



THE NETWORK NEWS

FASD-CAN Incorporated

March 2018

A word from the Chair

This issue is full of positive and inspiring stories from the coal face of FASD. It is always heartwarming to hear families have found their pathway to success. It comes in many forms as these stories clearly demonstrate. It strikes me that this success comes from within the family unit itself, a strengthening of resolve and knowing when to reach out for help and what that help looks like.

Many parents and caregivers are 'training as they go'. We have all been doing this for years. As we engage with various support people and organisations, we bring with us an informal FASD training manual that we each hold in our heads and our hearts.

In this vein, and as part of the FASD Action Plan, the Ministry of Health have secured a contract with Maua Raki to develop a training protocol for front line professionals. This work will develop over the next twelve months. FASD-CAN will work closely with Matua Raki to help inform their project. As part of this, we will be asking for input from parents/caregivers across all regions. We will keep you notified of this as plans progress over the next couple of months.

The committee have also undertaken to write to the new Labour-led Government to bring FASD to their attention and the apparent slow progression of the FASD Action Plan in terms of improving supports and services for affected individuals and their families. We will also keep you up-dated on this when responses are received.

There are a number of face to face support groups slowly developing around the country. We are very supportive of this kind of initiative and would love to hear more from you on how your meetings or informal gatherings are helping you.

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Kia Kaha
Claire Gyde

Our Science our Stories

Australasian FASD Conference



The 2nd Australasian FASD Conference is being held on the 21- 22 Nov 2018 at the Pan Pacific Hotel in Perth Western Australia.

The hosts *FASD Research Australia Centre* of Research Excellence aim to bring together people from all sectors of the FASD community including academics, clinicians, service providers and people with lived expertise such as individuals and caregivers. The conference provides the opportunity to share knowledge and strengthen international networks.

Keynote speakers will cover topics on prevention, screening & diagnosis, epigenetics, education, justice, parent & caregiver support, management strategies, life-span issues, mental health and economics.

FASD-CANs chair Claire Gyde has been asked to be a keynote speaker at this conference. Claire frequently speaks publicly to deliver her personal story in the hope that it helps others to understand the 'lived experience' We are very lucky to have New Zealand caregivers represented within an international forum.

Pre-conference workshops are being held on 20 November 2018

This event will be open to health, education, justice and disability professionals; parents and caregivers; policy makers and the research community.

[Keep up to date with information leading up to the conference, including key note speakers and submission of abstracts, and register your interest to attend.](#)

[Download the brochure and share amongst your networks](#)

Tauranga FASD-Informed Practice Workshop

On the 22nd of March, Bay of Plenty welcomed Dr Valerie McGinn from The FASD Centre and Christine Rogan from Alcohol Healthwatch presenting at the Elim Church hosted by the BOP District Health Board. More than 200 from the FASD community attended representing all sectors, as well as families and caregivers. They learned about how to manage and care for our children and young people and adults with FASD compassionately and differently in order to make their lives easier and better. There was robust discussion about how to better develop FASD awareness and services in their community. It was a great day and feedback suggested that those who attended left with increased skills to make a difference for those with FASD. Thank you Bay of Plenty for the great welcome and your enthusiasm.

Good News Stories from around Aotearoa

Supporting those living with FASD can be an isolating journey where families often slip in and out of crisis as we navigate rigid systems that often seem oblivious to our children's needs. The following 3 stories have been written by our FASD mums and highlight the success our children can achieve if accommodations/scaffolding is put into place to support them. This can be exhausting on already tired frazzled caregivers, so it is a testament to your determination and commitment to help your children to be the best they can be. Thank you for sharing your stories and inspiring us to continue to advocate for our loved ones.

Alex's Story of how accommodating need can lead to success

Ok, Let's start a couple years ago. It's 2016 - we enter into year 10 or what I call 4th form (lol). Well, the day a few of us and our kids were to be interviewed for 7 Sharp I get a call to say an incident happened at school and he is not to come back until we can get this sorted. So, the storm had arrived, later than I thought it would, but still arrived. We had a term of meetings and more meetings and ideas on the table from MOE and the RTLB that all three of us agreed could work but school put up the wall and said no can't do that. So, by end of term one I had had enough and we 3 realized and agreed that we were at the point of the fight of

correspondence school time. Took another term to sort out paper work and get started then another term to find a teacher aid for those lovely token 5 hours they give you.

