



# THE NETWORK NEWS

FASD-CAN Incorporated

March 2015

## A word from the Chair

Since our last newsletter, the committee have taken a well-deserved break from our FASD work and enjoyed some of the summer months holidaying and with our families. Our first meeting for the year is scheduled in March. We will focus on the year ahead and, in particular, formulating a plan for a parent workshop/seminar event.

In October we met with the Ministry of Education and over the summer break we read and critiqued the Literature Review that they had commissioned. We have yet to hear back on our submission but will keep you informed as this work progresses.

It is pleasing to read in this publication the list of milestones that our kids have achieved. These achievements are not only testament to the hard work and continued effort put in by our kids but also by the parents who are advocating, scene setting, planning, organising, heading off crisis and providing love and support.

Being an external brain is a fairly intense job as we have to continually remind ourselves that the reasoning we take for granted is just out of reach for those with FASD much of the time. I say 'take a bow'!

As we go to print, the stunning outcome from the Privy Council in the Teina Pora case has just been announced. This is a significant ruling for FASD and we are very grateful to the dedicated work by Dr Valerie McGinn, from our very own committee, to bring this to reality and put the spot light on FASD.

## In this issue:

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In Lord Kerr's summing up, he states:

*"The combination of Pora's frequently contradictory and often implausible confessions and the recent diagnosis of his FASD leads to only one possible conclusion and that is that reliance on his confessions gives rise to a risk of a miscarriage of justice. On that account, his convictions must be quashed."*



There are battles raging against discrimination and injustice in every corner of FASD – parents and professionals who are fighting for the rights of children and adults in their care. I hope that the outcomes will result in positive change and a complete paradigm shift for service providers. There is “**only one possible conclusion**”, that is to understand and provide support and

assistance suited to the disability of the individual and their family.

Claire Gyde

## New Year Resolutions

I posed the question to our committee. What are your FASD -CAN resolutions/goals for this year?

Claire Gyde, our Chairperson :

**To grow membership, hold a parent seminar and engage with Education in Policy Setting. Her personal goal is survival with some sanity and a sense of humour retained.**

Tracey Jongens, our Secretary :

- 1. That the FASD-CAN membership grows (50 plus would be a good goal for 2015) and FASD-CAN is able to pull together some form of training opportunity for our membership**
- 2. That there is a REAL possibility of diagnosis being a happening thing in Canterbury**
- 3. That new opportunities to share the FASD message will continue to cross my path.**

Christine Rogan:

**For me it is three-fold under the one title – Government! That the FASD plan proposed under the last National-led Government is in place; that it includes recognition of FASD as a disability eligible for disability care services based on functional need not IQ alone; and that the plan includes sufficient funding to support the improvement in service provider awareness, knowledge and integrated FASD care intervention for affected individuals and their families as set out in the September 2014 ‘FASD Call to Action’.**

Lisa Smith:

**For me it is to continue the fight, nationally and personally, to raise awareness, knowledge and understanding of FASD across all agencies. Also to look after myself by playing more golf so that I can remain a strong advocate for my son. There is nothing better than bashing that ball down the fairway as hard as one can.**

# Teenage and Adults with FASD

## On being Diagnosed with FASD as an Adult. – R J Formanek

The day an official diagnosis is given, a number of changes happen to a person living with FASD. There is of course, the emotional impact of actually having something on paper that indicates what is going on inside of your body and your brain, something that, up to this point has been invisible for the most part.

Oh, sure there are the 'small' physical traits that come with FASD

(..."It's no big deal... everyone can't be good at everything!") but to the outside world we don't look all that different.

So you deal with the emotions, one step at a time.

It can take a while to get this part figured out, but that's ok too.

So, now you have a name for this thing, this thing that is a part of you.

This thing...it's not something that grew in you, or was added to you...

it's what DIDN'T grow in you... it's not just a part of you... it IS you.

That is what is hard to accept for some people.

FASD affects every single aspect of our lives, from dusk to dawn, dawn to dusk again... 24/7... even HOW we see the world can be affected by FASD. We experience the world differently, we feel the world differently and very often we interact with the world differently. Many of us, even before being officially diagnosed have always felt and understood that there was a difference between you and I... even if I didn't know what it was. But now there is a name for this: FASD.

