

"FASD in Aotearoa – 10 years on" From a Community Perspective



What do you think this number represents?

587,987

Since 1999

- Potentially 58,799 children under 10yrs born affected since 1999.
- Based on the International FASD prevalence estimate of 1% of live births.
- Where there is a prevalence of binge drinking the number of children born affected by FASD may be far greater.
- New Zealand likely has on its hands a silent epidemic.

Binge drinking and pregnancy

- In a North Island provincial hospital in 1996, a survey of approx 100 women interviewed just after the birth of their baby.
- 66% reported 'binge' drinking before pregnancy (10% doing so weekly).
- Most quit or reduced their alcohol consumption when they became aware of the pregnancy.
- However over quarter continued to consume alcohol and 9% reported binge drinking during pregnancy.

Communities try to make a difference

- In the late 1990s thanks to some ALAC funding New Zealand got its first non-government national organisation
- The Fetal Alcohol New Zealand (FANZ) Trust's primary objectives were to:
 - Prevent FAS and FAE
 - Promote and guide good practice in the management of Fetal Alcohol Syndrome and Fetal Alcohol Effects
 - Providing information, advocacy and support that will assist those working with and affected by Fetal Alcohol Syndrome and Fetal Alcohol Effects

Fetal Alcohol New Zealand Trust

- Among early FANZ activities were:
 - The inaugural International FASDAY 9/9/99.
 - A national conference and a diagnostic symposium in 2000, sponsored by ALAC
 - A petition to parliament advocacy for alcohol warning labelling
 - Resource development and community workshops
 - Support groups for caregivers
 - With FADE, a yr 12-13 curriculum resource
 - With ALAC, a documentary and video, "Drinking for Two"
- FANZ was wound up in 2003.

2003 - 2009

- From Hamilton the Fetal Alcohol Support Trust continued to advocate for affected families.
- Alcohol Healthwatch continued to keep people connected and formed the Auckland Regional Fetal Alcohol Network (ARFAN).
- In 2007, ARFAN went nationwide and was renamed the Fetal Alcohol Network New Zealand (FANNZ).
- FANNZ is affiliated to FASWorld as signified by its logo.
- Initially funded by Alcohol Healthwatch the Ministry of Health now contracts for FANNZ activity.

FANNZ

- FANNZ is not a structured entity but through its coordinator, provides information and connection for people and support for community awareness and action.
- The FANNZ email updates reach up to 300 people from diverse sectors and communities and provides a source of contact for affected families.
- FANNZ has enabled advisory participation of expertise in the development of national policy.

FANNZ

- FANNZ has maintained global connections with researchers and service providers.
- International speakers to NZ have included:
 - Bonnie Buxton and Brian Philcox Toronto FASWorld 2003.
 - Dr Ko Asante and team from BC Canada 2004.
 - Australian Author & Birth Mother Elizabeth Russell
 - Judge Anthony Wartnik & Kay Kelly Seattle 2007.
 - Dr Teresa Grant, Seattle 2008.
 - Dr Paul Connor, Neuropsycholgist Seattle 2008.
 - Jenelle & Jordan McMillan 2009.

Has ten years of community efforts been in vein?

- Most definitely not!
- There are now hundred of individual Kiwis better informed thanks mainly to some brave and special people prepared to speak out.
- Denial, ignorance and misinformation among our health and social services professionals appears to be diminishing slowly.
- There is a strong willingness from the workforce to improve knowledge and skills.
- A national policy framework to guide action is forthcoming.

However

- A FASD diagnosis is rarely given.
- We are still miles from improving health, justice and social service practitioner knowledge and practice.
- FASD is still misunderstood and rarely qualifies for social services.
- There is no mechanisms for systemic training, research and service provision in place.
- Drinking by pregnant women remains too high.
- We are still waiting for basic product health warnings.
- We have no follow-up studies of exposed children.
- We can only guess at a prevalence rate.

Our Hope for the Next Decade

- That we all see enormous strides to address the gaps - starting in 2009!
- That all the hard work from the community over the past decade, is backed up by Government funded initiatives.
- Because its not about doing a whole lot more, its about doing differently what is already being done ineffectively!



It's Because 'Everyone is Part of the Solution'