



THE NETWORK NEWS

FASD-CAN Incorporated

December 2016

A word from the Chair

An annual ritual for me around Christmas time is to reflect on the year that was and think of things to be grateful for. Even in bad years, I find there is always something to give thanks for, if I look for it hard enough!

At times this year, due in part to some personal circumstances, momentum within FASD-CAN has felt slow to stalling, however, with that and our organization in mind..



1. I am always delighted to hear about the good works of other members in raising community awareness around FASD and, as you will read in this issue, engaging with charitable organisations to assist with funding (thank-you Lisa Smith).
2. I am grateful to the continued work and marathon efforts of Christine Rogan, Valerie McGinn and their colleagues. Without these professionals on our side, our struggles would surely be much greater.
3. I am satisfied with the collaboration that occurred with Ministry of Health in connection with the FASD Plan of Action. I am thrilled that we, as an organization, have forged positive relationships with MoH officials and continue to be consulted through the implementation plan.
4. I reflect on the initial purpose of our organization: "To unite caregivers, strengthen families, support individuals and educate about FASD across our communities". I am always happy to see this vision come to life with our virtual support network (on facebook) enabling us all to reach out, share our experiences and help each other.

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The holiday season is often a time of turmoil for our children as they must step outside their normal routines. It is often a period of high stress levels for us as parents and caregivers too as we try to manage home, work and kids struggling with change. *"Step with care and great tact, and remember life's a great balancing act"* – Dr Seuss. My wish for each and every one of our families and young people with FASD is to enjoy some happy moments over the holiday period. I hope we can each look forward to 2017 with renewed enthusiasm to make the world a better place for at least one person living with FASD.

Kia Kaha
Claire

Hawkes Bay Update

This year I decided to take a week off work and have an FASD Awareness Information Stand within the foyer at the Hastings Hospital ending on Fri 9th Sept with a service acknowledging International FASD Awareness Day. I received tremendous support from the DHB who helped with the design and funding to produce 100 large posters and 1000 flyers to raise awareness of FASD. The Local Health Promotion Agency also helped by providing T-Shirts for volunteers manning the stand for the week. There were plenty of volunteers helping me throughout the week and I was so thankful for the help of my husband, Nigel on the first day to help set up the display stands.

Like a pebble in the pond we very quickly received lots of publicity via the media. My friend Kim was asked to talk about her son on Maori TV along with Dr Russell Wills who now describes the rates of FASD as a "Tsunami".

On Fri 9th we had over 60 people attending and after a karakea, Russell Wills talked at length about the impact of FASD followed by Kim talking about her journey with her son finishing with a poem called "A Magic Wand". The CEO of Hawkes Bay DHB, Kevin Snee attended which really demonstrated the full support of the DHB. Next year I am planning to have the same event in the local shopping mall where it should reach an even wider audience.



Lisa Smith



I WISH I HAD A MAGIC WAND!

*I wish I had a magic wand
So I could change the way
I must live my **crazy** life
Each and every day.*

*I pray so hard for life to change
But this does not occur
It cannot change for quite some time
To time I must defer*

*It is unfair, this life we live
Where turmoil reigns supreme
Each day a challenge to survive
The wand unfound, unseen*

*I wish I had a life instead
Where peace and laughter bloom
Instead of angst and argument
I need that wand found soon!*

*So what has led me to this fate?
What awful thing occurred?
What twist or turn did my life take?
To what have I referred?*

*Well all I did, was want a child
To love and cosset dear,
And this I got, and love I do,
... 'tis not enough I fear.*

*My child was born so bonny bright
So happy, ... so contented
But this all changed when he could walk
Well, was the boy **demented?***

*He always was in trouble then
I could not turn my back
Or things were broken, ripped and torn,
And items painted black*

*An octopus on carpet drawn
With such **exquisite** care
A toy he wanted at playgroup
No prisoner was spared*

*Then off to school he duly went
My trepidation high
And I was right to have such fear
On fate I could rely*

*My child just could not concentrate
Was easily distracted
He could not learn the lessons taught
What blight had he contracted?*

*The teacher spoke too quick for him
He did not comprehend
The children all made fun and teased
Called names that did offend*

*So to the Doctor we did go
To find out what's amiss
At first it was A.D.H.D.
If only that was it ...*

*But things got so much worse at school
There was an escalation
Anger and aggression grew
To all our consternation*

*A frustrated, angry child emerged
And children they got hit!
And chairs were thrown, and walls were
kicked
If only school got it!!!!*

*No point in asking, "Why do that?"
He has not got a clue
So hard accepting "this the case"
... Alas it is so true
The crushing blow was then to come
A further diagnosis
They called it F. A. S. and D
A crippling, sad, prognosis*

*For when he was in birth mum's tum
She did not know to care
And he did drink the devil's brew
Before he could breathe air*

*Too late when born to see the world
The damage had been done
To head, to heart, to self-esteem
Cruel fate for my wee son*

*So each and every single day
This life's become our norm
Of anger, damage, and abuse
Now woeful and forlorn*