So, you start to notice the differences, now that you (many for the first time in their lives) KNOW what the differences are. For me, it was a point where I could say "Wow, so that is how neurotypical ( I HATE "normal") people see/do this? I've never been able to do that, in my brain .... etc" because for me the conversation about the differences is important.

It's important for me to understand what makes me different, not just how I am different... but how understanding the difference can make it possible to bridge the gap between your understanding of this world and mine.

I am on a journey to understand how you see the world, because I KNOW how I see mine...so I share what I see, you share what you see and between us we both develop a deeper understanding of being human.

Or, rather... that's the plan, and as we all well know, even the best plans can turn out wrong. Even with the best of intentions.

The difference between having a diagnosis and not is kind of like the difference between needing and having prescription glasses. (This is very simplified, not saying it's the same thing. )

With the proper diagnosis ... I can 'see' clearly now. And if you wear prescription eyeglasses you KNOW what a difference putting them on can make. Your whole world seems to change now that you can SEE what you could never see before. And it stands to reason that you would be excited because now you have a deeper understanding of the world going around outside your head.

So when a person who never had glasses suddenly has them, it stands to reason that they would 'drink in' as much of the world as possible, and be thrilled and excited about what they can now see.

And perhaps you want to share this new experience with those closest.

I mean, it's almost like a whole new world, in some ways.

It's not too long before you start hearing back, from those closest to you comments along the lines of "It's not all about FASD, you know." and "Ok so you know what it is, now get over it." and things like that.

I realize it's often because we can go overboard with our excitement at this new found realization and need to explore all aspects of how we understand this, and our place in the world.

We need to find our own place, as people living with FASD.

As human beings.

You see, for me it IS all about the FASD that has changed my brain and my body from the moment it was being formed in the womb.

In reality, even without a name... I have known nothing else.

Every aspect of my life has been touched by this, from how I think to how I feel and experience things to how I see, taste, smell and even how I get around in this world. But I never knew why.

Living with FASD can often be like standing in a dark room and being hit (not unlike a pinata) from different directions and never knowing where it was going to come from, or why.

Small wonder we are often so reactive.

So, when a person (older than a child) gets a diagnosis and is able to put a name to this thing it is life changing in so many ways. I am just asking that people in this position be given time and space to find out where they fit in, in their own time, in their own way.

They are often not making excuses for anything, they are learning!

So, the next time a newly diagnosed person starts 'going on and on' again about how 'it's about the FASD' please PLEASE understand...

It's all just a part of the learning process.

-Peace out.... Miigwetch.... Thank you.

## Useful Information

# FASD CAREGIVER SUPPORT GROUP

Hibiscus Coast, Auckland.

aDapt Family Solutions in conjunction with FASD-CAN, are hosting a regional carer support group which will be held on the 3<sup>rd</sup> Tuesday of every month in 2015:

|                           |                       |                            |                           |
|---------------------------|-----------------------|----------------------------|---------------------------|
| 17 <sup>th</sup> February | 19 <sup>th</sup> May  | 18 <sup>th</sup> August    | 17 <sup>th</sup> November |
| 17 <sup>th</sup> March    | 16 <sup>th</sup> June | 15 <sup>th</sup> September | 15 <sup>th</sup> December |
| 21 <sup>st</sup> April    | 21 <sup>st</sup> July | 20 <sup>th</sup> October   |                           |

**Venue:** Hibiscus Coast Youth Centre,  
214D Hibiscus Coast Highway, Orewa.

**Time:** 7-9pm

**Cost: FREE** – Tea/Coffee/Biscuits provided.

The purpose of the group is build connections between parents and caregivers by sharing our experiences, learning and expertise of supporting those living with FASD. Caregivers also welcome if they suspect their child has FASD but they have not received a formal diagnosis.

For further information please contact

Lee Tempest 021 176 8220

Paula Atherley-Dowling 021 318 879

## New DVD

A new DVD about four teenagers growing up with FASD called

### “Moment to Moment. Teenagers with FASD”.

This DVD demonstrates the huge variation under the spectrum and the struggles these young people faced. It gives some good insight into some of the practical strategies the families used.

The DVD can be obtained from the website [www.ntiupstream.com](http://www.ntiupstream.com)

Cost: \$25 for DVD plus \$25 for shipping from America



## Words of Wisdom

I have come across some words of wisdom from Jeff Noble's Page which have been very helpful when discussing FASD with others.