So now we are at 2017 and the start of a full year. Now we kinda know what we are doing. We have a teacher aide and he is brilliant. He was a scientist and maths was his strong subject before becoming a teacher. Alex went from strength to strength. His TA worked him out, and how he thought and did his work. It didn't take long really and we went from high school saying level 1 across the board, maybe a 2 for maths on a good day. Yea, lets say by end of year we were doing level 4 maths, and breezing it, and level 5 science. He even got a certificate for how far he had come and the achievements he had done. We knew he could only work well mornings so made all school work to be done before midday. To help socially we got involved in Te Kura's activities for sports, like ten pin bowling once a week, and digi circus group (robotics). He also did an extra digi circus class after school hours even though he was little older than the other kids but it worked well. Even the advisory that ran a sports class for a small group worked out that, for him and couple of the others, team sports were not a great idea after a big blow out between my boy and another. Instead of kicking both boys out they modified and changed sport and just had me and the other parent to come hang out in case. We didn't need to do that for long as the boys ended up becoming best friends as such and from then we started having the other boy over during holidays when the girls were at the holiday program.

Now we are here in 2018 and, although our TA resigned 2 weeks before we started the year, we have managed to find a TA that can start next term. We have been able to also sort a great routine, still with school work in the morning and adding in the bowling and flip out sessions with Te Kura and managed to get involved with disability training services which is going really well. Alex has gotten involved with a learner licence class and sounds like he won't be far from sitting it - eek!! , baking one arvo which he loves doing and helps the others with it. Then there is the Menz Shed he has gotten involved with through DTS and, wow, they are just brilliant with him. Alex has informed them of what he has. and one guy, turns out has had dealings through mental health with adults with FASD. They just love Alex and his passion to learn and he just gets stuck in and cleans up after himself (not at home of course lol). Today they were telling me about how they can give him a task and leave him to it and he does a great job. They are just so chuffed with him. Long may it last and I'm positive it will.

Something my Mom said today when we were talking about Alex and the Menz shed and she said FASD makes him-him and his personality, and they see Alex for Alex and who he is. I have learnt to be ready to change tact or direction when he seems to be losing it or not dealing with a situation. We have been able to modify learning to his interests and so, as a result, we are having success. We have routine and plenty of notice of things to come or change when we

can. We really do have a great system, him and me. He lets me do all the leg work and working stuff out and then I come to him with either a couple choices or with the end result of what's happening. But we talk and if it was not something he wanted to do I don't push it, no matter how good for him something is. We do have a good support structure with my Mom and we have just gone and found for ourselves those that support us and our choice in how we choose to do things to help Alex. Even if we have no services as such we have little bits here and there of people that understand. It's what has worked for us and is not necessarily the answer for everyone but what has been our success with our boy.

Jackie Prichard mum to Alex

Sporting Achievement



Ruslan (now 15) has been doing archery for about 2.5 years and even though he finds it hard to stay still when it comes to archery he has found he is a sharp shooter. He recently participated in the South Island Youth Archery Games near Christchurch. He won in two categories and came second in a third. He was shooting for several hours in back to back events.

Ruslan shows that by persistence and tenacity young people with FASD can still succeed. It's never been easy to concentrate or stand still but archery seems to help him steady his focus - albeit in short bursts - then he rests and does it all over again - great self-control training. One counsellor once said to the family - 'are you sure you should let him have a Bow and an Arrow?' well we answered he might well be impulsive but that

does not mean he's dangerous! Well done Ruslan, go the Olympics!

Anita Gibbs mum to Ruslan

FASD – Fantastic Aaron Succeeds Despite.....



We arrive back home to chaos on the 1st January after a few days boating on Lake Taupo. We were a bit late and Aaron was getting stressed and agitated. Things had escalated, and the police were called. Yet another trip back through the Court System which is always a long drawn out process. In bed that night I was thinking “Is this going to be how our year is going to be. Will he land up in prison due to his impulsiveness and inability in times of stress to make good choices?” I was feeling

hopeless about Aaron’s future and helpless to do anything to change it as no one was willing to take a chance on him. As in the past the chronic grief cycle kicks in and there is this feeling of rejection and isolation in a cruel society that doesn’t want to deal with our children. I prayed that a miracle would happen.

On the 2nd Jan the house was a sombre place as if someone had died. Aaron spent all his time in his room in the dark. He knew he had done wrong and felt really bad. However, something happened after dinner time which has changed the course of Aaron’s life and ours for the good. Aaron was friends with our boat mechanic, Kerry, on Facebook. Well Aaron was talking to him about how bad he was feeling. The next day Kerry offers to have him at his workshop. He has his own car and boat mechanic business which is thriving. Over the four years we have known Kerry, Nigel, my husband, had talked to him about FASD and Aaron never thinking that he would do something like this.

