Why I did what I did – why I do what I do

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Twenty-one years ago, my first child, Matthew was born. Having previously been a career woman, I had never thought much about marriage or children. At the age of 30 however, I met the man of my dreams and, less than a year later, we had our first child.

He was everything we ever wanted. A dream come true. Our beautiful little man who made our lives complete and who made me, an immigrant who had left her family far behind, finally feel at home in my adopted land.

When Matthew was 2 months old, like any conscientious parent, I brought him for his first lot of vaccines – DPT and oral polio. Our placid little baby changed immediately, crying non-stop, running a wicked fever and developing severe breathing problems which left him with a horrible rattle in his chest that you could feel when you held him and which also saw him stop breathing at night (sleep apnoea) when he slept – a terrifying thing to go through and one that made my husband and I lose a lot of sleep over that first year.

It wasn't until I went back to the doctor when Matthew was 4 months old that I discovered that his vaccinations could have been the cause of this issue. As ridiculous as this sounds, I was so ignorant that I thought vaccines could not possibly cause a reaction and what my son experienced was nothing more than a coincidence. Luckily, my doctor was not quite so unaware. He told me that he would leave the whooping cough portion out of Matthew's next shot which he did, and we continued to vaccinate until, at 18 months of age when I was 9 months pregnant with my second child, Matthew had a reaction to his MMR vaccine that put him in hospital for 3 days and changed his sleep and behaviour markedly.

That was the last vaccine he received and it was that shot and his reaction to it that started me on the road I have travelled for all the years since – the road of researching what it is in vaccines that can cause a beautiful, healthy baby to become sickly and sometimes even die.

Yes, I felt guilty for having vaccinated my boy without looking into the subject first. I berated myself for not taking responsibility for what has affected his health to this day. And as Matthew grew and struggled with some things that other children found so simple – and excelled in areas that others might not have also – we came to accept that we would never know the full effect those vaccines had had on our child – but at least we had our child to love, to adore and to watch him grow.

Along the way, there have been some events which have changed my course or steeled me to continue – even when times got hard as they have so often.

The first of these was in 1994. Dr Viera Scheibner, a research scientist who had been investigating the link between vaccination and cot death, came up to Northern NSW to give 2 lectures on vaccination. My husband and I drove through flooding rain to Lismore to see her first lecture.

My GP was there in the audience and when I saw him the next day and asked for his opinion of Viera's talk, he said to me that it made him very sad to think that for all these years, he could have been harming children with vaccinations. That's how persuasive her information was!

It was years later, after this particular GP had moved out of the area, that a mutual friend informed me that he had never vaccinated his own children. Something which, to this day, makes me so angry! This was a good, caring and kind man but he had such a fear of the medical fraternity, that he could not share his concerns with his patients though he took care to ensure that his own children were not placed at risk from vaccination.

Viera gave another talk the next day in Suffolk Park and I was inspired to go and see her there too. At that event, a mother came with her then 14-year old son who had been permanently brain-damaged by his DPT vaccine. After Viera gave her lecture, this mother stood up in front of the audience and told about how her son had been injured. How the doctors insisted that it wasn't the vaccine despite the fact that he developed seizures within hours of his first shot. How they told her that he needed to be vaccinated so they gave him another shot two months down the track after which, his seizures worsened and he began to regress.

Hearing her made me angry. It also made me realise that the information I had had to search for in the past 4 years since I began my research, needed to be more openly available. It wasn't fair that parents like the mother of this boy and myself vaccinated without information and that our families and our children ended up paying the price forever for the failure of the medical community to inform.

I went up to Viera and asked her if I could make an announcement about starting a local vaccination support group. She was very pleased to do that and I asked those in attendance if anyone would be interested in participating in such an organisation. Five people there said they would and from there, the Vaccination Awareness Network began – changing 4 years later to the Australian Vaccination Network as we went national.

I remember so many of the children whose parents have contacted me over the years.

I remember Stephen. Most of all, I remember Stephen.

My son, Matthew went to the Steiner preschool in Byron Bay. It was a lovely, gentle group run by a brilliant woman named Susan Perrot whose stories and songs enabled the children to grow through play.

One day, a new boy appeared named Stephen. He wore a helmet on his head and he had an aide who stayed with him through the morning.

