse population creates unique challenges that require innovation. And these challenges must be met in order to develop to provide a comprehensive understanding of the individual’s areas of deficit and areas of strength.

Follow up of clinic recommendations and assigning responsibility and resources depend on location and availability. We have used the “MAP” (Multi-Action Plan) to facilitate a community response to the client’s needs and to track the follow up of recommendations and access to resources.

**Results:** We present the development and utilization of the map to assign responsibility, facilitate communication and coordinate resources among health professionals and agencies.

**Conclusion:** The presentation will outline the development of the rural diagnostic clinic, use of the

map and the will also report on client outcomes and discuss the uptake of recommendations and services.

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**The power of networking – highlights of the work of Canada’s network action team on FASD prevention from a women’s health determinants perspective**

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**Objectives:** The aim of this presentation is to profile Canadian examples of FASD prevention activities from across research, policy, and practice which are linked through a Network Action Team (NAT) on FASD Prevention, funded by the CanFASD Research Network. In addition, the presentation will describe the virtual strategies that have allowed the NAT to work collaboratively across time and geographies, which may be of inspiration to others working on FASD prevention around the world.

**Materials & Methods:** Over the past six years, the NAT has been building a virtual network of over 40 researchers, health care/other service providers, community based advocates and parents, and decision makers/health system planners from across Canada. Team members lead academic and community-based research projects, hospital and community based programs, evaluation studies, a blog on women, alcohol, and pregnancy, and other local and national initiatives.

**Results:** The NAT has utilized a virtual Community of Practice (CoP) model as a mechanism for knowledge exchange, engaging researchers, policy makers, civil servants, clinicians, community-based service providers, advocates, and women concerned with FASD prevention. As the Network continues to grow with interest from new communities and stakeholders, additional strategies for maintaining effective working relationships and for ensuring the smooth uptake of knowledge into program and policy development are being explored.

**Conclusion:** Virtual and collaborative approaches to promoting women’s health can be an effective strategy for preventing FASD and allows researchers, policy makers, and advocates from multiple sectors to better address the range of proximal and distal factors that influence alcohol consumption during pregnancy.

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**FASD multidisciplinary diagnostic clinic model in a rural setting and outcome of adult patients seen in clinic in the last 10 years**

Hasu Rajani, Monty Nelson, Audrey McFarlane

Lakeland Centre for FASD

**Objective:** To share results of the outcomes for rural adults with a diagnosis of FASD, those that were diagnosed as children and are now adults; and those diagnosed as adults. These individuals have been diagnosed with a multi-disciplinary team that has been uniquely developed to meet a rural need.

**Materials & Methods:** This involved a file review and interview process with families and individuals covering the areas of school completion, legal involvement, employment, addictions, and mental health issues.

**Results:** FASD is a complex disorder and even more complex to address in rural communities of less than 20,000 people. This work focuses on the role of rural services and meeting the needs of adults diagnosed with FASD. Adult diagnosis presents its own issues requiring creative partnerships to optimize the diagnostic process to drive recommendations and services for the client.

**Conclusion:** Rural areas have capacity to meet the needs of adults with FASD. The news about the outcomes for adults is not all negative.

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### **FASD multidisciplinary diagnostic clinic model in a rural setting and neuropsychological profiles for the last 250 patients**

Hasu Rajani<sup>1</sup>, Brent Symes<sup>1</sup>, Vanna Thiel<sup>2</sup>

<sup>1</sup>Edmonton, Alberta, Canada; <sup>2</sup>Cold Lake, Alberta, Canada

**Objective:** Individuals with FASD present a unique psychological profile which has many implications for diagnosis. We will share the results of 250 patients diagnosed with FASD and their psychological profiles from work done on a rural FASD diagnostic multidisciplinary team.

**Materials & Methods:** Pediatrician, psychologist and speech Language pathologist have reviewed file information from the last 250 patients.

**Results:** The file review and clinical expertise has shown some surprising results that reveal the need for a standardized test battery for clinical teams; and the unique results of a rural multidisciplinary diagnostic team.

**Conclusions:** Over the past 12 years, we have been using a multidisciplinary model to diagnose children exposed to alcohol. Over the past five years, we have standardized the battery of neuropsychological testing

performed on these patients. Here we present the neuropsychological profile of these patients.

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### **Addressing FASD in remote and rural communities: A case example**

Audrey McFarlane

Cold Lake, Alberta, Canada

**Objective:** FASD is a complex disorder encompassing many factors of prevention, diagnosis, intervention, education, stigma and community capacity. Explore how a rural northern community has managed to address such complex problems.

**Materials & Methods:** This case study explored the work of the Lakeland Centre for FASD in Cold Lake Alberta Canada which has developed an unique organizations that serves individuals prenatally exposed to alcohol across the lifespan and their families.

**Results:** Community capacity is available in rural communities but it needs to be tapped into with passion, a good plan, and patience. The Lakeland Centre for FASD has been operating for over 12 years as an agency and 6 years before that as a general community committee. Offering diagnosis; post diagnostic supports such as transition planning, employment supports, training, education; and works with the women at high risk of having a child with FASD.

**Conclusions:** Learn the community development plan as well as the current models of the Lakeland Centre for FASD that has made it a leader in Canada.

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### **Improving knowledge and practice behaviors in medical and allied healthcare providers: results from the Great Lakes FASD Regional Training Center**

Georgiana Wilton<sup>1</sup>, David Wargowski<sup>2</sup>, Kristi Obmascher<sup>3</sup>, Barbara Vardalas<sup>1</sup>, Ronald Prince<sup>1</sup>, Raina Haralampopoulos<sup>1</sup>

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**Objectives:** The adverse effects of alcohol consumption during pregnancy have been widely reported, and represent a significant public health risk. Many physicians and other medical professionals feel inadequately prepared to provide appropriate services to reduce the risk of an alcohol-exposed pregnancy or provide the clinical care required for individuals affected by fetal alcohol spectrum disorders (FASDs). The overarching goal of the project was to increase knowledge and improve clinical skills and practice behaviors of medical and allied health practitioners and students around the prevention, identification, and treatment of FASD.

**Materials & Methods:** Utilizing the content of the *FASD Competency-Based Curriculum Development and Practice* (Centers for Disease Control and Prevention, 2009) the project conducted and evaluated 215 trainings in a seven-state region reaching 5,250 participants. Data was collected at four time points: pre-training, immediate post-training, 3-months post-training and 6-months post-training.

**Results:** Our findings demonstrated that training activities were effective in significantly increasing participant knowledge about FASD over time. Significant increases were also seen in confidence levels for screening, educating and referring women at risk for alcohol abuse as well as screening, diagnosing and treating individuals at risk for fetal alcohol spectrum disorders. No quantifiable changes were seen detected in clinical practice.

**Conclusion:** While knowledge and confidence increased significantly from pre-training to all post-training evaluation timepoints, this did not translate into a quantifiable change in clinical practice. Knowledge and confidence alone may not be enough to effect institutional change as practicing professionals face growing demands on increasingly limited time allotted for patient and client interaction. Changes in training format, content, and target audience were instituted within the training center to better target clinical practice behaviors.

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#### **Prenatal alcohol exposure and hypothalamic-pituitary-adrenal axis dysfunction: a systematic review**

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<sup>3</sup>Department of Chemistry, Faculty of Natural Sciences and Exacts, Autonomous University of Chiriquí (UNACHI), Chiriquí, Panamá

**Objectives:** To investigate the relationship between prenatal alcohol exposure and dysfunction of the hypothalamic-pituitary-adrenal (HPA) axis, as a probable etiological factor for neuropsychological deficits and late behavior problems in the offspring of alcohol abuse mothers.

**Materials & Methods:** A systematic review was performed by searching scientific articles through the bibliographic databases Pubmed, Lilacs, Web of Knowledge and Science Direct using the following search terms: “Prenatal Alcohol Exposure AND Cortisol”. Thirty-two papers were selected.

**Results:** Thirty two studies were identified, all written in English; most of them published in the United States of America (11) and Canada (15). Other studies were published in United Kingdom (2), Norway (1), Germany (1), China (1) and Netherlands (1). The oldest paper was written in 1994 and a total number of twenty four was produced in the last decade. This research found that HPA axis is highly susceptible to programming during fetal and neonatal development and that prenatal alcohol exposure programs the fetal HPA axis such that HPA tone is increased throughout life. This work also detected that maternal alcohol consumption increases HPA activity in both mother and the offspring. Therefore, this increment, by exposing the fetus to endogenous glucocorticoids along the lifespan, can alter the behavioral and physiologic sensibility increasing vulnerability to sickness and disorders later in life. Furthermore, we find possible differential effects of subjacent mechanisms of alcohol on male and female offspring, with special emphasis on effects at different levels of the HPA axis, and on modulatory influences of the hypothalamic-pituitary-gonadal hormones and serotonin.

**Conclusion:** Considering the amount of scientific evidence it seems very plausible to admit the influence of prenatally alcohol exposure to developmental changes in the maturation of the hypothalamic-pituitary-adrenal axis leading to its late dysfunction in life and, therefore,

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#### **The voices of youth with Fetal Alcohol Spectrum Disorder: transitioning from child welfare care to adulthood**

Linda Burnside<sup>1,2</sup>

<sup>1</sup>Avocation Counselling, Consulting, Research & Training, <sup>2</sup>University of Manitoba, Faculty of Social Work, Canada

**Objectives:** Fetal Alcohol Spectrum Disorder (FASD) is increasingly recognized as a serious disability affecting a significant number of children in child welfare care in Canada. Since 2004, researchers in Manitoba, Canada have examined the experiences of children in care with FASD, learning about their placement experiences, health care needs, educational outcomes, and financial costs to the system. This workshop will provide a brief overview of the results of this research, with an emphasis on their most recent study: the experiences of youth with FASD as they transition to adulthood from child welfare care.

**Materials & Methods:** Qualitative interviews were conducted in 2009 – 2010 with 20 youth with FASD who had grown up in child welfare care.

**Results:** This study provides a rare opportunity to hear directly from youth with FASD about their needs. The youth shared poignant information about their lives, their hopes and fears for the future, and what they need to transition to adulthood successfully. In particular, youth demonstrated that there is a mismatch between agencies' efforts to prepare them for adult responsibilities when they are developmentally unable to make use of these services until well into early adulthood. Their perspectives hold compelling insights for child welfare agencies who work with youth as they emancipate from care, both adolescents with FASD as well as other youth in care.

**Conclusions:** The impact of FASD is devastating for the children affected by the condition and has considerable implications for child welfare agencies that support them to adulthood. This research points to the need to develop unique transitional services to facilitate emancipation for these vulnerable youth, including a reformation of traditional child welfare services. These recommendations for reformation will be identified, outlining the benefits for youth with FASD and the implications for child welfare service delivery.

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**“to matter, to be heard, to make sense of oneself”**

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**Objectives:** Parents who are raising a child with FASD often feel alone and misunderstood. This presentation, “to matter, to be heard, to make sense of oneself” will outline a model of support for families that is based on applied research which has been validated and affirmed in the North American context. Through a look at this support group model, attendees will gain knowledge of

the importance of parental support as an essential component to long term success for individuals with FASD.

**Materials & Methods:** The author conducted research with a basic study group comprised of adoptive and foster parents and investigated how essential it is that parents receive appropriate support from professionals in order to be able to fulfill their roles and prevent family breakdown.

**Results:** This study has been reviewed by government and local community agencies and is considered a model to be replicated. The author has a co-written a curriculum based on this work for government and presented it to local practitioners.

**Conclusion:** Parents are vital stakeholders in the lives of individuals with FASD; however, they are often misunderstood, criticized, and isolated. As professionals and paraprofessionals help them “to matter, to be heard and to take sense of oneself”, parents are better equipped to be the lifelong advocates that their children need them to be.

