Dear Members & Supporters,

Welcome to our September Newsletter.

There is the strong possibility that September 2012 will be viewed as a pivotal time in the history of the recognition of FASD in Australia with the launch of The Australian FASD Action Plan at Parliament House in Canberra on Wednesday 12th September 2012. The Plan, facilitated and developed by FARE (Foundation for Alcohol Research and Education) was supported by the collaboration and involvement of leading Australian FASD experts including researchers, doctors, carers, communities and families. The launch commenced with a breakfast screening of Tristan, a documentary film about the life of a young boy with FASD produced as part of the Lililwan project. It was followed by a day of expert briefings for 55 politicians by fourteen of Australia’s leading experts in FASD including NOFASARD staff and volunteers. For more information including links to the Plan, media coverage and more see the Of Special Interest section of this newsletter.

Too often we hear negative stories about living with FASD however Sarah Sherwood, a young woman from the Gold Coast who lives with FASD, provides a more hopeful view by sharing her positive story with us. You can read her story in National News and Media. Thank you Sarah and congratulations!

Also in National News and Media there is a link to a fabulous new You tube video by well known Aboriginal comedian, musician and radio announcer Mary G (aka Mark Bin Baker) who spreads the message about FASD. There is also a link to the recently released Report from the WA Parliamentary Inquiry into FASD and an article about FASD by Associate Professor David Dossetor, a Child Psychiatrist with a special interest in Intellectual Disability and Autism and Area Director for Mental Health, The Children’s Hospital at Westmead.

Remember that we would love to hear your news and your personal stories and will discuss ways in which these can be shared ensuring your privacy is protected. The deadline for articles for our August newsletter will be August 26th (contact admin@nofasard.org.au) and it would be great if we could include a story each month.

We are always keen to expand our network so please encourage your family, friends, colleagues and network to join NOFASARD and support FASD prevention in Australia. Your information is private.

Happy reading!

Kindest regards,

Sue Miers
Chair
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Launch of The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016
The Australian FASD Action Plan was launched at Parliament House in Canberra on Wednesday 12th September 2012. The Plan, facilitated and developed by FARE (Foundation for Alcohol Research and Education) was supported by the collaboration and involvement of leading Australian FASD experts including researchers, doctors, carers, communities and families. The launch commenced with a breakfast screening of Tristan, a documentary film about the life of a young boy with FASD produced as part of the Lililwan project. It was followed by a day of expert briefings for 55 politicians by fourteen of Australia’s leading experts in FASD including NOFASARD staff and volunteers.

NOFASARD Media Release
More information including media reports, photos and video clips
Read the Plan

National News and Media

NOFASARD Chair Report 2012
Report from the NOFASARD Chair, Sue Miers at the 2012 AGM
Read Here

A positive story from Sarah Sherwood, a young woman from the Gold coast living with FASD
Too often we hear all of the negative stories about living with FASD. Sarah Sherwood, a young woman living with FASD provides a more hopeful view by sharing her positive story with us. Thank you Sarah and congratulations!

Mary G gets the message out about FASD
Well known Aboriginal comedian, musician and radio announcer Mary G (aka Mark Bin Baker) gets the message out about FASD in this fabulous new You tube video.

Report released for the WA Parliamentary inquiry into FASD
NOFASARD welcome the release of this very important Report. NOFASARD Chair Sue Miers was pleased to be given the opportunity to personally brief Principal Research Officer Dr Brian Gordon and Education and Health Standing Ctt Members, Dr. Janet Woollard MLA and Mr Peter Abetz MLA as well has provide them with an extensive list of contacts and further information of relevance to the Inquiry.
Fetal Alcohol Spectrum Disorders (FASD): Raising awareness of a preventable disability in our midst.
This article by Child Psychiatrist, Associate Professor David Dossetor, is published in The Children’s Hospital at Westmead School-Link Initiative newsletter.
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New research from the Salvos shows alcohol is damaging Australian families
New research from The Salvation Army, as part of its Alcohol Awareness Week initiative, reveals 4.2 million people (22%) say they know families where they think children are not being properly cared for and 2.9 million (16%) say they know of families where children may be unsafe because of someone’s alcohol abuse.
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International News & Media
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New book *Living with Fetal Alcohol Syndrome: Our Journey with Tisha* By Vivien and Peter Lourens and Jodee Kulp
Peter and Vivien Lourens are foster parents to a young lady who they have had since just after she was born in 1996. She has Fetal Alcohol Syndrome. They were emergency foster parents with Cape Town Child Welfare for sixteen years and in that time had many babies with Fetal Alcohol Syndrome. Vivien’s background is in child care, particularly special needs children. Together, they share their collective wisdom to help educators, medical professionals and families understanding and support children living with this disability. This hand book is based on the personal experiences of the authors and the knowledge they have gained as foster parents to a large number of babies who were in their care. It is not based on any medical or scientific research findings.
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Canada FASD Research Network 2012 Annual Report
This Report presents the results achieved by CanFASD in the fiscal year 2011-2012, within its key priority areas of diagnostics, intervention and prevention. Read Report
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At Emory University, experts try new approach to treating fetal alcohol syndrome
Health experts from the American Academy of Pediatrics issued a recommendation last week that every child be screened for Fetal Alcohol Syndrome. It is believed that nearly one in every three women drink while they're pregnant, and experts at Emory University have started a new approach to the treatment of those children born with FAS that involves helping them develop plans for action, then helping them stick to those plans.
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International Research