Now almost three months later, Aaron is like a ‘pig in strawberries’. This morning he was at work at 7am ready to get cracking. Is this my son??? During this time, I have slowly educated Kerry about Aaron’s ways and nothing phases him. I gave him the leaflet from FASD-CAN on FASD in the Workplace which is short, to the point and doesn’t scare people off. He also has our ‘Safety plan’ which we have adapted slightly after the knowledge I have gained from my relax kids training. We have now got Aaron to visualize his “safe place” and will say this to him when he is moving into the “amber zone”. His safe place is hooning down the river on his dirt bike and getting all muddy.

What is working:

1. Kerry, as an employer, understands his brain injury and reads the signs when he is starting to become overwhelmed (swearing, being defiant). He will then prompt Aaron to go and have time out on his bus in the yard. This is no ordinary bus. It has an Xbox, all round sound and a huge TV at the end of the bed. You would think Aaron would not want to leave but he goes, has time out and then comes back after a while to carry on with his work.
2. There is minimal stimulation/distraction. Kerry has no music in his workshop and most of the time it is just him and Aaron working quietly together. A lot of the jobs on the boats requires two people so Aaron is very much needed and feels useful to Kerry.
3. Good honest communication between us all. Kerry is a natural communicator and treats everyone with respect. He is very clear in his communication to Aaron. He has a whiteboard up where there is a list of jobs for Aaron to do. However, Kerry will be firm and if he sees Aaron on his phone or swearing he will reprimand him. Clear rules are important as the work needs to get done.
4. The work is a physically demanding job which is good for stimulating the 'happy hormones' in the brain, serotonin and dopamine. Kerry smiles and laughs a lot which is certainly the environment Aaron works well in.
5. I ensure they have a good meal every night as often they don't finish till 6pm. Also, a good time for Aaron and Kerry to talk about their day and iron out any problems.
6. Lots of positive encouragement from Kerry when Aaron is working well. Also, the philosophy that everyone makes mistakes and that we have to be honest about them. He has said to Aaron that this is how he learned and that it's best to let him know, he won't growl him for the mistake but will certainly growl him if he doesn't tell the truth. This is a learning curve for Aaron as he is the best confabulator out there.
7. Ongoing support from Community Connections who come and take Aaron away for a few hours each day to give Kerry some respite.

Currently we are taking each day as it comes. Last week he had his sentencing in court and has a 'good behaviour bond' for one year. That is a long long time in the world of FASD. However, with close support, supervision (24/7) and being busy and useful every day we hope he can stay on the right side of the law. I keep pinching myself every day as I still can't believe all that has happened in the last few months to turn our life around. To hear Kerry, say that Aaron has true potential and is a natural with engines just blows me away. That night of the 1st January, I did pray for something good to happen and that prayer was answered. The miracle I had prayed for had come along the next day.



Kerry has become part of our FASD family and is the glue which is keeping things ticking a long on a fairly even keel. He has learnt the practicalities of FASD through dealing with a number of meltdowns, observing and looking objectively at how to prevent the 'pressure cooker' from exploding. He knows that he has to read Aaron's behaviour and then respond in the right way to avoid escalation. In only three months, Kerry, can read Aaron like a book, and between the two of us we deal whatever comes our way. Perseverance (stuck thinking) is another

big problem with Aaron but with two of us being strong and following through with the same message, Aaron is processing things a bit better.

Lisa Smith

Beacon Aotearoa: Shining a light on FASD and Neurodisability

www.beaconaotearoa.org.nz

**FASD
doesn't heal with time.
Love people
for who they are
and not for who
you want them
to be. That's
where the
disconnection
starts.**

Child's Voice

FASD SUPPORT GROUP

For Parents and Caregivers

A support group for parents and caregivers who are caring for children, youth and adults who have, or may have FASD.



This will be our second meeting so come along and share the journey.

“However hard it is for caregivers to handle the stress of challenging behaviour, we must remember that it is the person with FASD who is truly burdened with living in a society that does not understand them.”

- Oregon Behaviour Consultation

We will meet at 7pm – 8.45pm
Tuesday the 10th of April
in the lounge at

Church of the Saviour
2 Heaphy Street, Blockhouse Bay,
Auckland.

Hosted by Anna, Ross and Trish

There is no cost to attend, tea and coffee will be provided.

For Caregivers, hosted by
Caregivers

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Review, Respond and Relate *Integrating Research, Policy and Practice Around the World*

April 18-21, 2018
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Interprofessional.ubc.ca/initiatives/adults2018

FASD-CAN would like to wish our members a very happy Easter. We hope the school holidays are not too stressful for those with school age children and you manage to get some quality 'you time' as well as family time during this period.