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**Canada Fetal Alcohol Spectrum Disorder research network: a provincial partnership model's evolution to a national entity**

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**Objectives:** Internationally, Fetal Alcohol Spectrum Disorder (FASD) is a significant issue and it is anticipated that generation and sharing of research data will have a positive impact on the lives of those affected by FASD through a better understanding of etiologies and interventions and through more effective program/policy development. Although there have been attempts to consolidate and coordinate efforts, FASD research remains fragmented in Canada and the reciprocal translation of knowledge from the research field that impacts policy and program development, and back, is inadequate. To address this, a new Canada FASD Research Network (CanFASD) was formed to support Canada's leadership in addressing the extraordinary complexities of FASD. The mission is to produce and maintain national, collaborative research designed for sharing with all Canadians, leading to prevention strategies and improved support services for people affected by FASD. The efforts of the Network

focus on generating/translating knowledge, building capacity and creating partnerships.

**Materials & Methods:** CanFASD evolved from a unique provincial partnership model with priorities that paralleled those of Canadians. The Canada Northwest FASD Research Network was established in March of 2005 through support of seven Provincial/territorial Ministers. Recognizing the importance of coordinating relevant research along thematic areas, the network led the cross jurisdictional coordination of FASD research. The outcome was collaborative Network Action Teams working in areas important to Canadians: diagnostics, intervention and prevention. Teams have been very successful at leveraging resources, creating research capacity and have made significant contributions to the FASD field.

**Results:** With increased capacity for FASD research and with the Network's facilitation and stimulation of research, Canada has developed a National vision and has demonstrated International leadership in the field of FASD. The Network will begin to work globally to build and share expertise, tools, platforms and experience that will ultimately improve the lives of affected individuals and their families.

**Conclusion:** Lessons learned from the evolution of this unique provincial partnership model can be applied in other jurisdictions to significantly increase capacity and knowledge related to policy-relevant FASD research.

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### To what extent is research informing service planning and delivery for individuals with Fetal Alcohol Spectrum Disorders in Alberta, Canada?

David St. Arnault, Jenelle Job, Cheryl Poth, Jacqueline Pei, Ellis Chan, Erin Atkinson, Wence Leung, Laura Gould, Kendra McCallum

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**Objectives:** This poster reports a research project assessing the impact of a cross-sectorial strategic plan for enhancing service delivery for individuals with FASD in Alberta, Canada. Specifically this poster is focused on the methods and findings related to the extent to which research informs the planning and delivery of provincial services from the perspectives of policy makers, program coordinators, program managers, and direct service providers.

**Materials & Methods:** A qualitative approach involving multiple focus groups (n=20) and semi-structured interviews (n=15) was employed with FASD specialists from across the province (total n=150). Participants included government officials who were

members of the FASD Cross-Ministry Committee, FASD Service Network coordinators, assessment and diagnosis FASD clinic managers and FASD service providers. Focus groups and interviews were transcribed verbatim, analyzed using thematic analysis, and compared within followed by across roles.

**Results:** Analysis is ongoing and preliminary results suggest that FASD specialists in Alberta are engaged in knowledge utilization (that is making research accessible and using it to inform decision-making) in both the planning and delivery of services. However, the method of access and the frequency of use varies by role. For example, policy makers generally reported having close relationships with academic researchers and research networks; while, service providers reported receiving much of their research information through their training sessions. Anticipated analysis includes further examination of the challenges to accessing and utilizing research knowledge for service planning and delivery for individuals with FASD.

**Conclusion:** Access and use of research as key for service planning and delivery decision-making has the strong potential for more relevant policy and services for individuals with FASD. This study provides a template for other jurisdictions to assess the extent of access and research use in their own organizational decision-making process.

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### A qualitative investigation of alcohol use advice during pregnancy: experiences of Dutch midwives, pregnant women and their partners

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**Objective:** Two studies aimed to explore the advice Dutch midwives give and the information Dutch pregnant women and partners of pregnant women receive about alcohol consumption in pregnancy.

**Materials & Methods:** Study 1 included individual semi-structured interviews with midwives. Study 2 involved focus groups and individual semi-structured interviews with pregnant women and partners. Interview content was based on the I-Change Model. Study 1 was conducted nation-wide; Study 2 was conducted in the central and southern regions of the Netherlands. Respondents were ten midwives in Study 1; 25 pregnant women and 9 partners in Study 2.

**Results:** Study 1 showed that midwives intended to advise complete abstinence, although this advice was

mostly given when women indicated to consume alcohol. Midwives reported to lack good screening skills and sufficient knowledge about the mechanisms and consequences of prenatal alcohol use and did not involve partners in their alcohol advice. In Study 2, pregnant women and partners confirmed the findings of Study 1. In addition, pregnant women and partners considered midwives as an important source of information on alcohol in pregnancy. Partners were interested in the subject, had a liberal view on prenatal alcohol use and felt ignored by midwives and websites. Pregnant women indicated to receive conflicting alcohol advice from their health professionals.

**Conclusions:** Midwives' alcohol advice requires improvement with regard to screening, knowledge about mechanisms and consequences of prenatal alcohol use and the involvement of the partners in alcohol advice during pregnancy. This research implies that training should be given to Dutch midwives to increase their screening skills and their alcohol related knowledge to pregnant women. Research is needed to determine how the midwife's alcohol advice to the partner should be framed in order to optimize the partner's involvement concerning alcohol abstinence in pregnancy.

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#### **Testing ethylglucuronide in maternal hair and nails for the assessment of fetal exposure to maternal alcohol: comparison with neonatal meconium testing**

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**Objectives:** The deleterious effects exerted by prenatal ethanol exposure include physical, mental, behavioural and/or learning disabilities that are included in the term fetal alcohol spectrum disorder (FASD). The measurement of ethylglucuronide (EtG) in alternative biological matrices, including neonatal and maternal hair, neonatal meconium, and maternal nails is receiving increasing interest for the accurate evaluation of the utero exposure to alcohol.

**Aims:** The aim of the present study was to evaluate the correlation between EtG in maternal hair and nails with EtG in neonatal meconium to further explore the

suitability of these biomarkers in disclosing prenatal exposure to ethanol.

**Materials & Methods:** A total of 151 maternal hair strands (0-6 cm), nail clips (2-6 mm) and corresponding neonatal meconium and nails samples were obtained from neonatal wards of 4 Mediterranean public hospitals: Rome, Florence and Belluno in Italy and Barcelona in Spain. Hair, nails and meconium were analyzed for the presence of EtG by validated liquid chromatography mass spectrometry assay. Meconium was also analyzed for the presence of fatty acid ethyl esters (FAEEs) as a complementary biomarker of in utero exposure to alcohol.

**Results:** On the basis of the accepted cut-off for EtG and FAEEs in neonatal meconium, 18 newborns resulted in utero exposed to maternal alcohol consumption. Unfortunately, none of these cases were confirmed by the presence of EtG in maternal hair and nails, which resulted all negative to this biomarker. Conversely, one high positive result in nails (24 pg EtG/mg nail) was obtained in Pakistan woman, whose hair resulted negative to EtG likewise the meconium of her newborn. Low maternal education level was associated with biomarker scores over the cutoff. There was also a significant correlation between the highest percentage of prenatal exposure in the capital and certain maternal sociodemographic characteristics.

**Conclusion:** Obtained results confirm that EtG and FAEEs in meconium are the best biomarker to assess in utero exposure to maternal alcohol. The 18 newborns exposed to maternal ethanol came from mothers who declared alcohol consumption through the entire pregnancy, but not on daily basis and with no more than 1 drink per day. This fact led us to suppose that firstly EtG in hair and nails is not a good biomarker to disclose an alcohol consumption lower than on daily basis and lower than one alcoholic unit per day. Secondly that both in case of hair and in that of nails, the amount of collected sample is crucial to obtain a positive result, since available methods are yet not enough sensitive for less than 20 mg keratin matrices.

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#### **“A Pregnancy Without”, a public awareness campaign for women about the incompatibility of alcohol consumption during pregnancy**

Juan Luis Delgado

Fetal Medicine Unit - Hospital “Virgen de la Arrixaca” (Murcia)

**Objectives:** According to a study at the Hospital Virgen de la Arrixaca of Murcia, only 29% of women don't drink any alcohol in the preconception period (the most critical to the fetus). The Royal College of

Obstetricians and Gynaecologists has announced that a low level consumption of alcohol (1 or 2 units once or twice a week) has not yet been found to be harmful to women or their babies (<http://www.rcog.org.uk/index.asp?PageID=1996>).

However, the Spanish Society of Obstetrics and Gynecology (SEGO), in cooperation with the Association of Brewers of Spain, has launched, since 2009, the educational campaign "A pregnancy without", which aims to raise awareness among pregnant women about the incompatibility of alcohol consumption during the pregnancy period, with the slogan "Because he drinks what you drink". The campaign is proposed to beer drinkers; who are pregnant; plan to become pregnant or breastfeeding, choose non-alcoholic variety.

**Materials & Methods:** During the campaign messages are disseminated through information materials, supervised by the Spanish Ministry of Health, gynecologists across the country providing useful information about alcohol-free beer as an alternative to the traditional one and how could integrated into the habits of the pregnant woman. Additionally, the campaign also includes the dissemination of information brochure that is aimed at pregnant women that has collected various recommendations to help them follow a complete and balanced diet. In order to increase the dispread of messages among pregnant women, and society in general, there was a wide broadcasting of campaign messages in the media.

**Results:** All members of SEGO (with 6,300 national partners) have received some information and materials on the properties of non-alcoholic beer as an alternative to traditional beer during pregnancy, emphasizing the dangers of drinking in this period. Also were distributed over 500,000 information brochure among pregnant women and women who want to be.

**Conclusion:** This campaign is an example of good practice in prevention and public health and scientific collaboration between an association whose objective is to ensure the health and individual sectors committed to preventing cases of inadequate intake of beer. Thanks to it has been possible to achieve satisfactory results in relation to the spread, helped by the information campaign in the media where the SEGO warned of fetal alcohol syndrome.

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**When nobody is there for you, it's the best thing that can ever happen": the role of mentoring in the lives of Canadian women with high risk substance misuse**

Linda Burnside<sup>1,2</sup>, Audrey McFarlane<sup>2</sup>

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**Objectives:** Mentoring has been found to be a critical intervention for women with high risk substance abuse issues, which can lead to giving birth to children with FASD. This presentation will provide an overview of the history of mentoring mothers with high risk substance misuse in Canada, focusing on the establishment of one of the first mentoring programs, at the Lakeland Centre for FASD in Cold Lake, Alberta, and describing the development of mentoring programs in northwestern Canada. Research regarding the experiences of women who have completed a mentoring program will also be shared, with an emphasis on the voices of women who participated in interviews about how mentoring changed their lives.

**Materials & Methods:** The presenters are the Executive Director of the Lakeland Centre for FASD, who will speak about the history of mentoring from a Canadian perspective, and a researcher who had conducted a qualitative study into the experiences of women who have a completed a mentoring program in Canada.

**Results:** Both the program experience at the Lakeland Centre for FASD and the results of the qualitative study demonstrate how mentoring is making a positive difference in women's lives, leading to healthier and more stable lives, better parenting, and reduced risk of using substances, especially during pregnancy.

**Conclusions:** Mentoring is an important strategy that should be expanded in Canada and implemented in other jurisdictions to prevent FASD and help women deal with substance abuse.

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**Patients with FAS: the significance of an early diagnosis**

Reinhold Feldmann

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**Background:** Alcoholism during pregnancy is one of the most common factors in western societies causing persisting congenital and multiple physical as well as neurological impairments. Finding the diagnosis at first sight puts medical professionals into a demanding situation. Therefore, the objective of this study was to detect patients' developmental characteristics with the main focus on the necessity of the diagnosis itself.

