Sisters inside Conference Presentation

Thank you for inviting me to speak today at this conference. My name is Elizabeth Russell and I am here as the founder of the Russell Family Fetal Alcohol Disorders Association.

Throughout my talk you will see a visual presentation of my family interspersed with dot points about FASD. This is the human face of which my colleagues have been speaking. The visual presentation is not designed to correspond with my verbal presentation but will run in the background as an additional source of information.

Not only am I a member of rffada but I am also an unwilling and unhappy member of a club which currently has very few members in Australia. No doubt as the years go by many more will find their way to its doors – more than most people would ever imagine. In fact when the inevitable census takes place there could be as many as 200,000 of us.

I never canvassed for membership and seek instead to ensure that fewer and fewer members are forced to join. It's exclusive but its members would rather belong to any other club other than this one. Membership is free but I for one would pay anything to have my subscription cancelled.

With information and education, without which very little can be resolved in society, we can ensure that as few people as possible become members and that is why I am presenting today…… in the hope that I can help reduce the number of people destined to belong to this club.

The members of which I speak are the biological mothers of children who have fetal alcohol spectrum disorder.

During this presentation I will discuss my experiences as the mother of a child with full FAS and the experiences he encountered as a reluctant but uncompromising sufferer of this condition.

It is interesting that the title of this session is 'Blaming Women' as the title of my second book currently at the publishers is 'Alcohol and Pregnancy – No Blame No Way".

Women should never be blamed for this condition but information should not be withheld from them on that basis. We can't allow ignorance to fester in the misguided belief that by not giving people the information and knowledge to make an informed decision about drinking, it will protect them from guilt, shame and blame.

Just as information is not withheld on the risk factors of SIDS for the sake of shielding a woman who may have unknowingly placed her baby on its tummy to sleep, we should be equally diligent in advising mothers on the dangers of alcohol and pregnancy. In both cases, we must armor women with all the risk factors in an effort to prevent further cases and future suffering.

Any medical professional who arbitrarily decides that he or she will not advise a patient on the dangers of mixing alcohol and pregnancy is neglectful. Any medical professional who is not willing to diagnose FASD or refer to someone who can is negligent.

I know from experience that tacitly giving a mother permission to drink during her pregnancy by either not talking about alcohol at all or by minimising the potential for harm is less threatening to some doctors than openly and honestly discussing the consequences to her baby. The key to prevention is open, honest, consistent and non-judgemental education by all medical professionals and health workers – this is not happening at the moment. A woman does not usually set out to deliberately harm her unborn child – if it occurs the reasons are multifaceted and complex. What is happening is that by not fully informing the mother it is effectively, sacrificing one person for the sake of another. However nine months fearing that alcohol consumption early in my pregnancies may have caused problems to my babies in hindsight would have been a welcome experience and would now be merely an unpleasant memory compared with living for the remainder of my life struggling to overcome the guilt of hurting my children, and my husband and I spending our retirement years looking after our disabled son. And hardest of all for Seth and others with FASD is living with a brain that sometimes works and sometimes doesn't.

I trust that in the future, with more understanding of the issues that brings mothers to this point in their life and more opportunities like this to present, that membership to the 'club' will not be so forbidding but will prove positive and inspirational. But this can only occur if there is no blame attached to this condition.

My colleagues have described the condition clinically and now it is my job to try and describe to you the appalling impact it has on the family unit paying particular attention to the tendency of the sufferer towards misconduct and delinquency.

I am a recovering alcoholic so it was relatively easy when I first found out about the condition to match Seth's symptoms with my drinking. It is important to remember that even though this is the story about an alcoholic birth mother, the impact of social drinking on the health of the fetus must not be underestimated as research in Canada has found that 96% of mothers who have children with FASD are social drinkers and only 4% are alcoholic women.

This means if there were 200,000 birth mothers in Australia, 192,000 of them would be social drinkers. These women may have a glass of wine or two at night with their husbands or may attend a party every now and then throughout their pregnancy.

There was a benefit to being alcoholic though – it wasn't a question of trying to think back over the fifteen or sixteen years to remember *whether* I drank during my pregnancies, it was a question of *how much*. And from what I can remember it wasn't as much as you might think. I probably drank 2-3 drinks most nights, more than that some nights, but I don't ever remember being completely drunk during either of my pregnancies. Some would say that is no more than a social drinker might consume.

