



THE NETWORK NEWS

FASD-CAN Incorporated

Sept 2013

Our Strategic Direction

Baby steps

The committee have met and recently agreed a three year strategic plan. The road map towards achieving our objective of “uniting caregivers, strengthening families, supporting individuals and educating about FASD across our communities”, looks like this:

Year One:

- Establish a website (www.fasd-can.org.nz)
- Formulate a communications strategy to lift organisational profile and grow membership.
- Officially launch on September the 9th 2013.
- Have organisational representation at Brisbane conference.

Year Two:

- Continue with web-site development and communications strategy (including development of

brochures and web-site resources).

- Parent/Caregiver workshop/seminar.
- Begin a national library – link to website
- Affiliate to international support group(s)
- Develop an education strategy.

Year Three:

- Continue with web-site development, communications and education strategies
- Form alliances with other groups that could be helpful in our bid to support individuals affected by FASD.

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- FASD-CAN strategic direction brief
- FASD-CAN represented at Brisbane Conference, 18-20 Nov 2013.
- Health and Disabilities Commissioner
- Acknowledgement of fund raising efforts
- Meet your committee

Those living with FASD are the best teachers...

Elephants & Turtles:

“I think that I’ve probably got the memory of an elephant. The trouble is my internal processor goes the speed of a Turtle. So all the information is in there, I just never have enough time to get to it!” *Jakob – aged 14*

Achieving our Goals

Sub-Committees

We have made the decision to appoint sub-committees responsible for the delivery of the key aspects of the strategic plan. To date we have two sub-committees:

Web Development Sub-Committee:

- Tracey Jongens
- Paula and Mike Saunders
- Christine Rogan

We have been lucky enough to engage the services of a friend of Tracey's who is doing a web-design course and has agreed to design our web site as part of her course assessment. This sort of work, when undertaken commercially can cost up to \$10,000 so we are very grateful to Alice Donnithorne for providing her services for free. The plan is to have a web site fully operational by December but in the mean time we have a shell web site (www.fasd-can.org.nz) available to provide contact details and application for membership.

Communications Sub-Committee:

- Claire Gyde
- Christine Rogan
- Valerie McGinn
- Lisa Smith

The finer points of the communications strategy are yet to be put together but one thing we are clear on is that when our organisation is represented in the public arena, we want to ensure that our message is presented in a consistent, sensitive and professional way.

We are working on bringing together a **Finance sub-committee** so that we can actively start applying for grants to help get more services and supports out to our members.

Brisbane Conference FASD-CAN represented

We are pleased to be involved in the Brisbane conference and assisting with pre-conference parent/caregiver afternoon,

"Our Common Ground". Christine Rogan and Claire Gyde have both contributed to this event and FASD-CAN has a small mention on the flyer. Quite exciting! The open mike session will provide parents and caregivers with the forum to speak with ease to a room full of people who will

understand exactly where they are coming from!

We are also lucky to have a number of our committee presenting at the conference:

Christine Rogan, Valerie McGinn, Andi Crawford, Raimond Jacquemard, Jackie Pritchard and Claire Gyde.

Meeting with Health and Disabilities Commissioner

Towards the end of May a few parents and professionals met with Paul Gibson, Disabilities Commissioner for Human Rights. The meeting was well received with the heart-felt feelings of everyone in the room being conveyed to the Commissioner. Whilst we would



love to report that this meeting drove some change and advocacy for FASD at a higher level, we were left with a somewhat empty feeling and, as far as we know, no further action has come of it. The Commissioner was, however, sincerely moved by our plight. Perhaps the timing was wrong so we will try again at a later date – that has to be one of our FASD-CAN mottos, “don’t give up”!

Bone Carving Fund Raiser Manaia-Koru

Paul Gyde has donated over \$1,200 to FASD-CAN and the committee would like to acknowledge and thank Paul for his time, effort and artistic skill in making the Manaia-Koru bone carvings. FASD-CAN Inc has adopted this image as our logo and also woven its’ symbolism into who we are as an organisation. *The Manaia, or bird form, is regarded as a spiritual guardian and means to ‘give strength, guidance and wisdom to another’. The Koru form is symbolic of growth and adds the elements of ‘hope, harmony and new beginnings’.*

The importance of the Maori design, the meaning and the use of bone all meant that this project needed Kaumatua approval and has received the blessing of Rev. Albie Martin.