**Patients:** 125 young patients, whose diagnosis of fetal alcohol syndrome (FAS) was made at the Muenster University Hospital, were followed up.

**Materials & Methods:** Biographic details such as living conditions, health, developmental problems and educational career were gathered using a structured interview. The diagnosis itself and the impact of this on the patients were also explored.

**Results:** Patients displayed characteristics of a less mature trait of character. The majority were looked after by foster parents. High rates of social and developmental problems could be found. The diagnosis was identified as a protective factor, with significantly better outcomes for patients being diagnosed in early childhood. A diagnosis established later in life was particularly helpful for the families and caregivers. Feelings of failure and self-blame could be diminished.

**Conclusions:** The early detection of affected children has to be improved as receiving the correct diagnosis, despite the persistent impairments, is of major benefit for both patients and their families.

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#### **Preterm birth: effects of patients with FAS**

Reinhold Feldmann

Department of Pediatrics, University Hospital Muenster, Germany

**Objective:** For children with Fetal Alcohol Syndrome (FAS) preterm birth (PTB) is frequently reported. Preterm birth may cause a variety of motor and cognitive deficits in the premature infant. The effect of preterm birth on the motor cognitive outcome in patients with FAS is unknown.

**Materials & Methods:** We assessed the mental and motor development of 48 children with PTB and 30 children with FAS using the Bayley Scales of Infant Development (BSID-II). Groups were matched for age (PTB: M = 25 months, SD = 3 months; FAS: M = 27 months, SD = 6 months). Of the children with PTB, 31 had bronchopulmonary dysplasia and/or intracranial hemorrhage, 17 had no birth complications. Of the FAS children, 12 had PTB (all without birth complications).

**Results:** In the BSID-II, PTB children without birth complications had a mean mental (MDI) and psychomotor development index (PDI) that were close to normal (MDI = 98, PDI = 92). PTB children with birth complications had a mean MDI of 85 and a mean PDI of 81. Children with FAS had a mean MDI of 79 and a mean PDI of 80. MDI was higher in FAS children with PTB compared to FAS children without PTB (81 vs. 77).

**Conclusions:** PTB, although frequently in FAS, seems not to contribute to the mental or motor development deficits in children with FAS. Deficits are caused predominantly by the prenatal alcohol exposure (PAE).

Moreover, in children with FAS, PTB without complications seems to moderate the effects of PAE.

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#### **Challenges and possibilities for learners with FASD through literacy interventions**

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**Objectives:** The main objective of the research was to explore early literacy interventions for children with FASD to prevent secondary disabilities and resulting adverse life outcomes. Early diagnosis, strengths and weaknesses revealed in brain domains, and MRI and FMRI's are evolving sources of information about how brain structure and functioning is affected by fetal alcohol exposure, resulting in different pathways of learning. Learning theories, on which education is based, are grounded on assumptions that may not match age-based functioning level of those with FASD. Some of these assumptions include: short term memory skills; ability to focus and sustain attention, self-regulate, multi-task; sequence, appreciate cause and effect or consequences; and ability to think abstractly, generalize, predict, problem-solve and comprehend abstract concepts all of which are often problematic for learners with brain-based disabilities such as FASD.

**Materials & Methods:** Most children with FASD have varied cognitive and academic profiles, with strengths and weaknesses which present a myriad of educational challenges. This naturalistic inquiry addresses dynamic assessments, which are mediated learning experiences and observations of the actual processes by which a learner participates and make meaning in literacy activities. The purpose is to estimate learning potential of a learner with FASD, assessing maximal activity through the presentation of learning tasks. Rather than norms, comparison of individual skills and strategies occur across time within a learner's personal profile.

**Results:** Approaches that can engage the learner must be cognizant of and responsive to their brain-based difficulties in order to be effective. Children with FASD may be able to read the words, but not always comprehend the meaning conveyed. Their executive functioning skills are also impaired, so they will need assistance in order to predict, sequence, organize, synthesize, remember, and apply what they have learned. One to one instruction, role-modeling and metacognitive strategies, learning through real life learning experiences, visual representations, "drawing-while-storying" and other multi-modal approaches to learning, are important factors in their learning. Due to

the plasticity of the brain, multi-modal instruction can help to stimulate the creation of new synapses or the finding of alternate neural pathways for learning.

**Conclusions:** Stimulating comprehension "before reading and during reading" through drawings, storyboards, concept maps, plot diagrams, charts, models, and digital images assists learners in focusing on, understanding, and comprehending what they read while they read. It is when the FASD learner becomes an active, engaged, multimodal, metacognitive, and meaning-making reader and learner that transformation occurs.

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### Systematic review on the effectiveness of prevention approaches for fetal alcohol spectrum disorders

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**Objectives:** Preventing fetal alcohol spectrum disorders (FASD) is a public health priority. FASD prevention programs can be broadly categorized into universal, selective and indicated based upon the breadth of the target population, the risk of having children with FASD, and the cost-benefit ratio of committing resources. Establishing and strengthening policies and plans for FASD prevention require an informed consideration of what is known to be effective. The objective of this systematic review was to evaluate the scientific literature on the effectiveness of FASD prevention on prenatal alcohol use- and FASD-related outcomes.

**Materials & Methods:** Searches in biomedical electronic databases and the grey literature were conducted for the period from 1970 to February 2012 to identify studies (i.e., randomized controlled clinical trials (RCTs), observational analytical cohort studies, and uncontrolled trials) assessing universal, selective, and indicated prevention interventions targeting the broad community, pregnant women, women of childbearing age, women at risk of an alcohol-exposed pregnancy (AEP) or of having a child with FASD.

**Results:** From 3,455 references retrieved, 59 studies met the eligibility criteria and were included in the review (Universal = 19, Selective = 30; Indicated = 10). The best scientific evidence on the effectiveness of universal FASD prevention is derived from two studies of moderate-to-weak methodological quality that evaluated a *multimedia education program* targeting youth in the community. Multimedia and macro-level

education programs produced a statistically significant improvement in the level of knowledge regarding FASD and the effects of alcohol drinking during pregnancy. Studies assessing universal interventions such as alcohol-related warning messages, health educational activities and alcohol bans were of poor quality; and, overall, did not show that these interventions lead to significant modifications in knowledge, attitudes and perceptions of risks associated with drinking during pregnancy. Compared to universal preventive interventions, the following selective preventive interventions have a better scientific evidence base (overall strong and moderate quality) for their effectiveness: motivational interviewing, counselling activities and health education programs for women of childbearing age who consume alcohol, pregnant women, and women at risk of AEP. The scientific evidence supporting the effectiveness of indicated approaches is weak and inconclusive.

**Conclusion:** The scientific base to support the effectiveness of universal and indicated approaches for prevention of FASD is limited. Moderate evidence for selective prevention activities such as counselling, motivational interviewing and health education for pregnant women and women at risk of AEP is encouraging.

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### What do we know from systematic reviews about prevention of fetal alcohol spectrum disorders?

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**Objectives:** A number of systematic reviews have been conducted in the area of prevention of fetal alcohol spectrum disorders (FASD); however, it is necessary to further evaluate their characteristics, methodology and results to attain greater confidence in their conclusions and contributions into prevention policy formulations. The objective of this overview was to identify the scientific evidence on best FASD prevention practices synthesized in systematic reviews.

**Materials & Methods:** Searches in biomedical electronic databases and the grey literature were conducted up to February 2012 to identify systematic reviews (SRs) that evaluated the effectiveness of FASD prevention interventions. A SR was required to: have a clearly formulated research question; a search strategy for identifying studies for inclusion; it should use explicit, reproducible, and uniformly applied criteria

for article selection and incorporate a critical appraisal component.

**Results:** From 207 references retrieved, six SRs met the eligibility criteria and were included in the overview. The scientific evidence analyzed in the overview indicates that prenatal screening tools (i.e., ACE-T and TWEAK) are likely to be effective in identifying prenatal alcohol use. There is some scientific evidence that brief interventions in the form of clinical advice and counselling about the risks of prenatal alcohol exposure can help to reduce the risk of alcohol-exposed pregnancy among women of childbearing age. The scientific evidence regarding other prevention approaches, such as home visits, education and counselling remains uncertain from an overview analysis. None of the SRs identified in the overview conducted subgroup analyses to evaluate the impact of prevention interventions in special population groups.

**Conclusion:** The development, evaluation and dissemination of preventive evidence-based interventions for FASD and prenatal alcohol use have lagged significantly since the disorder was identified in the 1970s. Encouragingly, some scientific evidence has accumulated regarding the effectiveness of prenatal alcohol screening tools and certain preventive approaches to FASD and prenatal alcohol use such as brief and intensive interventions. It is important to increase efforts to expand the scientific base that is needed to inform policy and healthcare decisions regarding prevention of alcohol consumption during pregnancy and the development of FASD.

## 98

### What is happening in the Russian Federation in terms of research on Fetal Alcohol Spectrum Disorder and prenatal alcohol exposure?

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<sup>1</sup>Department of Analysis and Implementation of Prevention Programs, National Research Centre on Addiction, Moscow, Russian Federation; <sup>2</sup>Department of Psychiatry, Addiction and Psychotherapy, Moscow State University of Medicine and Dentistry, Moscow, Russian Federation; <sup>3</sup>Department of Clinical Psychology, Moscow State University of Medicine and Dentistry, Moscow, Russian Federation; <sup>4</sup>Social and Epidemiological Research Department, Centre for Addiction and Mental Health, Toronto, Ontario, Canada; <sup>5</sup>Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada; <sup>6</sup>Epidemiological Research Unit, Klinische

Psychologie und Psychotherapie, Technische Universität Dresden, Dresden, Germany; <sup>7</sup>Factor-Inwentash Faculty of Social Work, University of Toronto, Toronto, Ontario Canada

**Objectives:** The Russian Federation has one of the highest rates of alcohol consumption in the world; however, little is known about the existing pool of research related to prenatal alcohol exposure, and particularly Fetal Alcohol Spectrum Disorder (FASD) in this country. The objective of this study was to locate and review published and unpublished studies concerning any aspects related to FASD and prenatal alcohol exposure conducted in or using populations from the Russian Federation.

**Materials & Methods:** A systematic literature search was performed simultaneously in the Russian Federation and Canada. The search was conducted in multiple (English and Russian) electronic bibliographic databases, using multiple combinations of the key words in both Russian and English. In addition, the search was conducted in several major libraries in Moscow.

**Results:** In total, only 60 studies were identified and included in the current review: 48 studies were in Russian and 12 were in English. The examined studies can be categorized into the following four major groups: those that 1) assessed alcohol consumption during pregnancy; 2) examined Fetal Alcohol Syndrome (FAS) and FASD prevalence in the general population, and/or foster homes and orphanages; 3) clinically examined children and adults and demonstrated the life-long polysystemic teratogenic effect of alcohol on the fetus; and 4) experimentally studied the teratogenic effect of alcohol on laboratory animals. The results of the studies are exceptionally alarming. Alcohol consumption during pregnancy varies from approximately 14% to 83% in various regions of the Russian Federation. Binge drinking is reported to occur in up to 21% of pregnancies. The prevalence of FAS in the general population was estimated in only one study, which reported the prevalence to be as 18-19 per 1,000 live births. This figure is approximately 20 times higher than that reported for the general population of Canada. The prevalence of FAS in orphanages for children with special needs was reported extremely high – ranging from about 427 to 680 per 1,000.

**Conclusion:** Given the alarming prevalence rates of prenatal alcohol exposure and FASD, very little is being done in terms of research in this area within the Russian Federation. An increase in attention by the research community is urgently needed in order to improve the overall awareness of the negative consequences of consuming alcohol while pregnant, as well as the initiation of preventive measures in this country.