Fetal Alcohol-Related Growth Restriction from Birth through Young Adulthood and Moderating Effects of Maternal Prepregnancy Weight  R. Colin Carter, Joseph L. Jacobson, Robert J. Sokol, Malcolm J. Avison, Sandra W. Jacobson, Article first published online: 26 Sep 2012 Alcoholism: Clinical and Experimental Research. The findings from this study confirm prior studies demonstrating alcohol-related reductions in weight, height, weight-for-height/BMI, and head circumference that persist through young adulthood. Stronger effects were seen among children born to mothers with smaller prepregnancy weight, which may have been because of attainment of higher blood alcohol concentrations in smaller mothers for a given amount of alcohol intake or to increased vulnerability in infants born to women with poorer nutrition.

Fetal Brain Function in Response to Maternal Alcohol Consumption: Early Evidence of Damage  Peter G. Hepper, James C. Dornan, Catherine Lynch. Article first published online: 14 Sep 2012 Alcoholism: Clinical and Experimental Research. Decreased information processing, reflected by poorer habituation, and increased variability in performance may reflect the initial manifestations of structural damage caused by alcohol to the brain. These results will lead to a greater understanding of the effects of alcohol on the fetus’s brain, enable the antenatal identification of fetal alcohol spectrum disorders, and lead to the early implementation of better management strategies.

The Effects of Prenatal Alcohol Exposure and Attention-Deficit/Hyperactivity Disorder on Psychopathology and Behavior  Ashley L. Ware, Jessica W. O’Brien, Nicole Crocker, Benjamin N. Deweese, Scott C. Roesch, Claire D. Coles, Julie A. Kable, Philip A. May, Wendy O. Kalberg, Elizabeth R. Sowell, Kenneth Lyons Jones, Edward P. Riley, and Sarah N. Mattson, CIFASD. Article first published online 13 Sep 2012 Findings indicate that ADHD diagnosis elevates children’s risk of psychiatric diagnoses, regardless of AE, but suggest an exacerbated relation between AE and ADHD on conduct disorder and externalizing behavioral problems in children. Findings affirm a poorer behavioral prognosis for alcohol-exposed children with ADHD and suggest that more than 1 neurobehavioral profile may exist for individuals with AE.