But because social drinkers form 96% of birth mothers and wont make the galvanizing connection as easily or as quickly as I did, there will be many mothers and fathers in Australia who have spent a good portion of their child's teenage years wondering what on earth has happened to their active and demanding but otherwise adorable child.

What sort of 'monster' has he or she turned into?

Parents of these children will be completely baffled by their teenager's behaviour.
They will be utterly lost wondering when they will ever understand the consequences of their actions. Why doesn't natural justice work with them?

And why, with educated and thoughtful parents do they do so poorly at school?

Why, when the work ethic has been so thoroughly ingrained in them by two working parents, can they not keep their jobs for more than a few weeks?

Why, when they were given every opportunity in life have they chosen to run around with peers who disrespect property and people and use drugs and drink?

And why do so many of these people end up in prison?

Babies with full fetal alcohol syndrome usually have a very difficult babyhood; however Seth was a perfect baby. He had an Apgar score of 10 and sailed through his early years with only a hint of the problems to come. He was very active, cute and adorable, but clumsy and demanding. At the time I thought it was clearly because of the genes he had inherited from me that caused these little idiosyncrasies – I wasn't the ideal child either.

Even though his difficulties increased incrementally from around three years old, the age of 13 heralded the beginning of behaviour so appalling that I have never spoken to anyone about some of it and I never will - out of respect for Seth.

It signaled a decline in his mental health that saw him suicidal, angry, sexually inappropriate, aggressive, threatening and time and time in contact with the police.

It has taken a great deal of heartache, lonely, sleepless nights and 'close calls' but at 22 I think we may possibly be over the worst of it as long as he continues to take his medication for schizophrenia. This mental illness is a secondary disability to FAS.

Prior to a diagnosis of schizophrenia, he seemed almost to stumble from one illegal, immoral or socially unacceptable behaviour to another, any of which could have led him to court and ultimately to prison. It was only through the aforementioned sleepless nights which saw me driving around town or walking the streets in our neighbourhood looking for him, in conjunction with liberal doses of good luck that he remained out of the courts.

His lack of impulse control, trouble understanding the consequences of his actions, difficulty planning, connecting cause and effect, his inability to delay gratification, explosive episodes and vulnerability to peer pressure made him prime prison material.

He was known to the police and would have been charged with assaulting a police officer had he not at the time been bleeding from a cut tendon in his wrist which required hospitalisation and surgery. He constantly flaunted road rules, picked fights, drank and used and sold drugs.

Potentially dangerous situations with overwhelming consequences shadowed Seth for years.

On just about any day or night during his teenage years he could have been charged with something. He was drinking underage for 5 years, he began using drugs and 13, dealing them at 17, driving without a licence, fighting, shoplifting and breaking and entering and truancy. I don't know how he wasn't caught. I lost count as to how many times the police knocked on our door or rang me at work about something he had done.

For me the boy about whom I am speaking and the person about whom you are hearing sound like two different people. I am sure you are hearing the history of a juvenile delinquent, a cunning, manipulative young miscreant who deserves what he gets. If other parents were asked to describe the behaviours of their FASD affected teenagers a similar conclusion may be drawn. But I am hearing the history of my son and the adjectives I just used do not describe the boy I know.

The behaviours I have described are not ***him*** they are his condition**.** Seth's FASD related behaviour is not who he is, it doesn't define him. He is a loving, thoughtful and beautiful young man. His desire to do the right thing by everyone is only exceeded by his desire for everyone to like him. He is well mannered and polite and will do anything for anyone. He will go out of his way to help his family and his friends. I love him beyond words, beyond anything I ever imagined or thought possible. I love him unconditionally and unreservedly and I am proud of his achievements no matter how small they may seem to others. He tries so very hard to do the right thing, harder than anyone I know and he deserves the very best that life has to offer.

My family has learned about alcohol and pregnancy the hard way.

But harder still is having the condition and not knowing. And this is the way it is for thousands and thousands of people in Australia and I believe this is why there are so many people in prison who are retarded or who have a mental illness.