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### Concurrent alcohol and drugs consumption in pregnancy

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**Objectives:** to describe prevalence and risk factors for simultaneous use of alcohol and drugs in a population of pregnant women attending a major hospital in Rome for antenatal visit.

**Materials & Methods:** Women attending an antenatal clinic in Policlinico Umberto I in Rome volunteered to be interviewed about alcohol and drugs consumption during pregnancy, through a semi-structured interview, while waiting for their visit. Data were gathered from June 2011 to May 2012.

**Results:** Consent to be interviewed was given by all the women approached (N = 991; mean age =32,3 SD=5,7). Main results showed that 68,6% drank before pregnancy and 5,4% used drugs, these behaviours being highly significantly related. Women using both alcohol and drugs before pregnancy were 5,9%. During pregnancy the percentage of women consuming both substances decreased to 2,2% in the first trimester and to 0,7% in the second one. None of the women interviewed consumed drugs during the third trimester. The majority (70,6%) of those consuming both substances before pregnancy was under 30, while during pregnancy all consumers were under 30. Moreover, consumers during pregnancy could be either married/cohabitant or single; 50% were manual workers and 50% were a managers. Even if 26,8% of women interviewed were foreigner, 100% of those performing both consumptions were Italian.

**Conclusions:** A minor but significant number of children are exposed in utero to the adverse outcomes of concurrent use of alcohol and drugs. The contemporary use of alcohol and drugs increases the risk of giving birth to an affected child. Therefore fertile age women using both substances represent a very high risk category, that needs to be targeted by selective and indicated preventive interventions.

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### The experience of the National Organization on Fetal Alcohol Syndrome (NOFAS): twenty three years of FASD prevention, media, and policy in the United States

Kathleen Tavenner Mitchell

Washington, DC, USA

**Email:** [mitchell@nofas.org](mailto:mitchell@nofas.org)

**Objectives:** Participants will learn about the twenty-three year history of the National Organization on Fetal Alcohol Syndrome (NOFAS). Attendees will be provided with an overview of historical timeline media, policy, prevention and treatment efforts in the United States.

**Materials & Methods:** The speaker will use a Power Point presentation including personal photos while describing her personal journey, 23 years of photos and campaigns from NOFAS projects, television excerpts and historical timelines. Participants will receive free FASD prevention materials from NOFAS and the Centers for Disease Control (Fact Sheets, brochures, FASD Diagnostic publications, posters, DVD's – English and Spanish).

**Results:** Conference participants will be able to describe the history of NOFAS and how the U.S. has adapted policy and programs to address FASD. The audience will be introduced to innovative approaches to FASD prevention designed to for specific target groups.

**Conclusion:** The audience will be able to describe the evolution of understanding and preventing FASD in the U.S. They will gain information about the role and purpose of NOFAS. Participants will understand the need for a grassroots advocacy group in educating policy makers and gaining government support of FASD research, prevention and intervention. The take away message will be to consider what Margaret Mead reminded us all: “that a small group of committed individuals can change the world.”

101

### Outcome of young adults exposed *in utero* with different levels of alcohol

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**Objectives:** The main goal of the study is to show the relation between different levels of mothers' alcohol consumption during the years 1985-1986 and the

outcome of their children at the age of 25 and 26. We want to examine specifically the following aspects: educational, scholar or professional issues, addictions or psychiatric diseases, loss of independence, positive and negative life events, violent or criminal behaviour. A second objective is to determine a possible threshold beyond which these items are significantly altered. At last, we can find out if the problems detected at the age of four when they completed a series of tests persist at *adult age*.

**Materials & Methods:** The protocol was submitted and approved by the CNIL (Commission Nationale Informatique et Liberté) and the CCTIRS (Comité Consultatif sur le Traitement de l'Information en matière de Recherche dans le domaine de la Santé). The sample is composed of 155 adults born in Roubaix Maternity Ward between 1985 and 1986. Their mothers were asked at the time about their habits during pregnancy. Alcohol and tobacco consumption were part of the questions. They were divided into four sub groups depending on the alcohol's assessment: from zero to six standard drinks a week, from seven to thirteen, from fourteen to twenty and above twenty-one. They all lived in Roubaix urban area in 1990, last time they were evaluated, but we had to update the mailing address list. We used the available data bases we had access to, such as the Social Security services and the Hospital administrative software. Then we interviewed the subjects of the study over the phone. The questionnaire was made of sixty seven items about health, education, professional life, life events and personal issues.

**Results:** The participation rate was 49.7% (77/155) with no significant differences between the sub groups. The 21 years span with no intermediate study to update personal information was an issue. Forty subjects were lost to follow up due to incorrect addresses. Twelve refused to participate. One was reported deceased. The complete results will be available for the Barcelona Congress.

**Conclusion:** The current study probably failed to show any significant difference in the health, psychosocial life of young adults related to their mother's alcohol consumption during pregnancy. The sample appeared to be too small. However, a slight difference in negative life events during the infancy tends to point out the social vulnerability of heavy drinker families.

## 102

### **The National Organization on Fetal Alcohol Syndrome (NOFAS): twenty three years of FASD prevention, media, and policy in the United States**

Kathleen Tavenner Mitchell

Washington, DC, USA

**Email:** [mitchell@nofas.org](mailto:mitchell@nofas.org)

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**Results:** Conference participants will be able to describe the history of NOFAS and how the U.S. has adapted policy and programs to address FASD. The audience will be introduced to innovative approaches to FASD prevention designed to for specific target groups.

**Conclusion:** The audience will be able to describe the evolution of understanding and preventing FASD in the U.S. They will gain information about the role and purpose of NOFAS. Participants will understand the need for a grassroots advocacy group in educating policy makers and gaining government support of FASD research, prevention and intervention. The take away message will be to consider what Margaret Mead reminded us all: "that a small group of committed individuals can change the world."

## 103

### **Preventing FASD in school age populations: twenty-three years of lessons learned**

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**Objectives:** This workshop will provide information on NOFAS (U.S.) FASD prevention targeted for school age populations. The presenter will review the steps taken to develop a highly successful peer youth project and the NOFAS K-12 FASD Prevention Curriculum. The peer program, known as REACH (**R**educing FASD through **E**mpowerment, **A**dvocacy, **C**ommunity action and **H**ealth education) was a community based demonstration initiative that included four sites in Washington, D.C. Participants will also receive an overview of the development process and dissemination of the K-12 curriculum. Other notable

youth efforts will be reviewed including the NOFAS FASD Teen Town meetings, FASD regional and national poster contests and a program designed to reach American Indian students.

**Materials & Methods:** Powerpoint, excerpt from DVD, FASD Brain model, K-12 curricula lesson plans, and posters designed by youth.

**Results:** Participants will learn about several programs designed to educate students about FASD and to get youth involved with FASD prevention.

**Conclusions:** Attendees will be introduced to a variety of youth focused programs that have successfully educated young people about the dangers of using alcohol while pregnant. different projects

#### 104

##### **Neurodevelopmental characteristics of newborns exposed to maternal alcohol as proved by meconium screening**

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**Objectives:** Alcohol is a known teratogen of the fetus. Early identification of an affected infant is important and may prevent secondary disabilities. Since maternal self-report is not **always** a reliable diagnostic tool, the development of a biomarker for in utero alcohol exposure becomes a necessity. At moment, fatty acid ethyl esters (FAEE) and Ethylglucuronide (EtG) are measured in neonatal meconium to demonstrate in utero exposure to maternal alcohol. What it has not yet known if these two biomarkers can be used for identifying children at risk for alcohol-related disabilities due to a relatively low incidence of diagnosis of Fetal alcohol spectrum disorders (FASD) among alcohol-exposed infants. As a matter of fact, alcohol-exposed infants may only manifest subtle fetal-alcohol effects at birth but show neuro-developmental characteristics at a later time. We aimed to carry out a prospective, case control study of infants with meconium positive to FAEEs and EtG vs infants with negative test, prompting active follow-up of the infant's development, and eventually identifying early neuro-developmental delays and adaptive inabilities suggestive of FASD.

**Materials & Methods:** Eight children (mean age 16 months; s.d. 2,3) positive for FAEEs and EtG in

meconium and eight children (mean age 17 months; s.d. 1,4) negative for the biomarkers in meconium were enrolled in the study.

Detailed evaluation was carried out on each child to get information about: **1)** physical growth and dysmorphological data collected by pediatrician, **2)** cognitive motor development and the adaptive abilities assessed using the Griffiths Mental Development Scales and Vineland Adaptive Behaviour Scale. T-tests were performed to evaluate the differences between the two groups (positive to meconium test vs. negative meconium test) concerning cognitive motor development and the adaptive abilities.

**Results:** None of the children (both positive and negative to meconium test) showed any dysmorphological feature typical of FASD. Physical growth measures always fell into a normal range. However, children positive to meconium test performed significantly poorer on locomotor ( $P<0.003$ ), and eye-hand coordination scales ( $P<0.049$ ) from the Griffiths Mental Development Scales and had significantly lower scores on the communication ( $P<0.05$ ) and socialization ( $P<0.039$ ) subscales of Vineland Adaptive Behaviour Scale.

**Conclusion:** The obtained data clearly demonstrated in the children positive to meconium test the presence of neuro-cognitive and motor developmental delays and adaptive inabilities suggestive of FASD, even in the absence of dysmorphological features.

#### 105

##### **Early ethanol exposure affects NGF and BDNF but not their receptors, TrkA and TrkB, in the aged mouse thyroid**

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**Objectives:** Alcohol consumption during pregnancy and lactation has been shown to induce severe damage to the fetus both at neurobiological and endocrine levels by inducing in children a variety of effects leading to Fetal Alcohol Spectrum Disorder (FASD). FASD may include physical, mental, behavioral and/or learning disabilities with possible lifelong implications. Some key features of FASD onset involve changes in the endocrine system, including thyroid, and disruptions at nerve growth factor (NGF) and brain derived neurotrophic factor (BDNF) levels also during aging as shown in animal models.

**Materials & Methods:** The aim of the present study was to investigate in the thyroid of a FASD mouse model the long lasting effects of ethanol exposure during pregnancy and lactation on NGF and BDNF and their main receptors, TrkA and TrkB. For this purpose we used aged male mice exposed during fetal life and during lactation to ethanol or red wine at same ethanol concentration (11% vol).

**Results:** We found elevated concentrations of both NGF and BDNF in the mouse thyroid tissue exposed to ethanol solution only but not in the red wine group. These findings were associated with no changes in TrkA and TrkB.

**Conclusion:** The present findings may indicate that early administration of ethanol may induce long-lasting damage in the thyroid at NGF and BDNF level implicating early endocrine programming. Furthermore, the differences in prenatal ethanol-induced toxicity when ethanol is administered alone or in red wine may be related to compounds with cell protective properties present in the red wine.

## 106

### Smoke and alcohol consumption in an Italian unselected population of pregnant women

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<sup>1</sup>Department of Gynecology- Obstetrics and Urological Science, Sapienza University, Rome, Italy; <sup>2</sup>Sita Onlus, Rome, Italy; <sup>3</sup>Alcohol Unit Latium Region, Sapienza University, Rome, Italy

**Objectives:** High-risk behaviours are associated with an increased risk of adverse pregnancy outcomes. The aim of this study is to describe risk behaviours in a population of Italian pregnant women. The main goal is make recognition of the reality of alcohol and smoke consumption in pregnant women.

**Materials & Methods:** Between November 2009 and April 2012 we collected data from 1000 unselected pregnant women, referring to Department of Gynecology-Obstetrics and Urological Science, Sapienza University of Rome. Pregnant women answered semi-structured questionnaire which investigated dietary habits, alcohol and smoke consumption before and during pregnancy.

