



Fetal Alcohol Network New Zealand

Kia ora everyone

Haere mai welcome to those who have just joined this network and are receiving this FANNZ update for the first time.

International FASD Awareness Day

Congratulations everyone for your contribution toward making International FASD Awareness Day 2008 happen around Aotearoa New Zealand. Thank you to those supporters who trod through libraries and malls, across fields, through schools, who wrote letters, gave money, set up displays, hosted and presented, blew up balloons, sang songs and tied knots! These are the sort of actions that collectively make all things possible!

From one of the Founders of FASDAY Teresa Kellerman of Tucson Arizona, this message:

“Greetings to all our wonderful awareness raisers around the world! Today is the 10th birthday of International FASD Awareness Day. We are having a birthday party here in Tucson. You all are so awesome to keep spreading the message in your community.” Teresa

In Auckland we were very fortunate to have Dr Paul Connor from the Fetal Alcohol Drug Unit of the University of Washington in Seattle, share with us his knowledge, clinical experience and research on FASD. **Attached are handouts from Dr Connor’s presentation.** One significant aspects presented was the research indicating that there appears little to distinguish the effects of the brain damage caused by alcohol, between those who have received a diagnosis of Fetal Alcohol Syndrome (FAS) and those diagnosed with Alcohol Related Developmental Disorders (ARND) - both diagnosis falling under the umbrella term Fetal Alcohol Spectrum Disorder.

New Zealand families wishing to connect

An email communication link for families affected by FASD in NZ is planned. Following the FASDAY seminar in Auckland, a group of families gathered to discuss how best to connect and support one another. There was some discussion about setting up a structured family-based organisation. However, there was also a recognition that this would required a level of capacity, commitment and resourcing that is currently not available. The potential of some sort of web-based communication such as a ‘blog’ was discussed but it was felt this needed to be part of a larger FASD communication strategy for NZ in future. So it was decided that in the meantime, a separate email link for families as a subset of FANNZ, would enable families to benefit from the experience, insights, ideas, information, moral support or advocacy that other families may be able to offer.

If you are a member of a family/whanau or know of one and would like to know more, please email the FANNZ coordinator, Christine Rogan fannz@ahw.co.nz to express your interest. All initial enquiries will be treated confidentially and no information will be shared without an informed consent process.

NZ researcher seeking FASD family participants

Doctoral researcher Jenny Salmon is seeking to interview young people affected by a fetal alcohol spectrum disorder over the age of 14 years and their families as part of her PhD study on the topic. Jenny completed post graduate research on “Fetal Alcohol Syndrome: New Zealand Birth Mother’s Experience” which has since been published by Dunsmore Publishing, Wellington

(2007). If you would like to know more about her study or would like to be involved, contact Jenny on (03) 454 4648 (H), 021 1768212 (mobile) or jvsalmon@ihug.co.nz (email).

Further delay to alcohol & pregnancy health advisory label decision

The following message was recently released by Food Standards Australia New Zealand (FSANZ) to parties interested in the New Zealand application to require a pregnancy health advisory label for alcohol containers – A576.

FSANZ released the Initial Assessment Report for Application A576 for public comment in December 2007. In May 2008, the Australia and New Zealand Food Regulation Ministerial Council (Ministerial Council) requested FSANZ to consider mandatory health warnings on packaged alcohol. The Ministerial Council made this request in the context of the Council of Australian Governments' concerted approach to curb alcohol misuse and binge drinking among young people. In response to this request, we have commenced a Review of alcohol health warnings.

Due to the overlap of subject matter between Application A576 and the Review, we have decided that the timelines for Application A576 and the Review should be aligned. This will enable us to evaluate the literature, engage with stakeholders and prepare the benefit cost analysis for both projects together. Each project will, however, remain discrete and we will prepare separate reports for each project.

We now expect that the Draft Assessment Report for Application A576 will be released for public comment mid-2009 and the Final Assessment Report completed by the end of 2009. Information on progress with the Application is always available from the Work Plan on our website at <http://www.foodstandards.gov.au/standardsdevelopment/standardsworkplan.cfm>.

If you have any questions about Application A576, please do not hesitate to contact Dr Diane Bourn at diane.bourn@foodstandards.govt.nz or by phone on +64 4 978 5630. If you are in Australia and wish to phone Diane, please ring the Canberra switch (02) 6271 2222 and we can put you through to the New Zealand office as if you were ringing the Canberra office.

USA top level call for action to address FASD

The President's Committee for People with Intellectual Disabilities has submitted a report to the President of the United States, "The Promise of Research and Prevention". The report includes a lengthy section entitled, "Defeating the Single Most Preventable Cause of Intellectual Disabilities in the United States: Fetal Alcohol Spectrum Disorders."

<http://beintheknownj.org/wp-content/uploads/2008/07/2008-pcid-report-to-president.doc>

Ka kite ano