From:

To: Community Affairs, Committee (SEN)

Subject: Re: UPDATED program for Senate Community Affairs committee Thalidomide survivors public hearing

Thursday 31 January 2019 - Sydney

**Date:** Friday, 1 February 2019 1:17:05 AM

Hello again

I have been thinking through some of the evidence I gave at the Committee yesterday and had a few additional thoughts that the Committee might find useful.

First, should you or any of the Committee like to see some of the scientific data that I discussed with the Committee yesterday please let me know and I will forward the relevant papers to you. In particular the data I discussed that show's thalidomide's action on the blood vessels causes damage to the developing embryo but nerve loss does not cause damage, rather nerve loss exacerbates the damage caused by blood vessel loss and gene expression failure, making the damage even worse. Which would also include having nerves in the wrong place which will likely impact on later life function and life quality. We also know vessel pattern changes persist after thalidomide exposure in embryos and it is well known that thalidomide survivors as adults have changed cardiovascular patterns (amongst many other problems) which make them more susceptible to cardiovascular problems – and as I mentioned this is further underpinned by clinicians having difficulty taking blood from a thalidomide survivors arm. I would be happy to send such published research papers – if the Committee would find this helpful.

As I discussed, I do feel there is highly likely a population of people damaged by thalidomide that do not have the classic clinical diagnostic criteria (which was devised in the 1960's by assessing the most severely damaged survivors) and some that may have been damaged through exposure outside the 'time sensitive window' - the damage would likely be internal organ maturation and functional issues – and may not be apparent till later in life when the organ ages and fails prematurely. These persons would be difficult to find and assess as they might not even know they were exposed to thalidomide. However, looking at records and published papers from the 1960s from the UK, Germany and Japan might help shed light on the full range of damage seen in thalidomide affected children. In particular the 1964 UK Government Inquiry Report on Thalidomide details all children born to mothers who took thalidomide and their outcome – a surprising range of damage is described that is broader than the diagnostic criteria now used. Also of help might be to look at recent scientific discoveries uncovering molecular targets of thalidomide – this will also help shed light on the type and full range of damage possible.

I would be happy to help assist in any way I can – if that is something the Committee would like to investigate.

Thanks again for the opportunity to take part in the Committee and I do hope my contribution has helped the Committee.

If I can help further, please let me know.

Best wishes

Neil Vargesson.