**Results:** Of the 1000 women interviewed 68,6% consumed alcohol before pregnancy in a variable amount and 15,3% of these had more than one drink per occasion. During pregnancy 36,3% of women continued to drink alcohol and 5,8 % of these had more than one drink per occasion. Analyzing how they changed alcohol consumption since the beginning of

pregnancy, 44,4% of women suspended it, 29,6% decreased it, 25,4% did not change it and 0,6% even started during pregnancy. As regards with smoking habits, 32,8% of women used to smoke before pregnancy, 59,2% continued to smoke during the first trimester, 45,9% during second trimester and 32,4 % during third trimester. Data also showed that there is a statistically significant association between those who drank before pregnancy and those who smoked before pregnancy ( $p < 0,01$ ).

**Conclusion:** Smoke and alcohol consumption seems to be related in pregnant women, especially before pregnancy. Universal screening for alcohol consumption should be done periodically for all pregnant women and women of child-bearing age. At-risk drinking could be identified before pregnancy, allowing for change. Health care providers should inform their patients about possible risks related to high-risk behaviours during preconception counseling. They also should create a safe environment for women to report alcohol and smoke consumption. The public should be informed that alcohol screening and support for women at risk is part of routine women's health care. To women who continue to smoke and drink alcohol during pregnancy, harm reduction/treatment strategies and psychological support should be encouraged.

## 107

### Pilot study: Fetal Alcohol Spectrum Disorders related behavior problems in children in foster care

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**Objectives:** Early diagnosis of Fetal Alcohol Spectrum Disorders (FASD) is essential for the prevention of secondary problems. There are, however, strong indications that many children and adults with FASD go unrecognized and are untreated. In addition, some individuals with FASD are incorrectly diagnosed and receive the wrong treatment. This pilot study investigates to what degree FASD related behavior problems are present in children in foster care in The Netherlands.

**Materials & Methods:** Approximately 270 Dutch foster parents will be approached to participate in our study. Data will be collected for children, aged 6 to 16, who have been in their current foster family for over 6

months. Foster parents will be asked to fill out a digital questionnaire including demographic and background variables and including two instruments that were developed to detect children with FASD. The Fetal Alcohol Syndrome Questionnaire (FASQ) developed by Feldmann (Scheffner, 2011) includes 38 items presenting social, behavioral and emotional problems of children and adolescents indicative of FASD. The Neurobehavioural Screening Tool (NST; Nash, Koren, & Rovet, 2009) is based on ten questions from the Child Behavior Checklist.

**Results:** Data collection is in progress. Parents are currently being approached and asked to complete the questionnaire. First results are expected in September 2012.

**Conclusion:** Based on the high risk background of foster children, we expect that children in foster care show elevated levels of behavioral problems related to FASD, and that there is a significant relationship between these problems and the consumption of alcohol during pregnancy of the mother. An increased rate of such behavior problems will be a strong indication for the need for diagnosticians and foster care workers to focus more on FASD.

#### 108

**The health communication campaign ‘Mamma Beve, Bimbo Beve’. Efficacy of the communication plan and future strategies to increase awareness on FASD in the area of the Local Health Authority of Treviso (Italy)**

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<sup>1</sup>Doctoral school in Sciences of Reproduction and Development, University of Trieste, Italy; <sup>2</sup>Addiction Department, Local Health Authority of Treviso, Veneto Region, Italy; <sup>3</sup>Epidemiologic Unit, Local Health Authority of Treviso, Veneto Region, Italy; <sup>4</sup>Department of Innovation, Development and Planning, Local Health Authority of Treviso, Veneto Region, Italy; <sup>5</sup>Obstetrics and Gynaecology Unit, Local Health Authority of Treviso, Veneto Region, Italy

**Background:** In 2010 the Italian Local Health Authority of Treviso (Venetian Region) launched the health communication campaign ‘Mamma Beve, Bimbo Beve’ (‘Mummy Drinks, Baby Drinks’). The campaign was targeted to local women of child-bearing age and their families living in the area of the Local Health Authority, and was aimed to raise awareness about the dangers of drinking alcoholic beverages during pregnancy and breastfeeding. The visual was

conceived by Fabrica, the communication research centre of Benetton Group, and consisted of the advertising message ‘Mamma Beve, Bimbo Beve’ accompanied by the symbolic image of a foetus inside a glass of a typical local alcoholic drink called ‘spritz’.

**Materials & Methods:** The campaign used social marketing principles and involved different stakeholders from the community. Different actions were performed to spread the health message, including visual and print materials, street banners and bus banners, and a dedicated website.

**Results:** In 2011-2012, two main actions were performed: - the evaluation of the level of awareness of the campaign in the target population. A survey was carried out to assess the impact of the image used by the campaign - the identification and implementation of new strategies to continue to spread the health messages at a community level. These strategies include actions as a video-clip, that involved local comedians, a Facebook profile, and viral marketing actions.

#### 109

**Design and validation of a food frequency questionnaire for use in pregnant women consuming alcohol**

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**Objectives:** Recent evidence has suggested that the teratogenic effects of alcohol are exacerbated in the presence of sub-optimal maternal nutrition. Low dietary intakes of folate, choline, and antioxidants have been suggested as potential mechanisms for FASD. Therefore we aim to design and validate a semi-quantitative food frequency questionnaire (FFQ) to measure the intake of folate, choline, vitamin C and carotenoids in women of reproductive age. Once validated, the FFQ will be used in a sample of pregnant women consuming alcohol, as part of an on-going PhD study. The objectives of the study are to determine the concurrent validity between nutrient intake as assessed by the FFQ, 24-hour dietary recalls, and concentrations of nutritional biomarkers in blood.

**Materials & Methods:** The FFQ was based on a validated instrument designed to determine folate intake in adult males and females\*. Commonly eaten food groups for folate, choline, vitamin C and carotenoids were identified using data from the

National Diet & Nutrition Survey and the Low Income Diet & Nutrition Survey. Food sources rich in folate, choline, vitamin C, and carotenoids were then identified using The Composition of Foods integrated dataset and the USDA Database for the Choline Content of Common Foods. A food portion size booklet to accompany the FFQ was designed using A Photographic Atlas of Food Portion Sizes. A convenience sample of approximately 60 female participants of reproductive age (18 – 40years) will be recruited and required to complete a short screening questionnaire. Participants will then complete the self-administered FFQ and participate in a multiple-pass 24-hour dietary recall interview. Two further 24-hour dietary recall interviews will be completed over the next three-week period by telephone. Red cell folate, plasma choline, serum ascorbate and plasma carotenoid content will be measured from capillary blood samples. Blood samples will be centrifuged within one hour of collection using a hematospin 1400 for 15 minutes to separate the plasma from whole blood. Plasma will be stored at -70C until assayed. Red cell folate and plasma choline will be quantified using chemiluminescence methods. Plasma ascorbate and carotenoids will be quantified using HPLC methods.

**Results:** Data collection will begin on June 6<sup>th</sup> 2012. Data will be presented on the correlation between these different dietary assessment methods and blood biomarkers.

**Conclusion:** Conclusions will be drawn once data collection and analysis are complete.

**Acknowledgements:** \*We would like to acknowledge Dr Maria Pufulete and King's College London for allowing us to use and modify their folate FFQ for our own research purposes.

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### **A systematic review of the current literature investigating attachment and fetal alcohol spectrum disorders**

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**Objective:** The aim of this systematic report was to review the literature regarding the attachment styles of individuals with fetal alcohol spectrum disorders (FASD).

**Materials & Methods:** AMED, BNI, CINAHL, Embase, MEDLINE, ProQuest, PsycINFO, Pubmed Central, and Science Direct were systematically

searched using various FASD (FASD, PAE, FAS, FAE) terminologies alongside the keyword of attachment. Papers were also checked manually against records.

**Results:** The systematic searches yielded a mere eight articles and two dissertation abstracts dated from 1987 to 2009. Only two articles were found that addressed a specific FASD condition; which reported no effects upon the child's attachment. Five studies argued for an association between prenatal alcohol exposure and insecurity of attachment in offspring, one reported infrequent effects of alcohol on attachment, whereas the remaining two found no significant relationship; with one article contesting that any differences in attachment may be explained by low-quality care instead. All of the articles suffered from methodological issues including sample size, choice of measures and control of confounding variables; however the specific variable of intellectual functioning, which is commonly damaged within suffers of FASD, was not appropriately considered. Studies into attachment within children diagnosed with disorders that are frequently co-morbid with FASD, such as ADHD and ASD, may help to shed the light on *the effects of FASD*.

**Conclusions:** With many children born to alcohol addicted mothers being taken into care or experiencing neglect the lack of research and high prevalence within this group of neurodevelopmental disorders, further research is required to understand attachment styles in children with FASD

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### **FASD Mothers-FASD Children: early follow-up by the team of the CAMSP\* (Early Medico Social Action Center) Reunion Island France**

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**Background:** Here in Reunion Island we are confronted with mothers carrying FASD like their children and the specific problems that we encounter for their follow-up.

**Materials & Methods:** The clinical observations of these families by our multi-disciplinary team, has shed light on a certain number of particularities in the mother-child interactions.



Competencies and disabilities of these mothers in responding to the affective and educative needs of their children and dealing with the daily organization of family life.

The goals are:

- 1) To describe the specificities of the interactions between FASD mothers and their children.
- 2) To list the keys to observe those families. How to create a therapeutical alliance? How to change our vision and comprehension? How to positively encourage these mothers to allow the settlements of specific supports in the fields where they encounter the most difficulties?

**Conclusion:** A better understanding of those particularities will help all the professionals serving those populations to adjust and fine-tune their care.

**Acknowledgements:** \*CAMSP (*Centre d'actions medico-social précoce*) = *Medico Social Center for diagnosis, rehabilitation and support for disabled children from 0 to 6 years old and their parents.*

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### The Hope is in the interventions

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**Objectives:** Participants will understand: intervening for those with an FASD within the context of Dynamic Case Managements (DCM); an innovative intervention theory that will potentially produce positive outcomes for the individual with an FASD; the possible ethical issues that can arise in relationship to the use of the intervention theory processes.

**Materials & Methods:** Apple laptop computer, PowerPoint presentation (on computer and flashdrive), LCD projector, laser remote, handouts of the presentation slides. Instructor will lecture and, if time permits, instruct participants through experiential activities that will deepen their understanding of the concepts taught.

**Results:** Participants will gain a deeper understanding of the many “layers” involved with the provision of interventions for those with an FASD. Regardless of their role (i.e., care givers or service providers) participants will have tools that will aide the provision of appropriate interventions/accommodations for those with an FASD resulting in outcomes that positively support the life style.

**Conclusion:** As an FASD specialist, I gain a great deal of satisfaction from being able to pass on what I have learned about interventions and those with an FASD. Sharing the information at the conference provides the

opportunity to “pay it forward” to others involved in the provision of services or caring for those with an FASD.

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### Associated factors prenatal abuse: preliminary results of a population register

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**Background:** The child abuse is a public health problem and a global health priority of the Catalan Public Health Agency. The prenatal violence such as: inadequate intake of drugs, tobacco or alcohol consumption, personal body care neglect, and voluntary or involuntary pregnancy control are considered a public health problem. In 2009, the Catalan Public Health Agency in collaboration with the DGAIA (General Direction of infant and teenager Attention) implemented a population register, the Unified Register of Child Abuse (RUMI) in 40 pediatric hospitals of Catalonia. The RUMI is a tool that is used for early child abuse detection and protection, allowing us to know the status of this problem in our social environment and to evaluate it.

**Objectives:**

- 1) To describe the pattern of child abuse in Catalonia since the RUMI's implementation to the first quarter of 2012
- 2) To know the risk factors associated with prenatal violence of babies reported in the RUMI

**Materials & Methods:** A cross sectional study. The sample is based on notifications of child violence cases in RUMI register from 2009 to the first quarter of 2012. The variables collected were as follows: sex, abuse gravity, suspected case of certainty, alcohol consumption, tobacco consumption, drug consumption, body carelessness during pregnancy, violence of genre, ingestion of psychotropic substances. Statistical analysis was performed using the SPSS program.