*Our life just one big crisis fest
Relationships in tatters
No wall or door is still in tact
Food everywhere in splatters*

*My child like a kaleidoscope
Of coloured, fractured hue
Deserved a better fate than this
But did not get his due*

*So I must dream of miracles
Of magic that is real
Of wands and spells and fairy dust
To change the way I feel*

*At night I sleep and always dream
That I can change our world
I dream that I have found my wand
I spin, and dance, and twirl*

*I gather will to make a spell
That will soon change our life
The wand I flourish with aplomb
It shimmers in the light ...*

*Wand touching on his precious head
The demons will obey!
The wand has worked and done its job
They've gone along their way*

*The wand waved over my dear son
And he is then set free
From chains and shackles binding him
A new life, my decree!*

*Alas my wand is just a dream
It never can be found
No magic cure awaits for us
FAS-D is too profound!!!!!!!!!!!!*

Revised Canadian Fetal Alcohol Spectrum Disorder: A guideline for diagnosis across the lifespan

Health professionals working in New Zealand in FASD diagnosis met in November 2015 to learn about and then decide whether to adopt the new guidelines recently developed by our Canadian colleagues. A consensus was met and from 01/01/16 clinicians have been diagnosing according to the new guidelines. The Ministry of Health has supported adopting these guidelines for FASD diagnosis in New Zealand. Up until then we were using the 2005 Canadian guidelines. The aim of the revision was to simplify diagnostic terms and to take into account the mass of new data available about FASD. Although some of us had hoped that the new guidelines would simplify the diagnostic process, this has not been the case. Prenatal alcohol exposure causes a range of harm and each individual is affected differently and we still need to do a comprehensive assessment to discover how or if each area of brain function is affected. The medical assessment takes into account the results of neuropsychological testing and considers other factors to determine if a diagnosis of FASD will be made. Each individual diagnosed with FASD will still show deficits across at least three brain domains indicating a severe and pervasive brain based disability. As well as the 9 brain domains already being assessed (cognition, motor skills, language, attention, memory, adaptive, executive, academic achievement and neuroanatomy) research has shown that affect regulation is a primary part of the condition for many if not most and this is now added as a tenth domain to consider in diagnosis.

Previously each FASD diagnosis was made ranking 4 areas of facial features, growth, brain function and alcohol exposure providing a 4 Digit code and then from that code a diagnosis was made of either Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS) or Alcohol Related Neurodevelopmental Disorder (ARND). FASD used to be an umbrella term encompassing the 3 conditions but it is now the diagnostic term. We no longer determine a 4 Digit code and there are only two diagnoses: FASD with Sentinel Facial Features (FASD with SFF) and FASD without Sentinel Facial Features (FASD without SFF). If your child was previously diagnosed with FAS then that is now termed FASD with SFF. If the diagnosis was PFAS or ARND then this is now termed FASD without SFF. There is no need for a reassessment as all individuals previously diagnosed under the 2005 guidelines will have FASD either with 3 facial features or without 3 facial features. The testing criteria remain unchanged. From our experience we were using the term FASD already and we welcomed the term becoming the diagnosis. PFAS and ARND implied a lesser condition and that was just not the case in terms of functioning day to day.

The Canadian database has shown that only 4% of diagnoses have the 3 facial features that alcohol can cause. The same data also shows that growth retardation is not common nowadays and is not related to the diagnosis. The growth retardation and facial features were markers that led to recognising the early cases of children with a severe and pervasive neurodisability related to

prenatal alcohol exposure. However, most individuals with FASD do not show these physical markers and it is how the brain works that is critical to understand in order to provide the right environmental adjustments to improve development and outcomes. Another change in the guidelines is that we now know that alcohol is not related to FASD, it causes FASD. Along with the shift to a causal link the guidelines have introduced a minimum threshold of PAE for diagnosis. It is not to say that any alcohol exposure is safe but to acknowledge that 1 or 2 standard drinks once or twice in pregnancy will not cause a severe neurodisability in most cases. We know that even light drinking has been linked to conduct problems in children exposed and no level of drinking in pregnancy has been shown to be safe. The guidelines and our Ministry of Health advise on no consumption of alcohol in pregnancy.

The other focus of the revised guidelines is taking a lifespan approach. There are specific recommendations for diagnosing young children with a designation of 'At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol exposure' when a child is too young or for some other reason cannot be fully assess. A child designated at risk requires early intervention services and monitoring with a diagnostic assessment taking place at a later time. There are also some diagnostic factors to take into account in adult diagnosis, ensuring that FASD can be correctly recognised at any age in light of it being a lifelong neurodisability.

At the FASD Centre, Aotearoa we have been finding the new guidelines more user friendly for families and staff alike. Our impression is that they are better than, but not inconsistent with how we had been diagnosing and the changeover was seamless. We would like to emphasise to families that all children previously diagnosed with FAS, PFAS and ARND have FASD and that all the new resources being developed internationally and here in NZ will be just right for all. Please contact your diagnosing teams if you have any queries about your child's diagnosis.

