



May 2023



Tēnā koe

An update from Dr Leigh Henderson Chair of the FASD-CAN Board

It's been a busy year for FASD-CAN so far, with the launch of many new initiatives – training courses, support groups, new Navigators and more. Behind all of these sits our organisation's strategy and the Board has recently reviewed this for the next 12 months at their annual kanohi ki te kanohi / face to face hui in Wellington.

Our primary objective is to provide direct support to our whānau through advice, support, training and resources.

However, over the past two years FASD-CAN has seen an increase in requests to provide training to the professionals who support our families and individuals.

The Board considers that the delivery of such programmes is an important way to change the environment in which our children and young people are growing up. We've also identified the need for service providers to have an increased awareness of FASD and will be considering ways to influence this to happen.

During our hui, the Board also held a meeting with the CEO of Whaikaha (Ministry for Disabled People), Paula Tesoriero. Many people have spent years advocating for FASD to be considered a disability which is eligible for support. Following the discussion, the Board felt there is a willingness to address this, albeit within the broader context of eligibility for neurodisabilities.

However, the mantra is 'no money without policy', so further developments will be contingent on a policy paper which is presently being scoped. But we are optimistic that there is progress being made within the new Ministry and we look forward to the government's response to the United Nations review to roll out Enabling Good Lives to those with FASD in Aotearoa.

The Board also considered how we heed te Tiriti. Since the election of Gilbert Taurua and Diana Kawana to the Board last year, they, together with existing Board member Huriana McRoberts, Tania Henderson and other FASD-CAN members, have formed a Māori caucus to plan what we can do to improve the lives of those with FASD in the Māori community. This welcome development is in its early stages – we'll report back on progress as it happens.

FASD-CAN Hui 2023



We're making exciting progress on the FASD-CAN Hui in September! The date falls on International FASD Awareness day on Saturday September 9th, and we have a

second half-day on Sunday 10th. We're holding it at the Distinction Hotel in Hamilton, and the theme is 'Reflecting Back, Pushing Forward'.

Some notes on the programme so far: we'll be marking the 10th anniversary of FASD-CAN; covering what has progressed in Aotearoa and what is still to be done; there'll be a symposium on Mental Health and FASD, with a great line up of NZ and international speakers; we'll update you on FASD research in Aotearoa and shine a spotlight on FASD in the Waikato.

Accommodation will available at the Distinction Hotel (photo above) at a reduced rate – all <u>details are available here</u> on our 'hold-the-date' event page. Registrations for the hui will be open from June 1 on this page. We'll let you know on our social media when you can register.

Note: if you are a FASD-CAN member and will find it difficult to get to the hui for financial reasons, you can apply to be reimbursed for your travel and accommodation costs from our Whanau Direct Care in the Community Grant – <u>click here</u> for more details.

New: FASD-CAN De-escalation Training

We have had so many requests from our members for help in managing dysregulated situations with tamariki and rangatahi that we've developed a new initiative to build your capabilities in de-escalation techniques – with some self-protection strategies also covered for those times when deescalation is just not possible.



Click here for more info and

<u>registration</u> – but please be aware that we are committed at this stage to making this training available to those who really need it right now – and you'll need to be a FASD-CAN member (join <u>here</u>).

We'll be creating a waitlist for others who are interested so we can apply for funding to run the course again at a later date.

Te Haututū Conference



We're excited to let you know about the first conference on FASD that is being run by Māori, for Māori. The hui will focus on indigenous ways of thinking about FASD and on how mātauranga Māori can help

guide ways of working with those affected by it. The conference will look at:

- how te reo Māori, the Maramataka, Taonga Puoro and other forms of knowledge can help us to assist whānau who have FASD.
- how can whānau ora, marae, hapū and iwi work to prevent the harmful use of alcohol
- what supports Kohanga and Kura need to support tamaiti who have neuro-disability.

The hui will happen from 6-8 October, at Te Whare Wananga o Awanuiarangi, Whakatane.

If you're interested in attending, please **email Janet Miller**, our Operations Manager.

New FASD-CAN Regional Caregiver Support Groups

Mindful of the well-researched fact that support groups are highly positive for caregivers and whānau, we have been working behind the scenes to set up some new options for kanohi ki te kanohi groups across the motu in the last couple of months.

These are listed **here**, along with a bit of background from each group facilitator. They're keen to make each group work for YOU so they'd like to get your input as to where and how each group should function. Please don't hesitate to get in touch with them, they'd love to hear from you!

• If you don't have a group near you or it's hard to get out, don't despair – check out our online support group which happens once a month via Zoom. It's a great way to stay in touch with your 'tribe' and feel empowered and supported.



 If you're interested in setting up a FASD caregiver support group yourself in another area of the motu, please <u>contact</u>
 <u>Kim Milne</u> and she'll talk you through what is involved and how FASD-CAN will support you.

Professional Groups



Don't forget our learning and networking groups for professionals!
There's one for <u>educators</u> and one for <u>social workers/support</u>

workers. Join at any time to find out more about FASD and connect with your peers.

Whanau Direct Care in the Community Grants

Our grants have been very well received so far this year and have made a great difference to the lives of some our members. However, as of May 16, we will only be accepting grant applications for travel costs to help people get to our De-Escalation training in Wellington, and our annual Hui in September. Caregivers, whānau and people with FASD can apply here for travel expenses for these events, but you will need to be a member of FASD-CAN – click here to join us – it's free!

Surveys and feedback

As you know, we often have requests for feedback and input by our members. While this can take up time, it is important and worthwhile to gather information which will



contribute to making life better for those with FASD!

To this end, we've now created a page on our website which lists <u>current surveys and other feedback opportunities</u>.

The latest important listings are:

• <u>an invitation from Oranga Tamariki</u> to be part of Phase 2 of their Disability Strategy. OT are very keen to involve anyone affected by FASD (including caregivers and individuals) to be part of a feedback hui to clarify the Vision Statement and the four 'key shifts' already identified, to better serve the disabled community. OT have set up a special Zoom meeting just for FASD-CAN which will be held on Wednesday May 31 from

10am-12 noon. We ask you to please **email Kim Milne**(kim.milne@fasd-can.org.nz) by 5:00 pm on Friday 26

May to sign up to attend – we really appreciate your feedback with this!

- <u>a petition from Carers Alliance</u> requesting more help from the Government for family carers, and the development of protective legislation, programmes, and services to support carers physically, mentally, and financially.
- other active surveys include neurodiversity in education, rangatahi voices in youth justice and caregiver involvement in clinical behaviour interventions. Please do support this mahi wherever you can! Click here to access all feedback opportunities.

Want to write about FASD for us?

Finally, a small job opportunity: are you FASD-informed and do you write and research well? We are looking for people to write pieces for our website from time to time. Please **email Janet Miller**, our Operations Manager, if you're interested.

Mauri ora
The FASD-CAN team

Want to join FASD-CAN?

We have a lot of exciting initiatives that are currently in development. Many of these will be specifically created for our members, so there's never been a better time to become part of the FASD-CAN whānau.

It's easy to join us and membership is free.

Fetal Alcohol Spectrum Disorder Care Action Network

Learn more about our work fasd-can.org.nz admin@fasd-can.org.nz

This email was sent to kathyhunter.nz@gmail.com. You received this email because you are subscribed to the FASD-CAN email list. You can unsubscribe from our emails **here**.