**Results:** 813 cases were reported in the RUMI, 9,7% related to prenatal abuse, 45,8% physical abuse, 37,5% sexual abuse, 18% neglect, 12,4% psychological abuse (80% accompanied by other types of abuse). The pregnancy risk factors with notification of prenatal abuse were: 22% drinking alcohol, 65% smoking, 71,4 % consumption drugs and 22% psychotropic (mainly amphetamines), others minor risk factors: 65% didn't have followed pregnancy clinical guidelines and 6,5% reported having had gender violence. Related to drug

abuse: 29% cannabis, 21% cocaine, 19% opiates, 12% cocaine and opiates, 7% cocaine, opiates and cannabis, 9,5% cocaine and cannabis and 2,5% cannabis and opiates. Pregnant women who consume alcohol 100% smoking, 78,6% drugs consumption, 71.4% didn't have followed pregnancy clinical guidelines ( $p < 0.005$ ) and 28.6% psychotropic consumption ( $p > 0.005$ ).

**Conclusions:** The prenatal abuse covers a tenth of all child abuse reported in the RUMI. A quarter of pregnant women with this abuse, voluntarily or not, were detected with alcohol consumption. The consumption of tobacco and drugs and lack of care of your body are high risk factors related to alcohol consumption. The most consumed drug in pregnant women with child abuse is cannabis and cocaine. The RUMI is an important prevention and protection child abuse tool in Public Health field and it is also important for the multisectoral professionals involved.

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##### Using technology to create knowledge translation opportunities for FASD interventions

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**Objectives:** Researchers and clinicians need to develop novel mechanisms for translating knowledge to relevant stakeholders to inform change in healthcare practice and delivery. There is also a need within the general public for access to reliable and valid research findings. The research knowledge that is available is often not presented to the public in a relatable and easily accessible way. Fetal Alcohol Spectrum Disorder (FASD) is a good example of how knowledge needs to be disseminated more effectively as the diverse needs of this population require a multifaceted intervention approach. This presentation reflects the Canada FASD Research Network's innovative uses of technology and web-based tools to provide empirically evaluated information in a context-specific way to improve knowledge translation related to FASD intervention.

**Materials & Methods:** Peer reviewed research findings are paired with user friendly information sharing platforms to create a "one-stop shopping" network of FASD intervention information. In particular, three key modes of communicating research to the community will be presented: an electronic newsletter, a blog site, and an interactive website

created through a unique partnership between a research group and a corporate group. The process of establishing these communication platforms as well as evaluative strategies to assess impact of these approaches will be presented.

**Results:** Each of these communication strategies has shown increases in number and diversity of viewers. Number of blog viewers has been increasing by an average of 26% each month with viewers from 41 countries. Search terms leading viewers to the blog site illustrate the need for sharing of intervention research information and working intervention strategies. Newsletter mail-out numbers have increased 145% since commencement. Viewer statistics for the interactive website will be collected and presented.

**Conclusion:** Increased use patterns indicate interest and need for reliable and easily accessible intervention information. Feedback and viewer statistics show that use of online technology is an effective means of community engagement and communication. Next steps will include creating a simulation of FASD intervention situations that enables users to see potential outcomes from their intervention actions and decisions. This can also be used as a training tool for front line workers. The game will be based on a finite set of scenarios structured into "choices" that the user will make followed by the realistic outcomes that would result in a "choose your adventure" type scenario.

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##### Non-linear dose-dependent formation of ethanol exposure biomarkers

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**Objectives:** Subjects abusing alcohol can be identified through clinical history, examination or self-report questionnaires. Additionally a range of biomarkers is available for detecting alcohol misuse and in utero exposure. Their analysis in both alternative (hair or meconium) and conventional (blood/urine) biological matrices is of relevance, due to limitations of the current clinical approach, for the prevention of prenatal exposure to alcohol. Ethyl glucuronide (EtG) and fatty acid ethyl esters (FAEES) are non-oxidative



metabolites of alcohol that can be detected in conventional and alternative biological matrices from several hours to up to several months. Their rate of formation in humans particularly at doses of alcohol lower than those producing intoxication are poorly understood.

**Materials & Methods:** The study design was double-blind, randomized, crossover, and controlled with placebo. Participants were distributed in three different cohorts: cohort 1 two doses of 18 and 30 g of ethanol were administered to 12 subjects; cohort 2 two doses of 6 and 12 g of ethanol were administered to 6 subjects; cohort 3 doses of 24 and 42 of ethanol were administered to 6 subjects. Thus each participant received two doses of ethanol, experimental sessions lasted 6 h. Ethanol and FAEEs (palmitic, stearic and oleic acid ethyl esters) in plasma were determined at predose and at 15, 30, 45 minutes, and 1, 1.5, 2, 3, 4, 6 and 24 hours after treatment administration. EtG was determined in urine samples collected before (spot sample) and at different interval periods after treatment administration (0-2 h, 2-4h, 4-6h, 6-12h, 12-24 h).

**Results:** EtG urinary recovery and plasma FAEEs concentrations showed a dose-dependent relationship with ethanol administered doses. This relationship followed an exponential trend.

**Conclusions:** The formation rate of ethanol biomarkers does not follow a linear trend and this observation should be taken into account when interpreting results in biological matrices.

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### Alcohol disrupts the maternal selenium transference to liver fetus decreasing glutathione peroxidase 1 (GPx1) activity

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**Objectives:** Maternal alcohol consumption affects nutrients transport across placenta and enhances oxidative stress. Both process inducing abnormal intrauterine fetus development. Recent studies have demonstrated body selenium (Se) homeostasis disruption in mother and offspring exposed to ethanol. The main goal of this study is to determine the effects of alcohol's ingestion on the maternal selenium transference to developing fetus, focusing on the hepatic Se concentration, its metabolic translation into

in the GPx1 hepatic selenoprotein, and its antioxidant activity in fetus liver.

**Materials & Methods:** Ethanol treatment (20% v/v) was administered in top water to dams for 10 weeks during induction, reproduction and gestation. Fetus and livers were extracted and weighed in 19 day of gestation. The Se levels in liver were measured by graphite-furnace atomic absorption spectrometry. The antioxidant activity of glutathione peroxidase 1 (GPx1), glutathione reductase (GR) lipids peroxidation (TBARS) and protein carbonyl (PC) were determined by spectrophotometric method. Liver GPx1 expression was detected by Western blotting technique.

**Results:** Alcohol in dams reduces the solid caloric ingest and the Se dietary intake, it also decreases in fetus body and liver weights, and liver Se concentration. The GPx1 expression and its antioxidant hepatic activity were also decreased in fetus exposed to ethanol, showing a high imbalanced GPx/GR ratio, GPx1 expression/GPx activity ratio, joint to an increase in lipids peroxidation.

**Conclusion:** The dietary Se restriction induced by alcohol exposition, affects the maternal transference to fetus. Therefore, alcohol disrupts antioxidant selenium role via GPx1 in hepatic fetal tissue. Apparently, this redox imbalance follows a selective reaction during later ontogenesis hepatic maturation that induces lipids peroxidation.

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### Validity of a maternal alcohol consumption questionnaire in detecting prenatal exposure

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**Introduction:** Ethanol consumption by pregnant women can produce severe effects in the foetus and the newborn, mainly in neurological and weight-height development, and are included in the term FASD (Fetal Alcohol Spectrum Disorder). Questionnaires are the most used screening method to detect prenatal exposure, but a previous population study questioned its reliability. The objective of this study was to compare alcohol prenatal exposure detection by questionnaire compared with biomarkers in meconium.

**Materials & Methods:** Sixty two meconium samples from mothers who denied alcohol consumption during

pregnancy by questionnaire were analysed. The objective analysis was made by determination of FAEEs (fatty acid ethyl esters) as exposure biomarkers in meconium as biological matrix.

**Results:** In the meconium from 10 of 62 newborns from non-alcohol consuming mothers by questionnaire (16.12%) FAEE values were positive ( $\geq 2$  nmol/g).

**Discussion:** Questionnaires as a screening method during pregnancy are not a reliable tool. It is necessary to identify prenatal exposure to alcohol as soon as possible by biomarkers analysis in biological matrices from the newborn or the mother. The early detection will allow these patients to benefit from follow up and treatment to reach the best possible neurological development.

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#### **Maternal ethanol consumption during pregnancy: prenatal exposure diagnosis, neonatal screening and postnatal follow up**

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**Background:** Prevalence, under declaration, severe effects on neurodevelopment (fetal alcohol syndrome), and associated expenditure of prenatal ethanol exposure are well known.

**Objectives:** (1) To study the measurement of prenatal alcohol exposure: questionnaire and biochemical screening techniques. (2) To design and to implement a prenatal diagnosis and a neonatal screening protocols of prenatal ethanol exposure. (3) To design and to implement an intervention protocol and follow up of exposed newborns.

**Materials & Methods:** Prospective study including mothers and newborns prenatally exposed to ethanol, in the hospital of the PI: 200 pregnant women for the prenatal diagnosis, 400 couples of mothers and newborns for the neonatal screening (200 previous and 200 controls), and 125 children prenatally exposed to ethanol for the follow up during 1 year. A questionnaire about consumption and exposure to tobacco, alcohol and drugs of abuse during pregnancy, will be administered, and in biological samples (maternal hair from the first trimester and after childbirth, meconium and cord blood) fatty acid ethyl esters (FAEE), EtG/EtS and phosphatidylethanol (PEth) of ethanol and drugs of abuse, will be analyzed

liquid chromatography coupled with tandem mass spectrometry and by immunoanalysis.

**Expected Results:** 1) To design and to implement (translational) a clinical prenatal diagnosis and neonatal screening protocol and follow up of alcohol fetal exposure. 2) To prepare a patent or a result to be commercially exploited from the EtG immunoassay in maternal hair.

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#### **Application of an *ex ovo* chick agar culture model to examine the morphological and molecular effects of ethanol on early-stage embryos**

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**Objectives:** The chick embryo is an excellent model for studying the direct effects of ethanol on embryonic development. However a major drawback using this system involves the reliable and uniform delivery of test agents. To counteract this problem we have developed a modified *ex ovo* chick agar culture technique<sup>1</sup>. In the present study we have applied this model to investigate the molecular and morphological effects of ethanol on early-stage embryos.

**Materials & Methods:** Hamburger-Hamilton stage 7-8 chick embryos were dissected onto filter paper carriers and submerged in varying concentrations of ethanol in chick saline (0%, 1%, 5%, 10%, 20%) for 2 minutes. Embryos were then rinsed in saline and placed ventral side up on an agar-albumen substrate at 37°C in a humidified chamber. Embryos were staged and morphologically assessed at explanation and again at 24hours post-incubation. Further parameters assessed after treatment included ocular histology and the expression of selected genes such as sonic hedgehog (Shh). In addition, the levels of embryonic ethanol uptake were assayed immediately post-treatment.

**Results:** This treatment caused a dose-related growth retardation as evidenced by significantly reduced somite number (n=20/group). Resin histology through the optic vesicle showed a dose dependent increase in apoptotic activity occurring within the neuroepithelium. Molecular analysis indicated that while Shh transcription remained unchanged, the expression of the active signalling Shh protein was found to be significantly reduced in ethanol-treated embryos compared to control counterparts. Measurement of ethanol concentrations in the embryonic tissue resulted in a peak ethanol uptake at 5 minutes post-treatment, which declined to baseline levels after 60minutes.

