# Sophie’s story – International FASD Awareness Month

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### In support of International FASD month, throughout September Drink Tank is sharing the stories of individuals, families and carers living with Fetal Alcohol Spectrum Disorder (FASD).

*In support of International FASD month, throughout September Drink Tank is sharing the stories of individuals and families living with* [*Fetal Alcohol Spectrum Disorder (FASD)*](https://www.nofasd.org.au/alcohol-and-pregnancy/what-is-fasd/)*.*

*This is Sophie’s Story, based on her opening statement to the Inquiry given in June 2020.*

*The hearings were held just prior to Australian and New Zealand food safety ministers voting in favour of mandating a clear, visible pregnancy health warning label on alcohol products.*

*To find out more about FASD, visit the* [*NOFASD website*](https://www.nofasd.org.au/)*. To find out more about referral, diagnosis or supports, call the NOFASD Helpline on 1800 860 613.*

## Senate Inquiry – Story of a birth mother

I am a birth mother of a teenager with FASD.

We received a formal diagnosis of FASD for our son, just two months ago, this is still new and a little raw for me; however, the opportunity to speak to the committee was something I could not pass by.

My story began when I was 30 and conceived my first child. I’d been married for four years to a medical professional. I started to prepare my body, making healthy choices for 12 months before I ceased taking the birth control pill. I drank alcohol at weekends socially, I didn’t know alcohol was a teratogen and could cause harm to a growing baby.

My husband and I believed it would take many attempts and several months before we would conceive, however, we were blessed and conceived our son on the first occasion of unprotected intercourse.

My pregnancy was confirmed at 6.5 weeks, we were shocked and delighted. The excitement was followed by trepidation in the following days as I recalled the night of conception, entertaining with friends. I also recalled two further occasions of dinners and wine with friends, at what would have been three and six weeks after conception.

My GP reassured me that I shouldn’t be concerned, and this was such a relief! I read the guidelines from the National Health and Medical Research Council, prior to 2009, it was deemed ‘safe’ to drink two standard drinks per day and no more than 10 per week. I asked my midwife about alcohol in pregnancy, “the odd one or two won’t hurt” was the reply.

I would drink one weak coffee per day, wash my salad and avoid soft cheese and pate for fear of causing harm to my developing baby. However, I still remember, standing in my kitchen for my “Friday night treat!” measuring 1 unit of wine, 9 units under the recommended NHMRC safe guidelines.

There were no clear health warning labels on alcohol products, an issue which, unbelievably, as I tell my story 15 years later, is still being blocked by the influence of the alcohol industry – an industry that is allowed to regulate itself.

Meanwhile, tens of thousands of babies are continuing to be born each year with prenatal alcohol exposure (PAE), while the alcohol industry continues to argue the semantics of a clear and visible health message for pregnant mothers and the community who can support them.

My son was born at full-term, a beautiful bouncing 9lb baby, physically perfect in every way. He was a ‘fussy’ baby, he cried a lot, didn’t sleep much, couldn’t breast feed, he had a number of ear infections, with a pain threshold which was incredible. He also needed dental work at 3.5 years due to decay, which came as a huge shock to us as parents who had provided a healthy diet and good tooth hygiene.

These things can be common in babies who have never been exposed to alcohol prenatally; however, I wonder when we took my son to a developmental paediatrician at three months, whether the outcomes may have been different if he had been FASD-informed.

My son met all of his developmental milestones… always slightly late but not enough to be a concern, from family day care at 10 months through to Year 5 of school. We took our son to a number of medical and allied health professionals, because I knew, as his mum, something wasn’t quite right, I just didn’t know what it was. The responses generally were, “he’s a late developer… he’ll grow out of it”.

I was often left feeling like an over anxious helicopter parent.

From Year 2 of primary school, my son had an Individual Education Plan, he was given extra support through literacy, numeracy and resilience programs, his reports would always include comments like, “if he focused more, if he talked less and paid attention, if he could learn to ask for help”. His grades were always limited but we praised him for his effort, not the outcomes. Homework was meltdown time, as he was so tired by the end of each day that homework was mostly too difficult.

At the beginning of Year 6, aged 11, the first REAL concerns were acknowledged by the school, following the end of year 5 tests.

On advice, we took our son for testing for dyslexia and dyscalculia, but he didn’t have either. However, his results were shocking reading. Our son was identified as ‘educationally at risk’ with significant impairments with his executive functioning, cognition, working memory, auditory processing and attention. This was alarming, yet there were no recommendations for further consults. We discussed this with his school and put in strategies to support him at home and at school.

In 2018, I came into contact with NOFASD. My life’s work had been working with young people in at-risk environments. I had seen firsthand the impact of FASD on individuals and families.

While doing some research on FASD, I learnt for the first time that there is no safe level of alcohol consumption during any stage of pregnancy. This hadn't been on my radar.

The more I read about the physical and neurodevelopment challenges of babies and children with FASD, the more I identified similarities with my son. There were so many parallels, and I could not overlook my alcohol intake prior to my pregnancy confirmation as a potential causal factor for his impairments.

I met two further clinical psychologists, I told them of my concerns, they were not FASD-informed. I spoke with two different GPs, and each time I was asked if I had considered Autism. I was told it was highly unlikely there would have been harm due to the low level of consumption. I knew this to be untrue statistically.

I arranged testing with a speech pathologist for the domain of language, I shared my concerns about pre-natal alcohol exposure, and again I was told this was highly unlikely. My son was diagnosed with a severe language disorder.

I discussed my concerns with the NOFASD Helpline Manager and NOFASD Founder Sue Miers, as I felt certain my son had been impacted by pre-natal alcohol exposure.

After further educating a GP and providing evidence of assessments, I was referred to a FASD-informed paediatrician whom I had sourced. My son was diagnosed with ADHD, prescribed medication and referred for further testing related to PAE.

To date, my son has been assessed with severe impairment in four neurological domains – three are required for FASD. He has been diagnosed with FASD and he will undergo further testing next week in two more domains initially.

My son is a relatively happy, healthy and stable young man, he is lucky, we are able to provide him with strong boundaries, consistency, routine, good nutrition and a life without trauma.

He attends school almost every day, but he struggles EVERY day. The school knows me well, as I speak with his teachers every week. He continues to be told to “pay attention, stop talking, stop distracting others, try harder, follow instructions”. Most of his teachers are trying, they are doing their best, but they have never received training to learn about FASD or strategies to support their students.

My son astounds me every day with his resilience, strength of character, determination, perseverance and self-control. Especially when time and time again he is told he isn’t trying, when in reality he couldn’t try any harder.

He has some amazing strengths which we see often, as do others who are able to take the time to understand him and who know how to support him with his challenges.

### Metadata