



THE NETWORK NEWS

FASD-CAN Incorporated

July 2017

A word from the Chair

The committee has met and determined some strategic focus areas for the next 12-18 months. We have three strategic priorities:

1. Unite caregivers, strengthen families and support individuals.
 - a. Provide forums for networking
 - b. Provide up-to-date resources
 - c. Provide opportunities for those with FASD to be heard.
2. Education and training.
 - a. Ensure that the lived experience and the parent voice is included in all FASD training to support services.
 - b. Increase media profile to raise awareness
3. Build relationships / Community engagement.
 - a. Work collaborative with Government and non-Government organisations to form policy and procedure.
 - b. Affiliate with other national and international organisations to ensure information sharing.

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I am pleased to report that some of these plans are already underway through the following initiatives:

- Established funding through Ministry of Health to hold at least one parent workshop event within the next year.
- Designed a 'welcome pack' to be sent to every new member including booklets, reading material and web site references.
- Web-site up-grade is in the discovery and design phase
- Affiliations with NOFASD Australia has been established and several meetings held.
- Follow up on progress on the FASD Action Plan and meet with Peter Dunne (August)

Most committee members are also parents who are juggling home life with work as well as contributing to FASD-CAN on a voluntary basis, so I thank them for all the work and effort that has gone into this plan to date. Please note and 'save the date' for our AGM, 9 September 2017 and help us unite caregivers and strengthen families.

Kia kaha
Claire Gyde



From Left, Rose Hawkins (Oranga Tamariki), Christine Rogan (Alcohol Healthwatch), Laurie Te Nahu, Andi Crawford and Kate Robershaw (Hawkes Bay DHB).

Kiwi's step up in Canada

I had the privilege of joining a dozen other New Zealanders attending the *7th International Fetal Alcohol Spectrum Disorder Conference: Integrating Policy, Research and Promising Practice Around the World*, in Vancouver Canada. As its name suggests, this was a global look at what is happening in the FASD field, and Kiwi developments were part of the large and very diverse programme.

Four oral presentations from NZ were included in concurrent sessions. The first two were back-to-back presentations, demonstrating how support for FASD in some regions of New Zealand had resulted in greater awareness and potential for effective prevention and intervention. The group of speakers highlighted the recent move to create the first Government level plan for NZ to address FASD matters and the elements that came together to achieve this fundamental shift. The session reflected the community viewpoint (from Alcohol Healthwatch) teamed with the clinical experience of identifying and assisting children and caregivers living with FASD (from the Hawkes Bay DHB Developmental Assessment Programme – DAP team). The second half of the session focused on the development of FASD-related resources and skill building of Ministry of Social Development staff & caregivers. Again, the value of working transdisciplinary shone through as a

positive way to achieve shared goals. The resulting innovative resources shared with the audience, met with strong endorsement.

In another concurrent session, the Hawkes Bay DAP teamed up with Iwi-based health services to present on efforts to merge Tikanga Māori models of health with conventional medical diagnosis in order to enhance cultural safety and engagement for Māori whānau experiencing FASD. This beautifully presented culturally rich session, captured the hearts and minds of the large audience, who responded with an extended standing ovation. Hawkes Bay is indeed fortunate to have such wonderful people looking after their needs!

I was privileged to be asked to participate in a four person FASD justice panel discussing activities addressing FASD within the criminal justice system in New Zealand, the USA and Canada; everything from politics to prisoner segregation, preventing recidivism and positive changes. A shared view was the recognition that it is never too late to intervene appropriately in their lives, not enough is being done to identify FASD early and take steps that steer those at greater risk away from such harmful endeavours, because families cannot and should not have to do that alone. Larry Burd, a Professor of Paediatrics from Dakota presented eye-watering numbers to illustrate the scale of this global problem and the degree of services that are required for new let alone existing cases of FASD. He challenged us to be pragmatic and innovative in finding solutions.

Other highlights from the conference was the panel of young people with FASD presenting the results of a survey they organised to gauge the extent of other health problems experienced by this population. Over 400 individuals with FASD responded. The preliminary survey results indicated a significantly increased risk of all manner of other health conditions and diseases experienced by those diagnosed with FASD. Though not scientifically validated, the survey did raise significant questions about the extent of damage alcohol exposure before birth might also be responsible for and the implications for individuals and families living with FASD. It also 'red flagged' the importance for families and medical specialist to become vigilant around looking beyond FASD to check for other disorders and diseases and their treatment. The dynamic young people who led this project are hoping to have the results published at some point.

A pre-conference 'Let's Talk' workshop on the subject of Stigma and Stereotypes was particularly insightful and I believe groundbreaking. Stigma was recognised and discussed in the context of alienation and judgement of mothers who drank during pregnancy, in the language used in prevention campaigns, or in the treatment of those with FASD and their families within services and society at large. It was a day that challenged the thinking of each and every participant. We were asked to examine and ultimately consider changes to their own views and practices that may be unintentionally contributing to stigma instead of reducing it.

Much of the conference shone a spotlight on scientific research underway such as identifying early biomarkers for FASD – for example, the potential of using computer games to track eye movement as a way to screen for areas of brain impairment. Others are looking to genetic or nutritional pathways to differentiate factors that might increase or decrease the risk for FASD. It was exciting to see so many brilliant young scientists passionately working to make a positive contribution to prevention, understanding of FASD and to treatment outcomes.

However, it was the high level of participation and contributions from individuals and families at a conference like this, that makes it so special and the best way for us all to learn. Long may that continue!

Some keynote addresses and concurrent presentations can be viewed on the University of British Columbia, <http://interprofessional.ubc.ca/initiatives/fasd2017/presentations/>

Artwork by Katie age 10



The following article encapsulates the depth and breadth of emotions that are often symptomatic of FASD and is one which many of us can relate to. Thank you to the young woman who gave permission to share her blog with us. Your voice is powerful and important.

The Surfer, the Wave

Every day I encounter my FASD, like a surfer and a wave. I am the surfer, trying to get on top of the waves of emotions. Sometimes, I can catch the wave and ride it smoothly; sometimes I think I'm on top but I tumble and churn within the waves. Sometimes the swells don't get too high, and on rare occasion they're over eight feet, frightening and crash in chaos. The swell, it builds and it feeds on the momentum. The heights it can reach is daunting, not just for the surfer, but the swimmers around here too.

I'm learning all the time, how to cope and manage my moods and emotions. It's a personal challenge with many stepping stones and great successes. Just four years ago, I was on the street and would've never dreamed of wanting to make these positive choices for myself. Now, I can breathe deeply when I am caught up in the waves and swim to solid ground. What an achievement that is!