**Conclusion:** Ethanol treatment using this *ex ovo* culture method has produced a more consistent and reproducible set of ethanol-induced defects by comparison to previously used *in ovo* regimes.<sup>2</sup> Using this culture model to administer an acute or ‘binge’ ethanol exposure has resulted in growth retardation, apoptosis and Shh disruption - key endpoints of ethanol perturbation previously validated in other model systems. Utilising this *ex ovo* technique further allows continuous visual access to monitor the embryo throughout the treatment period. In addition, reliable assessment of the timing of exposure and concentrations of test substances administered can be easily achieved. Overall, this simple modification of the standard agar culture technique provides a powerful new tool in the field of ethanol research. *References: 1. Chapman SC et al. Developmental Dynamics. 2001; 220(3):284-9. 2. Kennelly K et al. Reproductive Toxicology. 2011, 32(2):227-34.*

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### Challenges in managing growth problems in children with FASD- review of existing literature

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**Objectives:** Growth deficiency is a major feature in children with FASD and forms one of the key categories assessed in making a diagnosis of FAS/FASD. Children with weight problems and failure to thrive who have FASD make very poor progress on the regular dietary and caloric supplementation usually used in managing children with failure to thrive from other conditions. Families of children with FASD and growth problems may sometimes come under intense scrutiny by various professionals due to the sometimes wrongly perceived feeling that the children are not adequately fed.

**Materials & Methods:** A review of the databases (Medline, Psycinfo and CINAHL) was carried out on the outcomes and interventions for growth deficiency in children with FASD. There were four relevant papers relating to growth problems in children with FASD.

**Results:** Review of a 10 year follow up study on 60 children and adolescents with FASD who were living in Berlin and localities in Germany and a further 20 year follow up study on 37 of the 60 subjects followed up showed that growth restriction was still present in a significant number of the subjects although some of the

severely affected children showed some catch up growth as they grew older. Some of the subjects showed normalization of their BMI with differences noted in the growth outcome in males and females. The small sample size and the need to consider other confounding factors that may affect growth outcome makes it important for clinicians to carry out more long term studies on outcome of growth deficiency in Children with FASD. Few studies have shown that the level of growth hormone is raised in children with FASD although there was poor response at tissue level which suggested some degree of peripheral tissue insensitivity. There are no studies showing effective evidence based approaches in managing the growth problems in children and young people with FASD.

**Conclusion:** There is a need to carry out prospective long term follow up studies on the growth outcome in children with growth deficiency as a result of alcohol exposure in utero. There is a need to carry out further studies on interventions that work in managing the weight problems in children with FASD. The author is in the process of carrying out a Pilot study through the Health Care Professionals Forum for FASD to address these questions.

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### Maternal risk factors for fetal alcohol spectrum disorders in a province in Italy: combined analyses from two waves of study

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**Objectives:** As part of population-based prevalence study of FASD in the Lazio Province of Italy, researchers conducted in-depth maternal interviews with mothers of all cohort subjects (n=976). The objective was to examine and better define the maternal risk factors of the mothers who produce children with an FASD.

**Materials & Methods:** Lazio contains the city of Rome and the study area is characterized by small and medium sized towns and rural areas. The study consisted of two waves of dysmorphology screening, child testing, and interviews of mothers all with affected children and controls from first grade classes and their mothers.

**Results:** Analysis of the maternal demographic and drinking characteristics of mothers of children with FASD, mothers of randomly-selected controls, and

community mothers of other first grade children provided many statistically significant results including height and body mass index (BMI) differences, with mothers of the FASD children being the shortest ( $F = 5.95$ ,  $p = .003$ ), and having the highest BMI ( $F = 3.45$ ,  $p = .032$ ). Mothers of FASD children report the highest lifetime alcohol consumption ( $X^2 = 7.85$ ,  $p = .020$ ), as well as more drinks consumed per month ( $F = 10.72$ ,  $p = .000$ ), and in the past week ( $F = 8.27$ ,  $p = .000$ ) at the time of interview. In addition, total drinks consumed per week three months before pregnancy is significantly higher for mothers of children with FASD ( $F = 5.03$ ,  $p = .007$ ), as is the percentage of that group who report consuming three drinks or more per occasion during pregnancy (e.g., binge drinking;  $X^2 = 5.70$ ,  $p = .058$ ). Correlations illustrate the importance of maternal demographic (e.g., mother's occupation and monthly income) and other drinking variables (e.g., variety of alcohol types consumed, total number drinks consumed per week three months before pregnancy, binge drinking), as they correlate significantly with child physical traits that are key to FASD diagnoses. In addition, paternal and family variables are examined, including reported alcohol problems in the child's family and father's legal problems, both of which differ significantly by group (FASD, Control, and Community;  $X^2 = 11.74$ ,  $p = .003$  and  $X^2 = 8.03$ ,  $p = .018$ , respectively), with the greatest problems in the FASD group.

**Conclusion:** Maternal risk factors for FASD in Italy have been better defined by this study, and the results may be relevant to other European countries.

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### Assessing the impact of the health communication campaign "Mamma Beve, Bimbo Beve", to raise awareness on the risks of alcohol use during pregnancy in a local area of Italy

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**Background:** The health communication campaign "Mummy Drinks, Baby Drinks" ("Mamma Beve, Bimbo Beve") was launched in 2010 to raise awareness

on the effects of drinking alcohol during pregnancy in the childbearing-aged population of the Local Health Authority of Treviso (Italy).

**Objectives:** To assess the impact of the advertising image used in the campaign. The image depicted a foetus inside a glass of a local alcoholic drink.

**Materials & Methods:** A survey using a semi-structured self-reported questionnaire was carried out. The questionnaire was administered by nurses to a consecutive series of 690 parents or caregivers who accompanied children aged 0–2 years in the local vaccination clinics during a 30-day period 1 year after the start of the campaign. The questionnaire measured the level of exposure to the image, emotional reactions and awareness of the health messages conveyed by the image.

**Results:** Eighty-four percent of the sample said that they had seen the image. Ninety-three percent recalled the warning message and 53% recalled the health behaviours suggested by the campaign. The image generally seemed to arouse a high emotive impact: 38% indicated distress and 40% liking as a general opinion. We did not find unequivocal relationships between the level and kind of emotional reactions and the recalling of the health behaviours.

**Conclusions:** The image obtained a high level of visibility. We hypothesized that individuals approached the picture like an open task, that is, the image can lead to emotional elaboration and interpretation before being placed in their cognitive patterns. This may be due to the complexity of the tasks evoked.

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### Combining challenging restless day-time behaviours with challenging restless night-time behaviours

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**Objectives:** In Canada FASD incidence is 9/1000 live births (3000 babies per year). A significant percentage of children and adolescents with an FASD are prescribed stimulants for challenging day-time behaviours, such as ADHD and/or selective serotonin reuptake inhibitors (SSRIs) and/or psychotropic medications for other behavioural and mood disturbances. ADHD related restless daytime

behaviours occur in up to 95%, sleep problems (SP) in up to 85% of children with an FASD. However, SP are not routinely assessed in clinical encounters. First publications on SP in children with a neurodevelopmental disorder/disability, such as an FASD, show that day- and night-time behaviours are interconnected and should be examined together.

**Materials & Methods:** We analyzed commonly used ADHD questionnaires that are used for clinical assessments and therapeutic interventions, in regards to their ability to elicit SP.

**Results:** Five standardized questionnaires were investigated: BASC-2 Behavior Assessment System (160 items), Vanderbilt ADHD Diagnostic Rating Scale (82 items), SNAP-IV Teacher and Parent Rating Scale (90 items), ADHD Rating Scale IV (18 items), and Conners' Rating Scale Revised (80 items). None of them screen systematically for sleep problems. Questions associated with behavioral sleep problems (BSP), excessive daytime sleepiness (EDS), Willis Ekbom Disorder (WED), Sleep Disordered Breathing (SDB) were identified. The number of items describing possible ESD varies between 0 and 10, BSP 0-1, WED 1-4, and SDB 0-3.

**Conclusion:** Currently used ADHD questionnaires are inadequate to capture the connections between day- and night-time behaviours. The definition of 'challenging day-time behaviours', 'therapeutic interventions' and 'treatment success' depends on how specifically or broadly outcome measures are rated by the individual physicians and care teams. In addition, there are currently no mechanisms for monitoring the effects of stimulants and psychotropic medication, inclusive adverse drug reactions that present as behavioural deterioration. Given the methodological challenges, clinical results are difficult to compare. We suggest widening the Active Surveillance Programs for monitoring the effects of psychotropic medication, inclusive of the adverse drug reactions that present as behavioural deterioration using individualized 'Goal Attainment Scaling'.

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### "They silently live in terror" why sleep problems and night-time-related-quality-of-life are missed in children with FASD

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**Objectives:** Children and adolescents with Fetal Alcohol Spectrum Disorder (FASD) are at high-risk for developing sleep problems (SP) that can trigger daytime behavioural co-morbidities such as inattention, hyperactivity, and cognitive/emotional impairments. While daytime morbidities are easily recognized and treated with psychotropic medications, clinical experience has shown that the underlying SP, mainly Insomnia and restless sleep, may remain masked and appropriate treatment missed.

**Materials & Methods:** To understand the reasons for the lack of recognition of SP in children with FASD, we conducted qualitative interviews with parents and health care professionals (HCP), performed comprehensive sleep assessments for patients referred to our clinic for unresolved SP, and analyzed patients' medical records using the concepts of narrative schema and 'therapeutic emplotment'.

**Results:** In the qualitative interviews, parents and HCP exhibited awareness of the significance of SP, its effects on the child's daily function, and the associated suffering of the parents due to current practices, which may lead to a breakdown in care. This systemic inattention to the sequelae of SP and the affected family's wellbeing can be due to insufficient understanding of factors that contribute to SP and their sequelae. In our comprehensive sleep assessments, we found that the exclusive focus on prominent daytime sequelae led to ignorance of chronic SP in children and adolescents. Daytime behavioural and emotional problems were targets of pharmacological treatment rather than the underlying SP. Consequently, SP were also targeted with medication, without an investigation of underlying causation.

**Conclusion:** Our study highlights deficits 1) in the diagnostic recognition of chronic SP in patients with a life-long chronic neurodevelopmental disorder/disability, 2) which leads to uncontrolled pharmaceutical treatment and 3) we propose a clinical practice strategy that acknowledges the contribution from parents and community-based HCP in recognizing SP and related sequelae.

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### Let us talk "night-time-related-quality-of-life" for children and adolescents with FASD

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**Objectives:** Insomnia is a major sleep problem (SP) for children and adolescents with neurodevelopmental disabilities/disorders (NDD/D), like Fetal Alcohol Spectrum Disorder (FASD). Children and adolescents with FASD and SP are often sleep deprived and have significant challenges staying awake during normal activities. Their daytime sleepiness, inattention, or paradoxical hyperactive behaviour are often seen as part of an FASD and are medicated.

**Materials & Methods:** Focusing on children with FASD, we employed a narrative approach based on the concept of 'therapeutic emplotment' and analyzed how decisions are made in the clinical setting and the factors that encourage or impede working towards optimized patient outcomes. We conducted qualitative interviews with parents/caregivers and health care professionals to understand the lack of recognition and ineffectual treatment of paediatric SP. In addition, we investigated 27 patients with FASD and SP (mean: 6.3 years; median: 5.25 years; range 2-14).

**Results:** All patients had SP and several co-morbidity diagnoses: 19/27 affected daytime wellbeing and challenging behaviour; 5/27 anxiety disorder. 22/27 patients were medicated with melatonin, 14/27 for ADHD and 11/27 with antipsychotics/-depressants. 22/27 patients had symptoms suggestive of Willis Ekbom Disease and associated Periodic Limb Movements in wakefulness which had not been diagnosed before. Qualitative interview data revealed that caregivers who report SP are not given appropriate attention by health care professionals. The interviews also verified that symptoms were identified, but not connected to possible SP. Clinical investigations revealed that the provision of a categorical diagnosis of FASD obscured the need for full functional assessment and intervention.