Susan knew of my interest in the vaccination issue and that I had just started a group here and she asked if I would speak with Stephen's mother because Stephen was vaccine-injured. Allison, Stephen's mum, and I became friendly. She told me that Stephen had only ever had one group of vaccines – a DPT and polio at 2 months of age. He began convulsing straight away and his seizures never stopped. Drugs were not able to control them and that's why he had to wear a helmet all the time – so that he would not fall down and hit his head.

Stephen was the eldest of 4 children and though he was totally unable to speak or to care for himself. He was a gorgeous little boy who enjoyed playing with the others at the preschool. And in the way young children do, the children accepted Stephen without question. He was only able to attend 1 morning a week, but I do think that the other kids got as much out of interacting with Stephen as he did with them.

About a year later, when Stephen had left preschool for another facility, I got a call from Allison to say that he had had a seizure in his sleep and never woke up. They found him dead on the floor next to his bed the next morning.

My husband Ken and I went to his funeral and it was, without a doubt, one of the saddest things we had ever seen. Stephen's parents and siblings had painted his little white coffin with some of his favourite images and though the celebrant performed a wonderful service, I kept thinking what a waste it was for this dear little boy to have died so young and to have lived in such pain because of a vaccine.

Another little girl in Matthew's preschool class (keep in mind, there were only about 16 children in this class and, being a Steiner school, most of those kids were completely unvaccinated) was blind in one eye, having developed a cataract and a muscle weakness which caused her eye to turn inwards within hours of one of her vaccines.

There are so many other children who come to mind when I think over the years that I've been running the AVN. So many families I've been blessed to know – who have blessed me with their stories.

There was Anthony who had severe high-pitched screaming after each vaccine. Even though the reactions got worse with each shot, the doctors continued to tell his parents that it was totally coincidental. His parents stopped after the 18 month injection, but by then, Anthony was blind, epileptic, was diagnosed as developmentally delayed and had cerebral palsy.

Mary in Wollongong was in her late 70s when she first contacted me. Her daughter, Milvie, was almost exactly my age – in her late 30s at the time. Mary had emigrated to Australia and did not speak English well. Milvie had a severe reaction to her DPT vaccine and the doctor said she was never to get another dose. At the age of 2, her mother brought her to a different doctor because she was sick with a minor infection. Mary didn't understand what the doctor was saying so she didn't protest until the needle came out and by then, it was too late. Milvie had immediate seizures –the doctor put them into a taxi and told her to go to the hospital. Milvie was permanently brain damaged – her mental development stopping at that point, leaving her a 40 year old with the brain of a toddler. Mary was legally blind and elderly and didn't know what she would do with Milvie when she became too weak to care for her. The couple of times she had put her daughter into respite care, she had returned with bruises all over her body. Mary confided to me that if she reached the point where she felt she could not go on, she would have no option but to take an overdose of pills and give Milvie the same so they could die together just as they had lived together for all those years.

I couldn't help but think of all the pleasure (and angst!) my parents had gotten from me and from seeing me grow up, have children and make a life for myself. Parents of severely vaccine injured children like Milvie would never know that and instead, would have to worry for years about what would happen to their children once they were gone.

Lara was 12 months old when she was given her MMR (Measles, Mumps and Rubella) vaccine. She went limp almost immediately and began convulsing. The doctor escorted her mother to the car and with tears in his eyes, handed her the box the

vaccine had come in and said to her, "Take her to the hospital and tell them I'd given her this." She was hospitalised for weeks and was not expected to live. Today, her epilepsy remains uncontrolled and she has the mental age of an 8- month old baby.

Luke was a normal, healthy child until, at just two years old, he received the measles / mumps vaccine. He then became unsettled, moody and physically swollen where he had been vaccinated. Six days later he complained of a sore head and toes. Luke then became limp and lifeless. Doctors gave no diagnosis. In hospital 3 days later he was said to be brain dead and his life-support system was turned off. His doctor admitted that Luke died from the vaccination.