*In order to change our minds and the minds of others about Foetal Alcohol, we have to change some of the terminology. So, instead of saying 'behaviours' try saying 'symptoms' ... just by changing your words, you'll change your mindset from punishment to support.*

*A person living with Fetal Alcohol's brain is like that light bulb in your house with a short in it. Sometimes it works perfectly and shines all day, other days it flickers on and off. Then there are THOSE days when no matter what you do the light is not coming on at all.*

## The Alaska Mental Health Trust - [mhtrust.org](http://mhtrust.org)

New PSA developed in an effort to expand FASD prevention. Starts with a group of four young woman out to dinner and they all order wine with their meal. Then it goes through the journey of one of the ladies finding out she is pregnant, then the birth followed by an irritable baby. The journey takes this young boy with FASD and the problems he has with learning and behaviour at school through to the teen years where he is in trouble with the police and shows these parents stressed out. Then eventually he retraces the journey back to these four young woman at dinner and one of them says she would rather have water instead of wine as her periods are late. Well worth a watch and it would be a huge step if the New Zealand Government were to produce a similar advert here.

## Break away for mothers

**RecreateNZ** have a weekend retreat for mothers of children with special needs at Vaughan Park, Long Bay, Auckland. It costs \$250 for a weekend and includes all meals, massage, facials, reflexology etc.

Email: [bookings@recreate.org.nz](mailto:bookings@recreate.org.nz) or look on their website.

# Sharing **YOUR** story

FASD-CAN would like to hear your story unedited, unscripted. If you are an individual with FASD, carers, birth parents, adoptive parents and anyone who has been closely involved with FASD we want to hear from you as this is the only way to make your voices heard and for people to really understand the reality of our day to day lives dealing with FASD. We want to remove the stigma that FASD only happens to certain types of people and in reality it is present in all areas of society.

## Guidance for writing your story

1. Introduce yourself – you can remain anonymous if you wish, but including at least a first name is recommended. (Pseudonym is fine!)
2. Give a brief description of yourself – your age, a person living with FASD, a family member, your job, support role, family members
3. Talk about your experience including some examples that were challenging and the actions taken and the outcome. Make it as real as you can so that readers can really picture what it was you had to deal with; what your life is like.
4. Highlight what things helped especially with regard to support received from others. What helped keep things stable
5. Make a request of the reader to act in some way on the information they have just received which would inform others of FASD

## Spreading the Word

### Paediatric Society of New Zealand Nov 2015

I attended this conference which was held in Napier this year and listened to Russell Wills, the Children's Commission Speak and as he does in many of his public announcements he made a reference to cheap alcohol and the amount of children who present in his clinic with the effects of pre-natal alcohol exposure. On the Thursday I listened to Melissa Wake, Consultant Paediatrician from Royal Children's Hospital in Melbourne who gave a summary on Population Based Research. Interestingly the Top 6 New Diagnoses in the last 10 years were at the top ADHD/ADD followed by learning problems, language delay then eczema and asthma. Often individuals with FASD are misdiagnosed with ADHD.

On the Friday Bernice Gabriel, Senior Psychologist from Child and Adolescent Family Services, Hawkes Bay talked about the Training Programme "Fostering Security" for caregivers which was developed in 2009. This programme has now been rolled out in Auckland and Christchurch as many children brought into care have serious emotional/behavioural problems. Again many children with FASD are taken into care due to their challenging behaviour and the aim of this programme is to provide the tools for carers to successfully manage these children to prevent placement breakdown. I found her talk very informative and this is a programme which I feel would help all parents and carers who have children/young people with FASD. It also provided a good support group for the caregivers. This is definitely a person who would be good for a presentation at our parent/caregiver seminar which we hope to hold sometime this year.

Lisa Smith

## Public Submissions Invited

The public consultation on New Zealand's Periodic Report under the United Nations Convention on Rights of the Child was held in Auckland on the 12<sup>th</sup> Feb. It was set up as a workshop and we had to go round the tables putting our views re this report on paper. It was a great forum for pointing out the gaps for FASD and how our children's human rights are being ignored in every sector. Christine Rogan and Lee Tempest were present and there is still an opportunity for the public to have their say on this report but needs to be in by the end of February. Lee urges everyone to grab this opportunity and make our voices heard.