**Conclusion:** Our study highlights the deficits in current clinical practice and education regarding diagnostics and treatment of SP in vulnerable populations. To assess children and adolescents with NDD/D, such as FASD, we propose the use of a different clinical strategy that acknowledges and formalizes the input from the patient and caregivers.

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**Is challenging behaviour aggravated by sleep problems? Home based sleep assessment videos for insomnia diagnostics**

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**Objectives:** Up to 85% of children with FASD suffer from chronic insomnia. Many have global developmental delay and/or intellectual disability, often resulting in difficulty expressing verbal discomfort. Advanced video technology is available for sleep-laboratories and is used as a supporting tool to PSG or EEG. However, low-cost equipment that can be used independently, sent out for screening, and analyzed quantitatively has not yet been identified and tested.

**Materials & Methods:** Different combinations of hardware/software were tested and used for clinical purposes. Prerequisites for in-vitro testing were: 1) low cost/physical bulkiness/weight, durability for infrared-light camera and net-book; and 2) synchronized audio/video software with live time-stamp, constant frame-rates, automatic splitting of the recordings into multiple smaller files.

**Results:** We suggest an "ideal set of hardware/software" that is reliable, affordable (~\$500) and portable (=2.8kg) to conduct non-invasive home-based-overnight-video-sleep-studies. The equipment consists of a net-book, a camera with infra-red optics, and a video capture device. The recording software and video encoder provide consistent frame rate (>29 fps), are time-stamped for analysis, and allow standardized qualitative and automatic quantitative analyses. The equipment can be couriered to patient's home. In order to optimize results of clinical observations and to facilitate equipment setup at their homes, patients should have internet connection for remote access from the research lab. Since September 2011, we have had 45/46 successful recordings; problems occurred in one case due to software programming.

**Conclusion:** Home based sleep assessment videos allow us to observe the sleep patterns of patients in their normal sleep environment. Using the videos as a screening tool, we identified familial Willis Ekbom Disease (WED) as one main cause of insomnia and challenging behaviour. The strategy of using sleep videos opens the floor for a new 'observational sleep medicine' that has been useful in describing discomfort/urge-to-move/pain-related behavioural movement patterns in patients with FASD and WED.

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### **Prenatal exposure to alcohol and neurobehavioural development at age seven**

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**Objectives:** the purpose of the present study was to investigate the effects of prenatal cumulated alcohol exposure and binge drinking on neurobehavioural development at age seven.

**Materials & Methods:** Sample: the Danish National Birth Cohort (DNBC), comprising information on 100.000 pregnant women and their offspring. *Exposure:* separate information on average alcohol intake and binge drinking from three interviews gathered at app. weeks 15 and 30 prenatally and 6 months post-natally. The interviews cover the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> trimester respectively. Inclusion criteria were information from these three interviews as well as from the seven year follow-up (N=37,152). *Outcome measure:* The four problem scales of the Strengths and Difficulties Questionnaire (SDQ) measuring hyperactivity/ inattention, conduct disorder, emotional and peer problems. *Confounders:* register-based information on maternal and paternal education and maternal and paternal past history of psychiatric problems, and self-reported information on maternal and paternal smoking and maternal well-being in pregnancy. *Mediators:* self-reported information on family/ home environment, maternal and paternal alcohol intake at age seven of the child, and child physical activity and BMI at age seven. *Analysis strategies:* multivariable linear regression measuring continuous externalising (combined hyperactivity/ inattention and conduct problems) and internalising (combined emotional and peer problems) scores and multivariable logistics regression measuring above cut-off hyperactivity/ inattention, conduct, emotional and peer problem scores.

**Results:** The multivariable linear regressions revealed that binge drinking had a negative effect on boys' internalising problems. The multivariable logistic regressions showed that binge drinking was associated with >1 odd ratios (OR) on all four problem scales for boys (hyperactivity/ inattention, conduct, emotional and peer problems) and >1 OR on hyperactivity/ inattention and emotional problems for girls. No effects of cumulated alcohol exposure were found in any analyses.

**Conclusion:** Binge drinking is negatively associated

with emotional and behavioural scores for boys at age seven, and to a smaller extent on girls. This finding is supported by the literature on animal models. No effect was found on exposure to small to moderate amounts of cumulated alcohol exposure. It may be due to residual confounding that was not possible to control for, or it may be that the 25 SDQ items are too broad and thus not sensitive enough to detect possible effects of exposure to smaller amounts of alcohol. It may also be that possible negative effects are not present until later in childhood.

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### **'As I see it...' Using social media to bring out the voices of people with FASD, their families and carers**

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**Background:** Fetal alcohol spectrum disorders remain poorly recognised across the UK despite the passage of almost 40 years since Fetal Alcohol Syndrome was first named. Children and adults who are diagnosed with an FASD often find themselves isolated with limited professional support and care. Volunteer-developed support groups for FASD are a major source of advice and guidance for individuals and their families.

**Objectives:** The objectives of the project were:

- 1) to identify whether social media could be used to ascertain perceptions and views of people with FASD, their families and carers about diagnosis and about living with an FASD
- 2) to develop and distribute an electronic survey to members of a closed social media site for FASD
- 3) to collate, analyse and interpret responses to the survey
- 4) to present the findings of the survey to national decision makers to influence service development.

**Materials & Methods:** The start-up of a new closed FASD social media community provides an opportunity to collect the perceptions and views of the membership on the challenges and opportunities they face. A semi-structured questionnaire is being sent to members of the group (number=100 at 4<sup>th</sup> September 2012). Included in this survey are questions about the members (age group and gender), role (person with FASD, parent, carer), whether or not they have a diagnosis of an FASD, and about the diagnostic process and post diagnosis support received. Questions



are also included around the positive and negative aspects of a diagnosis of FASD and the most important aspects of prevention of fetal alcohol harm.

**Results:** The results of the survey will be presented at the conference together with the actions that have been and are being progressed. It is intended that the UK and Scottish Governments will be presented with the survey report and requested to respond.

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### **Characteristic of women who drink – and do not drink – alcohol in pregnancy: a large-scale descriptive cohort study**

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**Objectives:** The majority of studies investigating possible long-term effects of a prenatal exposure to alcohol define alcohol exposure solely on the basis of first trimester intake. The present study aimed 1. to investigate possible effects of using exposure information from three trimester interviews and pre-pregnancy intake rather than only using exposure information from early part of pregnancy; and 2. to compare possible trends in background characteristics between exposure groups with trends in estimates of multivariable linear and logistic regressions between alcohol exposure and behavioural scores on the Strengths and Difficulties Questionnaire (SDQ) controlling for a large number of confounders.

**Materials & Methods:** Sample: The Danish National Birth Cohort (DNBC), comprising information on 100.000 pregnant women and their offspring. Alcohol consumption in first trimester: grouped 0, >0-2, >2-4, >4+ alcohol containing units/ week. Alcohol consumption pre-pregnancy and during entire pregnancy: grouped 0, >0-5, >5-15, >15-45, >45-90, >90+ cumulated alcohol exposure. Outcome measures: 1) Descriptive measures on background characteristics including demographic and lifestyle factors deriving from either registries or self-reports. 2) SDQ continuous scores for use in linear regression and above cut-off SDQ scores for use in logistic regressions.

**Results (preliminary):** 1). Abstainers defined on the basis of full pregnancy information were more extreme (in either direction) compared to the abstainers defined from first trimester. Reversely, the high exposure group defined from first trimester scores more extreme on a large number of parameters compared to the high intakers defined from full pregnancy information.

2) No effects of alcohol were observed in the multivariable linear and logistic regressions with SDQ

outcomes. However, the trends in estimates from the regressions for the two groups resembled the trends observed for the key variables for the two groups in the background characteristics tables.

**Conclusion (preliminary):** The study shows the immense impact classification of alcohol groups have on the observed results. Although studies may control for relevant confounders there seem to be immense amounts of residual confounding that that is not possible to control for. This may seriously affect the results to such a degree that possible true effects of prenatal exposure to small to moderate amounts of alcohol on behavioural outcome is not detectable. The findings question whether this type of epidemiological design is at all appropriate to investigate the association between small exposures and outcomes later in life. The finding may also explain the alcohol j-shape curve that has puzzled researchers for years.

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### **Treatment in institutions for pregnant women and their partners, voluntary and by force**

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**Objectives:** Norway has an opportunity to give treatment in institutions for pregnant women with substance abuse problems. There is the possibility of compulsory admission if "the woman's abuse is of such a nature that it is highly likely that the child will be born with defects" (health and care Act § 10-3). The aim of introducing this possibility was to protect the child. But it also an intention that the woman should be offered help for drug problem, and help to prepare for motherhood. It is possible that the partner also takes part in the treatment. The main focus of the treatment is meeting the women with respect and establishing a good relationship between the hospitalized women and the clinicians. The woman often changes from a state of strong opposition to participate in the program, to active engagement and preparations for motherhood. Many also gradually change lifestyle. Some of the families stay voluntarily in the institution after birth to take part of an intensive family treatment program. We recommend a stay for minimum one year.

**Materials & Methods:** We want to present the content in treatment by pictures and written information. We will emphasize the content of compulsory treatment when we are aware of no other European country has the same chance of forced hospitalization of pregnant women. The voluntary offer for parents will also be presented. Most patients have a mixed abuse, but women with a pure alcohol problem are also covered



by the law. Dr. Egil Nordli will have a parallel presentation where he will present results of his study in the same treatment unit. This deals with the children's birth weight. This study will also be presented at the poster.

**Conclusion:** We want to show that the forced hospitalization of pregnant women with substance abuse problems can be a good measure for both parent and child.

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#### **Challenges in managing growth problems in Children with FASD- review of existing literature**

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**Objectives:** Growth deficiency is a major feature in children with FASD and forms one of the key categories assessed in making a diagnosis of FAS/FASD. Weight problems in children with FASD also poses significant challenges to the clinician. Children with FASD and failure to thrive generally make very poor progress on the regular dietary and caloric supplementation usually used in managing children with failure to thrive from other conditions. Families of children with FASD and growth problems may sometimes come under intense scrutiny by health and social care professionals due to the sometimes wrongly perceived feeling that the children are not adequately fed. The teratogenic effect of alcohol on the developing brain has been widely studied and the behavioural and cognitive profile and outcome of children exposed to alcohol in the prenatal period have been widely studied. Alcohol is known to alter neuronal migration in the nervous system and affects development of effective neural networks. The effect of alcohol on the gastrointestinal system and feeding behaviours of affected children with FASD is less well studied. It is known that Alcohol can affect the maturation of the myenteric plexus and the development of the gastrointestinal myocytes. There is very little research being carried out on the feeding behaviours and pattern of growth if infants with FAS/FASD and very little is known about the growth outcome in infants with FAS/FASD.

**Materials & Methods-** A review of the databases (Medline, EMBASE, Psychinfo and CINAHL) was carried out to check for relevant literature on the outcomes and interventions for growth deficiency in children with FASD. Journals search was also carried out and references listed in selected journals were also reviewed.

**Results:** There were very few earlier studies which discussed certain gastrointestinal pathologies that were seen in Children with FAS/FASD. Vasiliauskas et al (1997) described a pattern of chronic intestinal pseudoobstruction which could be seen in children with FASD. The children could present with chronic constipation. Van Dyke et al (1982) described a pattern of severe feeding dysfunction in some children with FAS. Oral dysfunction was seen in some of the affected children. This presented as minimal oral movements, swallowing difficulties and fatigue during feeding. These feeding behaviours were noted to contribute to the failure to thrive seen in some of the children. Sujay et al (2012) have described severe gastroesophageal reflux in some of the affected infants.

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