Each carving is made with a good deal of heart and Paul’s wish is that you wear it often, gain strength from its symbolism and share its meaning.



Meet your Committee

	<p>Claire Gyde lives in New Plymouth with her husband Paul and two teenage sons, one of whom has FASD. Claire works full time as Finance Manager for Tegel Foods Ltd so she brings her many years of organisational and management experience to the table in her role as Chairman of FASD-CAN. Claire is passionate about raising awareness of FASD and providing a collective parent voice to the issues. You can contact her by email claire.gyde@fasd-can.org.nz</p>
	<p>Tracey Jongens lives in North Canterbury with her husband, two teenage boys and spoilt English Springer, Rupert. Tracey says that receiving a diagnosis of FASD for their youngest son 'changed her life'. She is a passionate advocate for her son and has dedicated many hours to public speaking and raising awareness of FASD in her region. Tracey is a trained primary school teacher and currently works part time as an RTLB – Resource Teacher of Learning and Behaviour. She is Secretary for FASD-CAN and you can contact her by email tracey.jongens@fasd-can.org.nz</p>
	<p>Paula Saunders is mum to two special needs children. She is the founder of Families With Differences – FWD on the North Shore Auckland. Paula has a real passion for educating people about FASD and loves talking about her three awesome kids! In her spare time she teaches craft classes so that folk can take a break, relax and enjoy themselves. Paula lives in Auckland with her husband Mike and three kids. She is the Treasurer for FASD-Can and can be contacted by email paula.saunders@fasd-can.org.nz.</p>
	<p>Christine Rogan is a Health Promotion Advisor for the Alcohol Healthwatch Trust, a non-government organisation based in Auckland working to reduce alcohol related harm through effective health promotion. Christine coordinates the Fetal Alcohol Network NZ established to connect the workforce and families and projects aimed at identifying and reducing the harm associated with drinking alcohol during pregnancy.</p>
	<p>Andi Crawford is a Clinical Psychologist who is involved in the assessment and diagnosis of children with developmental difficulties, including FASD, at the Child Development Service at Hawke's Bay DHB. She is enrolled in the Doctoral Programme at the University of Auckland and her PhD research aims to investigate executive functioning, social cognition and adaptive behaviour in children with fetal alcohol spectrum disorders.</p>



Lisa Smith lives in Hawkes Bay with her husband Nigel and adopted son Aaron who is 15yrs old. Aaron was diagnosed with Fetal Alcohol Syndrome at age six and she shares that their journey continues to be a very interesting one. However in spite of the ups and downs, they strongly believe that **Fantastic Aaron will Succeed Despite** his disability. Lisa works as a Paediatric Nurse at Hawkes Bay DHB. She is keen to raise awareness of FASD and is pleased to be involved with FASD-CAN so that we can become a stronger collective voice throughout New Zealand.



Dr Valerie McGinn is a Paediatric Neuropsychologist who specialises in the diagnosis and treatment of FASD. She works in a multidisciplinary team in private practice in Auckland. Valerie is affiliated to Alcohol Healthwatch and is involved in training of the NZ FASD workforce as well as working towards the development of services and support for people with FASD and their families. Valerie presents widely at conferences and workshops in New Zealand and overseas to raise awareness of and educate others about the effects of prenatal alcohol exposure on the development of our children.



Dr Raimond Jacquemard is a general paediatrician in New Plymouth. He has a special interest in Developmental Paediatrics and has been doing multidisciplinary FASD assessments in Taranaki for a few years.



Louise McIntosh lives in Auckland with her husband Richard and nine year old son who has FASD.



Jackie Prichard lives in Hawkes Bay with her husband Simon and is kept busy as stay-at-home mum to her three young children, the oldest of which has pFAS. Jackie is a vocal advocate for her son and for the organisation.