

45 YEARS LATER... WHERE DO WE STAND?

Mercédes Benegbi

The Thalidomide Victims Association of Canada, Montreal, Canada

Corresponding Email: mercedes.acvt@bellnet.ca

“The Thalidomide Victims Association of Canada (TVAC) was founded in 1988 and is the only organization in North America to work with and for Thalidomide victims. Our mission is to empower our members and to improve their quality of life through various programs and customized services. With the return of Thalidomide on the market, TVAC also took on the mandate of informing the public on the devastating effects of this medication and to promote awareness and caution when using any teratogenic products currently available”.

Forty five years ago, by negligence, lack of professional conscientiousness and a very poor sense of responsibility, our health system leaders failed in their duty. They allowed the Thalidomide medication to be marketed, a drug that was “not approved” by our American neighbours. In addition, our government only forced the manufacturer to withdraw the drug from the Canadian market three full months after Germany, Great Britain and Australia did and this, despite all the toxicity warnings that they received. Consequently, more than one hundred Canadians were born with major birth defects, forever affecting their quality of life and their ability to participate as full members of the community. Moreover, this does not take into account those who did not survive or the families that were affected. To this very day, the Canadian government remains in denial of its responsibilities and its obvious negligence in relation to the Thalidomide tragedy and has left the victims virtually uncompensated.

“Avoiding one’s responsibilities never makes one less guilty!”

This human tragedy, which has inevitably proved the foetus’ vulnerability, later gave rise to an unprecedented awareness and initiated vigilance and an ultimate warning with regards to the use of pharmaceutical products and other potentially toxic substances during pregnancy. The thalidomide disaster has enabled the world to understand and has clearly proven that a foetus is

an integral part of the pregnant woman. Considering what has happened in the past, have we truly imposed all the possible safeguards necessary to protect our pregnant women who are fundamental to the wellness of our future generations? With the 45 years of experience gathered from the Thalidomide tragedy, what responsibilities have we assumed as a society towards the “*cradle of humanity*”, that is to say pregnant women, with regards to toxic substances, medications or drugs to which they are exposed?

I bring these questions forward in the hope of shedding some light on the following situation. In order to fill obvious needs at the national level and in a preventative capacity, Motherisk took the initiative of providing authoritative information and advice to pregnant women and their doctors on medications, alcohol, illicit drugs and their potential adverse effects. Motherisk also took on the mandate of addressing diverse pharmacologic and safety issues left unanswered to this day on pregnancy, in addition to maintaining university and graduate level training and education programs in the field of toxicity during pregnancy.

Their noble mission has spread all across Canada. Yet, Motherisk still remains exclusively funded by the Ontario provincial government and private companies. Working with a limited team of professionals who must be available to cover a global schedule of 9 to 5 for all Canadian time zones, Motherisk listens attentively and compassionately to pregnant women facing their particular medical conditions.

To this day, we still wonder - what recognition does Health Canada concede to this brilliant and national scale initiative? And where are the other initiatives and great projects of this order? It would be commendable for our Canadian government to humanely and scientifically show pro-activity and leadership with regards to its duty to implement all the necessary measures and provide favourable conditions to ensure the protection and the blossoming of women's health during their pregnancies.

To that end, shouldn't our government prove it holds the health of Canadians at heart and assemble the various medical societies, professional corporations and patient groups in order to rally the necessary support and expertise to assure that the best practices available in the world are offered for the well being of pregnant women and for the protection of the developing child? Where does our government stand today, as far as its duty to gather, maintain and disseminate existing scientific data on the various medications available in Canada and their desirable or undesirable impact on pregnancy? Does Health Canada have in place an appropriate follow-up process for pregnant women taking medications to register their effects? Do they support research on this specific matter? Why doesn't Health Canada have an official department exclusively dedicated to pregnancy?

Doesn't this current lack of priority unintentionally place pregnant women in a hazardous ignorance and extreme solitude when they must take an ultimate and necessary decision? And what are the consequences? How is it that in today's world, children are born in Canada with birth defects caused by drugs such as Accutane, when we have full knowledge of its teratogenic properties?

Do we sufficiently take into account the contra-indications when we write a prescription? Is the wording of the contra-indications always written adequately and precisely?

Why are teratogenic drugs such as Accutane available in Canada, not subject to more restrictive and safer distribution programs? And when the government approves the manufacturing of a generic medication with teratogenic properties, shouldn't the exact same distribution controls and education programs to the

appropriate healthcare professionals also be mandatory?

Finally, 45 years later, following the Thalidomide tragedy, what do we have to offer to pregnant women and to humanity?

We hope that the Thalidomide tragedy never disappears into oblivion and that the personal suffering of the members of our group prevents suffering in future generations. Then we can say that our fate will have served a purpose, that it provided an awareness of the respect of life and its fundamental source. That exceptional measures for safe distribution of any medication for pregnant women, when necessary, be applied with such rigour, that it will forever prevent any foetus' exposure to toxicity and that another generation of human beings not pay the price with their mutilated bodies or their lives, due to negligence.

Also, and nothing less, that the target population of pregnant women be finally considered with unconditional respect for the integrity of their life and health. Our future generations depend on it!

Deontology, ethics and professionalism cannot be measured in simple situations, but rather in complex situations that require a major and integral reflection on cultural, social, scientific and humanitarian factors. From a personal and professional point of view, I only wish that in the future, we always consider the best interest of both the pregnant women and her foetus in order to preserve their health and dignity in courses of action surrounding the development, marketing and prescription of medications or potentially toxic substances to treat or relieve sicknesses or discomforts, either pre-existing or associated to the pregnancy.

In conclusion, I wish that our individual and collective willingness protect us forever from all interests that would be contrary to the well being and respect of our so fragile, unique and wonderful community that are the human beings.

POSITION

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Acknowledgements

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