One mother that I never spoke with but whose story, to me at least, epitomises the evil that happens when the community denies that vaccines can cause harm or death, is Sally Clark (www.sallyclark.org.uk). Sally was a qualified solicitor in the UK. Her first child, Christopher, died a couple of hours after receiving his first DPT, Hib and Polio vaccines. Her second child, Harry, died 24 hours after receiving his first dose of the same 3 vaccines. Christopher's death had been deemed to be of natural causes. Had the vaccine been linked to his death, Harry might still be with us, as would Sally. When Harry died, Sally Clark was charged with MSBP – Munchausen's Syndrome By Proxy – and causing the death of both her babies. Not only was she not allowed the normal grieving process, nor was her husband; but she spent 3 years in gaol charged with murdering her babies. She was later exonerated and released when Sir Roy Meadows, the doctor who invented the name MSBP and put hundreds behind bars in the UK as a result, was completely discredited. Sally was never able to overcome her grief and the fact that she had been accused of killing her boys. One year after her release, she committed suicide – a sad end to a very sad chapter.

Theirs are the ghosts that come to me when I lie awake at night. These parents had the right to have complete information about the benefits and risks of vaccination before their children were harmed. They had the right to say no. But because of the way in which the vaccination issue is handled by government, the medical community and the media, their rights were taken away – as were their children.

Why am I sharing these stories with you? Well, it's 1 in the morning and I have not been able to sleep nor has my husband. For 17 years, we have worked together on this organisation – a 5th and most troublesome child. We do this because we both have a very strong sense of natural justice and a belief that if you do something for the right reason, it will all come out right in the end.

This last 6 or 7 months has begun to make us question that belief.

Apart from the complaint filed with the HCCC against both the AVN and myself, stating that we were a danger to society and should be legally silenced and potentially charged as criminals, a series of actions by members and supporters of the Australian Skeptics have taken up much more of my time and energy then they should have.

A series of websites, Twitter pages and Facebook pages have been set up with the specific aim of getting the AVN to shut down.

This has all come to a head with the case of a little girl in my area who was diagnosed with pertussis at approximately 2 ½ weeks of age and who died in hospital at 4 weeks old. When she died, the fact that she lived on the North Coast, home of the 'antivaccination' AVN (for some reason, it is very important to groups like the Skeptics and the media to label us as anti-vaccination) led to us being blamed for her death with a Channel 7 program speaking about the poison lurking in the air up here, due to a supposedly high number of unvaccinated children.

When this little girl's death was announced, the media were reporting several things that made me question what this baby had actually died of. Her parents were quoted as saying that she had received blood transfusions and that her heart was enlarged. It is very rare for an enlarged heart to be caused by B. pertussis, the bacterium that causes whooping cough. It has been linked with another bacterium in the same family however, B. holmesii. Also, blood transfusions are a highly unusual treatment for this disease.

In addition, I know that many times when pertussis has been diagnosed by doctors without laboratory testing, the diagnosis turns out to be wrong. The test for whooping cough takes about 10 days for a result. This baby was in hospital for less than 10 days but had been diagnosed almost straight away. It didn't make sense to me.

I contacted the head of the Public Health Unit and asked if this case of pertussis had been laboratory diagnosed. I was told that it had been by a quick test. I asked if there had also been a bacterial culture taken because I was not familiar with this test and knew that the culture was considered to be the 'gold standard' of pertussis testing. I was told that this was privileged information. Quite ironic when I discovered that the gentleman I had spoken with or one of his off-siders informed the child's parents that I had called their office requesting information about their daughter's death – I don't know if they were told what information I had requested or not, but they were incensed that I had done this.

To my mind, while an entire community of conscientious objectors were being victimised by the government and the media and being blamed for the death of a child who was too young to be vaccinated, I had every right to ask for this information.

What I discovered afterwards was that the quick test is worse than a joke. It produces many more false positives than true diagnoses and has been responsible for declarations of epidemics of pertussis overseas which have turned out to be caused by B. parapertussis (a related but quite different bacterium and one that is not included in the pertussis vaccination), adenovirus or even the common cold. There are many other diseases whose symptoms mimic pertussis but which are viral in nature and aggressive antibiotic treatment may prove to be counter-productive in these cases so it is a good question for anyone who has a pertussis diagnosis to determine – how was the diagnosis made?

In any case, the parents went public saying what a terrible thing I'd done in contacting the PHU and stated on the channel 7 Sunday Night program (which I was on as well) that they had received hate emails from AVN members though they did not say what the emails contained nor who they were from. I would be very disappointed if any of our members would have been callous enough to have written hate mail to newly bereaved parents, but even though I did not write these emails, I wholeheartedly apologised to both parents for the pain this would have caused them.