As my colleagues have said, mental illness and contact with the justice system more often than not commencing in the early teens are both secondary disabilities of FASD. That is certainly our family's experience.

If it hadn't been for the support Seth had from his family he would now be in prison. There is no doubt in my mind – absolutely none. He would be in prison at best, dead at worst.

Seth was cast as a juvenile delinquent when all he was doing was following his congenital imperative. From a very young age until just recently, 99% of his actions or the trouble that dogged him were out of his conscious control. He could not have changed what he did during this period of his life if his life had depended on it which it often did. The impulsivity, lack of ability to generalise learning, inability to link cause and effect combined with perseveration and immaturity all conspired against him to turn him into what other people in their ignorance would label a juvenile delinquent. Even though by all accounts this was what he was, there was a very marked difference.

FASD can cause behavioural problems similar to those caused by the environment. However the antisocial or delinquent behaviour caused by the environment sometimes can be resolved if given appropriate and consistent assistance at the right time, because while the behaviour and the psychology are abnormal, the brain has not been physically injured. People who have FASD have a brain injury so will not be able to make the necessary changes, even though they seem to have the ability to do so. FASD is not an excuse for bad behaviour; it is the reason for it.

Sufferers often try to do what is expected of them, but it is like assuming persons in wheelchairs will be able to walk just because we tell them to. The difference, of course, is that we wouldn't expect people with paraplegia or quadriplegia to walk if we yell at them enough, but every day people with brain injuries are expected to "walk" when they are in metaphorical wheelchairs. Moreover, no one can see their "wheelchair", no one knows about this injury because it is not visible; and it would certainly not be obvious that they have FASD simply by talking with them for a short time, unless they have the distinctive facial features or a lower IQ.

A common mistake is to assume that because a person can "talk the talk" he or she can also "walk the walk". This is not true for people with FASD. Their expressive language is far better than their receptive language and so they can say they understand what is being said, and can even repeat what has been said, but if it's a complicated or abstract concept or if there is more than one idea, instruction or topic, then it is unlikely that information will be accurately interpreted.

So with no diagnosis, friends, family and other significant people in their lives will not fully understand the reasons for their behaviours. They may believe it's because of dysfunctional parenting, abuse, mental illness, genetics, drugs, alcohol, or just plain irrepressible immaturity when in fact their brains were saturated with alcohol, destroying brain cells, when they were in their mother's womb.

The presumed origin of certain delinquent and antisocial behaviour in Australia needs to be revised immediately because we are sending people with disabilities to prison for behaving in a manner that is consistent with every expert opinion on that disability.

I see people with possible FASD in the news every day. A young woman charged and subsequently convicted for assault 'shows no remorse' for her actions.

The young mother who has been convicted and imprisoned for murdering her children? What if it is almost casually written in another news story that this young mother's mother is an alcoholic? Even worse, what if no one who has the power to help her has put the two together despite the young mother having many psychological and psychiatric assessments?

If these instances are qualified by an understanding of the effects of prenatal alcohol exposure, instead of immediately condemning, people may instead think more deeply and not so critically. These people have a disability! To paraphrase a good friend of mine David Boulding who is a lawyer in Canada and very familiar with FASD, "If you think that sending a person with a brain injury to prison will rehabilitate them – you're delusional!' And that's what we are doing – every day! Every day in Australia we are sending people to prison who have a brain injury and can't help what they are doing. And the people who should know, who are there to help, don't have a clue!

Even though I am an alcoholic, my husband Don and I have a long term relationship and both our boys know that they are loved and cared for. Seth has never been neglected, has never been psychologically or emotionally ill-treated, and knows that he is an integral and much loved member of our family. How much worse would it be for someone who has been affected prenatally by alcohol and then for years lives in a dysfunctional, unsupportive and abusive home? Even in a 'good' home, Seth was unable to move outside of these self defeating behaviours and continued for many years to use drugs and alcohol, shoplift, steal, drive without a licence, play hooky from school and the few jobs he had.

There were many years that I thought prison would be the end of him but when he became suicidal, I wondered if the routine and structure of prison would have been the best thing for him and the only thing that might keep him alive. Prison would have kept him out of further trouble and while it may have destroyed him in one way it would probably have kept him physically alive.