Further Development of a Neurobehavioral Profile of Fetal Alcohol Spectrum Disorders  Sarah N. Mattson, Scott C. Roesch, Leila Glass, Benjamin N. Deweese, Claire D. Coles, Julie A. Kable, Philip A. May, Wendy O. Kalberg, Elizabeth R. Sowell, Colleen M. Adnams, Kenneth Lyons Jones and Edward P. Riley, CIFASD Article first published online: 13 Sep 2012 The results of this study indicate that the neuropsychological effects of AE are clinically meaningful and can be used to accurately distinguish alcohol-affected children from both typically developing children and children with ADHD. Further, in combination with other recent studies, these data suggest that approximately 70% of children with heavy prenatal alcohol exposure are neurobehaviorally affected, while the remaining 30% are spared these often-devastating consequences, at least those in the domains under study. Refining the neurobehavioral profile will allow improved identification and treatment development for children affected by prenatal alcohol exposure.
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Second EUFASD Conference - Barcelona 21 to 24 October 2012
The main goal of this conference is to bring together European researchers, public health workers, FAS-related NGOs and parents in order to share latest knowledge and promote collaborations. The high quality of all speakers, the large momentum of the field in Spain, the international participation and the well-known attractions of Barcelona will certainly make the Second European Conference on FASD a success.
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1st Annual MOFAS Statewide FASD Conference Building Brighter Futures: Working Together to Create Change in Minnesota November 1-2, 2012 Bloomington, Minnesota This conference offers a unique opportunity for professionals, families and caregivers to learn more about the prevention and treatment of Fetal Alcohol Spectrum Disorders (FASD)
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The 3rd Health & Wellbeing in Children, Youth and Adults with Developmental Disabilities
Challenging Behaviour - The Tip of the Iceberg Main Conference: November 15 – 16, 2012
Focused Workshops: November 17, 2012 Vancouver, BC, Canada. This conference will provide educational and informative updates on psychiatric, behavioural and complex health components specific to individuals with DD, and showcase best practices in the field. Specifically, the conference will focus on approaches to complex challenging behaviours, contributing medical issues and new developments in medication and behavioural treatment.
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Research: Results and Relevance - Integrating Research, Policy, and Promising Practice Around the World will be held in Vancouver from February 27 to March 2, 2013. This conference brings together experts from multiple disciplines to share international research, to discuss the implications of this research, and to promote scientific/community collaboration. It provides an opportunity to expand our understanding of the relationships between knowledge and research, and how this can apply to critical actions related to FASD. For the past ten years, the conference has brought together people passionate about this area of work and provided a stimulating environment for them to make new connections and partnerships.

This free event will take place at The Law Foundation of British Columbia, 1340-605 Robson Street, Vancouver. Significant criminal justice and other legal developments have occurred in relation to FASD in a number of jurisdictions over the past few years. The Canadian Bar Association presented its resolution on FASD in 2010. This was followed in 2012 by the American Bar Association's resolution. Moves are now afoot to follow this with resolutions in Australia, New Zealand and elsewhere. This is an invitation to all who are engaged in working with FASD in the context of the law or who are interested in the subject to come together to discuss these developments and share ideas about how to move forward on the difficult issues surrounding justice for those with FASD. Please email faslaw@uw.edu to indicate you will attend and if you'd like to talk about the work you are doing on FASD and the law.
Name: Sarah Sherwood
Horse: Janevelyn Tsunami (Nippa)
Location: Gold Coast

Hi my name is Sarah, I am 19 years old and was born with Foetal Alcohol Syndrome, I live with my maternal aunt Deb and it was through her love of horses that I started riding at 4 years of age.
I have had some wonderful ponies through my life but it wasn’t until Nippa arrived with his fantastic temperament that I have started to do serious competing.
Now that I have been accepted into Para-equestrian I am hoping to have an exciting time competing and making new friends.
NOFASARD supports FASD Action Plan
The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) strongly supports the Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016, released today by the Foundation for Alcohol Research and Education (FARE).

NOFASARD National Project Manager, Ms Vicki Russell, says the Plan builds upon the work done over several years by researchers and dedicated individuals to raise awareness of Fetal Alcohol Spectrum Disorders (FASD) and help prevent fetal alcohol exposure in Australia.

“It is extremely important that the message is put out there that any amount of alcohol can cause damage to the unborn child. FASD is preventable and the damage is irreversible”, Ms Russell said. Fetal Alcohol Spectrum Disorders (FASD) is a non-diagnostic term given to a range of disorders resulting from fetal alcohol exposure. It is often referred to as the ‘invisible disability’ as the most prevalent adverse fetal outcomes affect the brain. Without appropriate supports in place, FASD can often result in poor education outcomes, criminal offending, substance abuse, lack of employment opportunities and mental health issues.

The fully costed $37 million plan presents a comprehensive list of recommendations focused on both prevention and management of FASD, complete with cost estimates for each action item. NOFASARD National Policy Officer, Ms Leila Picken, emphasised that this issue is very much about improving life outcomes and enabling people with FASD to reach their full potential.

“It is heartening to see that the Australian Federal Government has begun to take notice of the issue of FASD through funding and the recent Federal Government Inquiry, but there is much work that still needs to be done. Parents and carers in Australia continue to struggle to be understood by service providers about the problems their children face on a daily basis”, Ms Picken said.

NOFASARD calls on the Federal Government to formally recognise FASD as a disability and to adopt the National Action Plan as a matter of urgency.

Media contact: Vicki Russell – Ph: 1300 306 238 or 0400 133 107