

## **Submission to the Post Market Review of the Life Saving Drugs program (LSDP).**

As a lay person with a personal experience and over 20 years watching and learning about the power and effectiveness of vaccines providing widespread community protection from communicable diseases by preventing them I have a real conflict in seeing the logic of excluding vaccines in the Life Saving Drugs program.

My experience is anchored by the experience of our middle daughter contracting a life threatening and debilitating disease at age 6 months in 1989. The disease was pneumococcal disease and she had and still suffers from the after effects of pneumococcal meningitis.

No Drugs will correct or remedy her cerebral palsy, her deafness, her inability to walk or talk or her significant intellectual disabilities. They do assist with controlling her epilepsy though.

My thinking is that LSDP should recognise and include vaccine preventable diseases and the role and effectiveness of registered vaccines and include them in the criteria. To prevent life threatening diseases such as meningitis is more beneficial on all fronts. They are rare, rapid and deadly diseases which impact our children such as my very young daughter but can affect us all.

Forgive me for being hard on this but it appears that the lasting challenges and costs of a person's disability over decades needs to be better understood so that the power of preventative lifesaving interventions such as vaccines are emotionally and financially better understood by all.

Our community is told repeatedly of the death statistics from diseases and the lives that will be saved by spending government funds and of course this is important but the greater numbers and the true burden in both financial, physical and emotional terms is related to the disabilities they cause. Normal lives 'lost' could easily be lives saved by lifesaving vaccines.

A clear demonstration of this in current terms is the federal government's enormous commitment to the National Disability Insurance Scheme. Their real concern though is how much will it cost?

The conflict here for me is at what point do we pay and how much and for how long?

My time over the past 22 years has included concurrently running three businesses and chairing two advocacy organisations and a government department board but as importantly has been to share our family experience with pneumococcal meningitis to assist others to protect their very young from a disease which can kill and or disable within 24 hours.

Time and quick decision making when meningitis is around are critical elements to saving the lives of babies and young children by their medically inexperienced and unsuspecting parents. Some 8% will die and 15 – 50% will be left with a range of lifelong disabling outcomes.

How unfair is this?

Medical interventions are assistive and reduce the potential level of impact but we should continue to protect our communities and in turn our country by being proactive at every opportunity with preventative measures.

My experience as an affected parent since 1989 and a concerned community member led to learning of the history of effective immunisation programs and how they have benefited us all and to add where I could to the continuation of these 'hidden' benefits to society. Having witnessed firsthand the devastation of a daughter's life lost to significant disabilities caused by a vaccine preventable disease my mission has been well based and has benefited many in our country.

The role of preventative vaccines and the immense long term benefits they offer should not be clouded by short sighted and convenient distractions. They are an investment in our people.

Since 1992/3 when the hib vaccine was introduced in Australia and in 2003 with the menC vaccine's introduction and again with the 7 and 13 valent pneumococcal disease vaccines from 2005 the incidence of these diseases has been dramatically reduced.

Today these are rare diseases and as such their status has changed because of the reduction in numbers as a result of the introduction of the vaccines to the NIP.

As we achieve success via vaccines with the headline diseases my concern is that the remaining rare forms such as the meningitis causing meningococcal b disease which can kill or maim or cause intellectual disability will be seen as rare on the surface because the landscape of these diseases has been largely cleared and that the true depth and cost to individuals and community will not be advocated by groups close to our decision makers. It will rely on external parent/patient advocates, the media and key opinion leaders to provide pressure on government via the political process.

In my daughters case we conservatively estimate the cost of servicing her needs will be at least \$ 8 million Australian dollars from now to her 65<sup>th</sup> birthday- a term of 40 years. She is healthy and currently receives a \$200,000pa package of services. She is unable to care for herself nor work in any capacity. She lives with us. Her accommodation and past costs are not included.

There are many of us out here and there are more to follow.

I have been working voluntarily in support of all these vaccines across these years and continue to do so. The conflict which drives me is the lack of community awareness of these diseases and the why vaccinate stories. We need organised advocates both formal and informal , professional and at the community level.

As this review of the LSDP is being conducted my passion for achieving a blanket cover of protection for our many defenceless young (at least) against life threatening 'rare' vaccine preventable diseases makes me appeal for the review to consider how to include these diseases and the vaccine approach in the LSDP criteria.

True and continuing stories from the front line must be told and learned from for others and our support systems to benefit. Not enough are told or sought in my experience.

This strategy if supported will better inform decision making by better quantifying the true cost on individuals lives and those of their families and the real cost to the community high or low at some stage. Prevention or post disease and for a life time.

To separate the strategies when we are looking at a Life Saving approach generally does not make sense as I see it when we are seeking an equal opportunity and equitable future for all.

Thank you for the opportunity to contribute.

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