Dr Valerie McGinn

Merry Christmas from Dunedin



I moved to Dunedin in 1999, with my husband Mike, and I have worked at the University of Otago since then, teaching social work, criminal justice, family practice and research. In 2001, our birth daughter was born, and in 2007, we adopted our 2 boys from Russia (as you do and that's a book in itself). We always knew our boys (now 12 and 13) were quirky and dramatic (polite for WILD). Over time it became necessary for us to seek additional help and get their FASD acknowledged and diagnosed, both here and in the UK (due to living back there when I had study leave opportunities). We found it much harder to live with our boys in the UK, than here in NZ, as the intolerance and disapproval was far worse for FASD, although that is slowly changing. We became active around FASD awareness and support for families from about 2013 in the Dunedin area. This has meant facilitating a monthly parents/ caregivers support meeting, running the FASD Dunedin Facebook page, and helping with workshops and seminars. I had the opportunity to travel to Alberta in July this year, and I met up with wonderful researchers, practitioners, some caregivers and young people, all connected to the FASD community there. This has inspired me to continue to help promote FASD awareness and support for families here in Dunedin. In early December we had Christine Rogan, Valerie McGinn and Zoe McLaren down from Auckland running professional and caregiver workshops and Mirror counselling was also involved. We are now very keen to get Dunedin's first diagnostic and assessment service up and running by mid-next year, cross fingers and find money toes! I am also doing numerous seminars - for Corrections primarily but as I have so many students in my classes from psychology, education, law, social work and many others, I plan to give all of them at least one seminar on FASD. While our family has all the usual struggles with all that FASD brings we try to be ever hopeful. Some days that hope is non-existent but on others there's plenty of it. One of our boys has a passion for diving and has participated in national competitions and has won medals, in spite of being phenomenally wiggly at all times. The other lad is into archery and art, and this helps him use up some of his excess energy. Our girl has a glorious classical voice and has been the best big sister any boy could wish for. Mike is the main caregiver at home while I work at Univ. and he attempts to keep the rest of us sane by his calm and reassuring presence. It has been wonderful to connect with FASD-CAN members this year through travelling to workshops and participating on the facebook page.

Anita Gibbs



NZ Methodist Women's Fellowship Convention

November 2016 - Hastings

This year FASD-CAN have been fortunate to be the recipients for funding initiatives from the NZ Methodist Women's Fellowship. Church Delegates from throughout NZ convened in Hastings. I gave a short presentation on the impact of FASD on families and the community. This was very well received with many relevant questions afterwards. Lee Tempest attended the presentation and answered some of the questions from the audience. The next convention will take place in Christchurch when FASD-CAN will receive a cheque for the funds that have been raised throughout the year.

Lisa Smith

Defining Success

The dictionary definition of success is:

"The favourable or prosperous termination of attempts or endeavours; the accomplishment of one's goals".

This is then extrapolated out and links the notion of success with the attainment of something, often tangible and usually acknowledged publically – an award, a new car, a degree, a nice house, good career etc. For our children and young adults living with FASD, there is often a need to redefine success not only for them but also for their families, friends, teachers and workmates. This is one of the most important aspects of change needed to enable those living with FASD to be the best they possibly can be. What success will look like will be individual. It will not only depend on the strengths of the young person with FASD, but also on the deficits. In order to really search and see success, we must step back and recognise what they are good at but also understand what they struggle with and the challenges they must over-come. Once we *really* understand and appreciate that, then we can begin to see it. It may not be anything grand, but it can still be miraculous. It may not be easily seen by others, but you will know.

Over the past six months my son has been highly successful and I am extraordinarily proud of him. He has, on a couple of occasions and on his own, cleaned up his flat, done his washing and managed to put the rubbish out on rubbish day. He borrowed \$20 off me and paid it back! He kept his cool during a power outage and helped an elderly neighbour by sharing a torch and transistor radio. He has managed to get to work on his own, on time for at least the last four weeks. He persevered like a pro and passed his motorbike learners theory on the 10th attempt. He has engaged with the local community well and to such an extent that the local Z service station now has a Coffee/Chocolate/Hazelnut concoction named after him! He has passed a nationally recognised qualification in food manufacturing through workplace development. He has bought himself a kitten. He looks after it well and has saved to get him de-sexed and vaccinated. He has, just this week, put money aside for petrol so that he doesn't run out before next pay day (this is a first which I am quite excited about!). He has suffered disappointment and, aside from a few expletives, has not lost the plot or broken anything as a consequence.

Is my son a success? I think so. To me, these are massive milestones but others may not see it in that way, and, to be honest, that doesn't matter. He is a fantastic human being and a delight to know. He is a compassionate, loving, caring person with a heart of gold who works hard every single day to do the right thing. He does not always succeed in this but some days, like those noted above, he does. As his mother, I take those days and hold them close. It has been important for me not to chase someone else's definition of success, I needed to define my own.

*"Success is improving **any** aspect of your own or someone else's life.
Success is being at peace with the decisions you make.
Success is to love and be loved without boundaries."*

Claire Gyde