Details are: [UNCROC Public Consultation msd.govt.nz](https://www.msd.govt.nz/uncroc-public-consultation)

Lets channel all our grievences around FASD re the lack of assessment, diagnosis and supports available. We all have a different stories to tell and it is important that those at the level of making change know what is really happening.

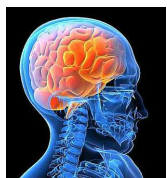
## Hawkes Bay

Another series of workshops commencing from March through to May which is free and available for everyone within the community to attend. The two workshops that took place last year were both full within a space of a few days and I would imagine it will be the case again. This is run by the team who carry out the full assessment programme for diagnosing FASD.

## Celebrating Success



I don't have any individual stories this time but I thought I would summarise the ups and downs that we lead with our quirky but awesome kids. I don't think we realise how well our kids do despite the brain damage that has occurred in utero.



We have had lots of successes with some of our teenagers:

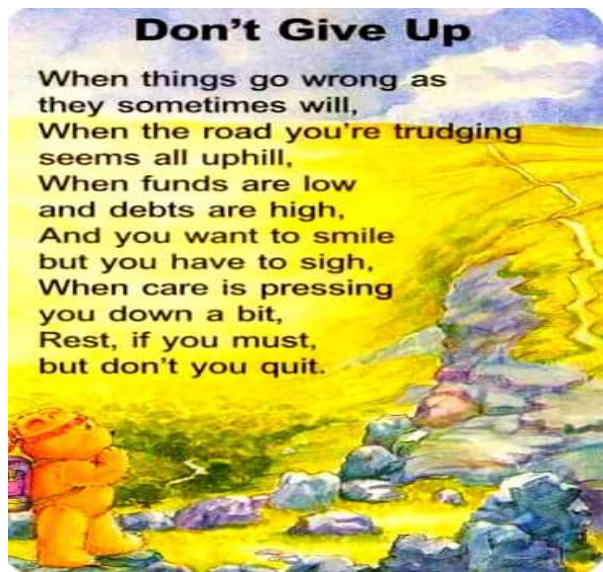
- One achieving success academically in gaining NCEA level 2 and passing the restricted driving license – first time!
- Another has managed to secure full time work and has had great feed back from the boss.

- Another is doing well on his farming course and is happily driving a John Deer tractor about the field.

Over the summer holidays a few kids have gone on camp and managed very well.

- One lad has just started at high school and so far is coping well mainly due to the close communication back and forward between school and home plus extra funding through the Ministry of Education this year. More and more teachers are being informed of FASD and strategies to help pupils.
- Another child has just started primary school and used the “All about me” booklet which Tracey Jongens explained on the FASD facebook page a while ago. The school were very supportive and things went very well for this young girl.
- Another girl has started showing empathy and caring towards her baby dolls and has started dressing, cuddling and put them in her cot each night next to her bed. Something she never did before.

There are the really tough times that we all know too well especially when we have to deal with people who don't get it but we are all in it together and together we can make a difference so that our children, youth and adults can grow and achieve despite the constraints of their disability. I know our journey is a hard one but don't give up. Keep sharing and keep fighting. Have a rest and some time out but get back on the road and keep going as we know our kids better than anyone else.



I have yet had another couple of situations recently dealing with people who have limited understanding of FASD leading to discrimination and exclusion. Initially I was heatbroken and did very little but I did not wallow for long and came back fighting for my son but did this using the documents to support this.



The documents that are helpful to look at when writing a formal complaint are:

Health and Disability Consumers Act 1994

Human Rights Act 1993

New Zealand Bill of Rights Act 1990

Human Rights Commission – Disabled Children’s Right to Education 2009

United Nations Convention on the Rights of the Child 1993 – lots of helpful information on the Childrens Commissioner’s Website.

There are many more which can be found on the Government website under Education and Disability but the above are the ones that I have utilised the most. As a result I have had success in getting the support needed for my son. However, I could not have done this without having a good circle of support around me and having good advocacy from others:

Our Paediatrician, CCS Disability Key Worker and others throughout the years.

It is a long hard road but its worth it for our kids and ..... **just don’t give up!**

*Lisa Smith, Editor.*