I am in a better position than most parents of children and teenagers who cause them concern. I don't need to ask "What did I do to cause my children to behave in this way?" or "What could I have done differently?" or "Why is this happening?" I know what has caused these problems for my sons. There is no need for me to wonder and, while it is difficult, it is better than not knowing at all.

Before Seth knew he had a "condition" it was hard for him. He experienced an inordinate amount of emotional and psychological pain. He lost friends, has had suicidal thoughts most of his life, he knew that he wanted things but when he tried to get them nothing worked out the way he planned.

He has had the pain of addiction, the challenge of appearing outwardly capable, and the anguish of not being able to meet others' expectations.

He has known the sorrow of awareness that others feel contempt towards him but does not know how to make the changes that would turn that opinion around.

When he first found out he had a “condition”, a medical problem from which most of his problems stemmed he was as relieved as I was distraught. Now that I can comprehend just how much he needed to know that his problems weren’t because he was a “loser”, I am also relieved ---- and thankful that circumstances provided us with the opportunity to discover this.

Along with the heartbreak of being a birth mother, there is also the very real and hugely complex task of parenting a child or children with FASD. It is exceptionally demanding, in fact, to paraphrase Diane Malbin, a FASD worker in North America ----- parenting children with FASD is like trying to navigate around Sydney with a map of Melbourne.

In most cases the affected child will do things regardless of the wishes, advice, demands or approval of the parents. Many of the things Seth did when he was young were not done with my approval or my husband’s approval, they were not part of the value system with which he was raised, they were not socially acceptable nor desirable, but most were outside his control and very indicative of his brain injury and the condition itself.

So what is happening to the children in Australia who aren’t aware that they have a brain injury and whose parents, relatives, friends and teachers aren’t aware?

The condition is slowly but inexorably grooming them for the justice system.

It is my hope that along with information about FASD my presentations serve to generate a more balanced discussion about the most recent news item or the latest figures on bullying at school, or the increase in cases of ADHD.

Instead of immediate condemnation of these people perhaps we can listen with a more informed ear and speculate whether there might be more to these cases than first meets the eye.
But how can we help?
We MUST identify current sufferers and put strategies into place to assist these young people through life so that they don’t become involved with the juvenile justice system. For those people who are already in prison, we MUST develop a process of diagnosis so they can serve a sentence commensurate with their disability. Appropriate life skills training and linking with a mentor will assist them to gain skills which will help them when they leave prison.

We MUST talk about alcohol and pregnancy, discuss it openly and help mothers give birth to children not burdened by this preventable condition. We must always remember that regardless of the circumstances, regardless of whether the mother knows that alcohol is harmful, and regardless as to whether they are alcoholic or social drinkers, there MUST be a “NO BLAME – NO WAY” ethos. Without that mothers may not seek assistance for their alcohol abuse or they won’t disclose that they drank during pregnancy. We must all be caring, compassionate and prepared to help. This HAS to be a ‘no blame’ condition. For most mothers the life long sentence of guilt and remorse will be punishment enough – there is no need to add to it publicly, the price of watching while your child slowly kills himself or herself is surely enough for anyone.

When you are wondering why so many people with an intellectual disability or a mental illness are in prison please think of fetal alcohol spectrum disorder and what we must do to prevent it and assist those who suffer daily from its primary and secondary disabilities.

When there is so much devastation and horror happening to people every second of every day around the world, it is so important to control the things we can control and help prevent at least some of this misery occurring. And this is one thing that we CAN control, we can reduce the incidence of FASD, through education, open and honest discussion, not even a HINT of blame on our mothers, and through the support and understanding of those who are suffering from this condition, because they are suffering, you can be certain of that.

I personally believe that suffering is a state of mind, but regardless of that, I know that Seth has suffered, his brother Mick has suffered, my husband and extended family have suffered and I will forever be telling myself that I have the choice not to feel the way I do – but this is by far the best way for Seth. If he HAS to have the condition then we HAVE to know about it.

Thank you for allowing me to present to you today, it is guaranteeing that my family's experiences can be their contribution to others.

Anne Russell

Elizabeth (Anne) Russell