Since that time, this family has been in the media quite often. They have also participated in government policy meetings to try and increase pertussis vaccination rates (I guess our current 95% vaccination rate isn't high enough any more?). They have filed complaints at least twice that I know of when I have had an interview on a radio station or in a newspaper and have made it even harder than it usually is for me to issue any statements about any vaccination issues.

The last straw I guess was two weeks ago when a totally slanderous article was published in our local newspaper, the Northern Star. I believe that most people who read this article, would have been left with the distinct impression that both myself and the AVN were responsible for a huge decline in the vaccination rates against pertussis, leading to the deaths of children.

I wrote a letter to the paper which was severely edited but even so, the editor informed me that he had received an angry phone call from the father of this little girl, asking why they would run any information from an anti-vaccination group.

I sympathise with the grief these parents have suffered. I feel for them so deeply! But they are not the only parents to have lost a child and though their child was the world to them, there are many other parents whose children were also the world to them and who have to face the rest of their lives with their world turned upside down because of vaccination. These parents are not out there telling others that they do not have a right to state their opinion about vaccination in public.

Last week, for the first time in several months, I visited the Facebook page which has

been set up in honour of the short life of their daughter.

I did not see what I expected – a memorial to this poor little baby who was snatched away too early and left her grieving parents seeking support and comfort from the community. Instead, what I discovered was a discussion list which seems to have been taken over, lock stock and barrel by many of the same people who have been harassing the AVN for years. It appeared to me that this Facebook page, which had been set up to honour a baby, had instead degenerated into yet another Stop the AVN franchise.

And if not just for my son – but for the other children – all those hundreds of children whose lives have been blighted by vaccines and whose families have contacted me over the years, I got angry.

When this little girl's death was first announced and I was interviewed about it, I said that it was tragic that she had died. But I also asked why a child who had died from whooping cough was front-page news when the many others who have died from vaccines are not only invisible – they are denied. And if their parents are very unlucky, the death is called SBS (Shaken Baby Syndrome) or MSBP (Munchausen's Syndrome by Proxy) and the parents are charged and put in prison as Sally Clark and so many others have been and still are today.

It all came back to me. A child is a child. A life is a life. They are all important and they must all be recognised.

These parents have a right to their grief – but they do not have the right to provide a protected platform for others who amongst other things, call parents who have lost children to vaccines criminals. They do not have the right to provide a safe harbour for those who say that the grief of a parent who dies from whooping cough is somehow stronger or more important than the grief of a parent whose child dies from a whooping cough vaccine.

The parents of children who die from vaccines not only have to go through the grief of losing that child; they have the double burden of the community's denial. Not for them the awards, invitations, appointments and public condolences.

No parent should ever have to go through what the parents of this baby have gone through. Or what Stephen's parents or Milvie's or Luke's parents have gone through.

In my anger, I posted two items to this Facebook page. The postings were made in anger but they were not angry postings. I simply uploaded my press release about winning the Bent Spoon award (underneath the posting from the Australian Skeptics about this same award) and also, my letter to the editor of the Northern Star about the true increase in vaccination against pertussis. I also started a new post with 5

questions about vaccination which have been submitted by PhD Candidate, Judy Wilyman, to the Minister for Health, Nicola Roxon.

If I have caused this family any pain by posting these items, it was certainly not my intention.

I would like to apologise for any extra burden I have placed on them.

But I would also like to ask them to consider the other parents – across Australia and across the world – who have lost children, just as they lost their precious little girl. Parents who do not have the support and love of 34,000 Facebook fans for the simple reason that their children died from a vaccine and those deaths were not acknowledged in the way that their daughter's was.

A tragedy that can be turned into something positive is a wonderful thing. It doesn't make the event any less tragic, but it gives you a reason to go on – something to work towards. For me, having my son vaccine injured caused me to spend the last 17 years trying to make sure that other parents don't go through the same thing. For this family, their inspiration is the same and I applaud their efforts and their strength.

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Freedom is not merely the opportunity to do as one pleases; neither is it merely the opportunity to choose between set alternatives. Freedom is, first of all, the chance to formulate the available choices, to argue over them -- and then, the opportunity to choose. - C. Wright Mills

The authority of any governing institution must stop at its citizen's skin. - Gloria Steinem

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