Support for Australia's thalidomide survivors Submission 17

Introduction

I am the partner of a recognized thalidomide survivor who has two legs (one malformed), not many toes and only one arm which has a thumb and a couple of stumps where fingers should be. This morning we treated ourselves to a café breakfast after a morning walk and were discussing who had been responsible for our late start. Out of the blue he said to me "I was just lying in bed awake dreading the thought of putting my feet down". That short announcement stopped me in my tracks. I had no idea that was a problem for him.

The ongoing problems for thalidomide survivors is not just coping with a body that was damaged irreparably before birth; it is also the associated problems of wear and tear over the years and more recently the emergence of new pains and excruciating sensations related to the neural damage caused by thalidomide. This is a dreadful drug which just keeps dishing out more pain. My partner is a strong and patient man who went about his life proving for the most part that he was as able bodied as the next man. But he is 56 years old now and the effects of thalidomide can no longer be ignored. We own a business and due to a number of health issues he can only work part-time due to pain and chronic fatigue. His health issues have included: nearly losing a leg to infection because the leg was severely damaged by thalidomide, ross river, glandular fever, pneumonia, hepatitis and five years ago a \$40,000 back operation to repair a disc which was crushing his spinal cord. Having only one arm means that his body is under constant risk and strain of twisting and this results in multiple trips to the chiropractor each year. Now, in recent years, he has started experiencing the same pain and burning sensations in his feet that other Thalidomiders are reporting. And putting his feet down each morning when he gets out of bed is an excruciating moment.

The role of the Government

Other governments around the world, where there have been thalidomide disasters, have actively participated in compensation and support. In Australia the survivors have had to rely on the incredible efforts of Ken Youdale and Peter Gordon.

It's a relief to know that the Australian Government is now examining their role in this tragedy but it is long overdue. There was no thalidomide tragedy in the United States of America and some other countries. These countries exercised caution and refused to be bullied by the companies selling thalidomide.

It is important that this inquiry finds in favour of the government remediating past transgressions by providing adequate compensation and ongoing support for the remainder of the Thalidomider's lives.

In addition to compensation and support I believe that the government owes an apology and this is something that my partner is quite bitter about. There needs to be an apology.

Compensation and Support

What is compensation? There is some irony in the fact that Monsanto, like Gruenthal, the manufacturer of thalidomide, is also a German company (recently ordered to pay a \$290million damage caused by a poisonous weed killer).

It's my opinion that lump sum compensation is necessary to acknowledge the loss of opportunity, the inability to lead a "normal" life and the associated deprivations which result from that inability, the stares and insensibilities of the ignorant, the shortened life expectancy and a life of pain and discomfort. Compensation would go some way to remediating the injustice of allowing the drug to go on sale in Australia without proper testing; particularly in light of the USA FDA Regulators refusal to approve the drug thus averting an American disaster.

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What is support? I can tell you categorically that the support payments receives do not cover his loss of income from his inability to work fulltime nor does it cover the medical expenses related to his thalidomide related health issues. The support payments he is receiving are inadequate and, in any case, they come to an end in ten years – what then? We have no idea how deteriorated his health might be then and it is a major concern that we may not be able to pay for treatments which might need to make his life comfortable.

Conclusion

My partner, was one of the lucky ones! He wasn't abandoned by his parents despite the government putting pressure on them to have him institutionalised. He received a normal school education through to Year 12 but only after my father-in-law spent a night in jail following a confrontation with the Minister for Education; he insisted that his son be treated equal with ablebodied children. Can blow his own nose, wipe his own bum, doesn't have to worry about the mess of menstruation, he can stroke his partner and participate in a hug; he has avoided much of the embarrassment and humiliation that has been a lifetime ordeal for the Thalidomiders who have shortened arms and legs or no arms and legs but he didn't avoid the stares and insensitivities.

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Many victims of the thalidomide drug died but I do not know how some of the surviving Thalidomiders have endured their life. They are brave and strong beyond belief and deserve to live out their lives with support and dignity, compensation and with an increased level of ongoing financial support because what they have received to date has been manifestly inadequate.