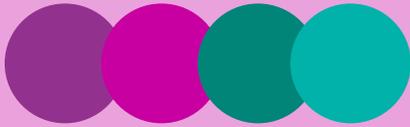




Alcohol, Pregnancy & FASD Research Program Newsletter November 2015



There is no safe amount or safe time to drink alcohol during pregnancy which is why we recommend

“NOT DRINKING ALCOHOL IN PREGNANCY IS THE SAFEST OPTION”

You can make a difference

Talk to your patients, colleagues, friends and family about alcohol use in pregnancy and share this message

Latest News

- ① Awards
- ② NHMRC Grant announcements
- ③ New Projects
- ④ Project Updates
- ⑤ FASD Clinical Network
- ⑥ FASD Clinicians Forum
- ⑦ Focus on our team
- ⑧ Reports & Publications

Contact us

For more information on our research please contact
Heather Jones, Manager FASD Projects
Phone: + 61 8 9489 7724
Email: [Heather Jones](mailto:Heather.Jones@telethonkids.org.au)
Visit our [website](http://www.telethonkids.org.au)

Awards

Congratulations Professor Carol Bower

Winner of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) Distinguished Service Award



The ICBDSR brings together birth defect programs from around the world with the aim of conducting worldwide surveillance and research to prevent birth defects and to ameliorate their consequences.

The Western Australian Register of Developmental Anomalies (WARDA), at King Edward Memorial Hospital, has been a member program of the ICBDSR since 2002 and Carol has been the Head of WARDA since its inception in 1980.

The ICBDSR Distinguished Service Award honours an individual who has provided distinguished service to the International Clearinghouse. Carol has served as Secretary, Vice-Chair and Chair of the Clearinghouse, and has been an active contributor on Clearinghouse research projects. She also tutors on the birth defects surveillance training programs run most years in Geneva – a joint venture of the Clearinghouse, WHO and the US Centers for Disease Control and Prevention.

“I am deeply honoured to be given the distinguished service award from the Clearinghouse this year,” says Carol.

“I thoroughly enjoy my association with the Clearinghouse, the collegiality, the friendship, the shared passion for the causes and prevention of birth defects.”

Read about the [ICBDSR](http://www.icbdsr.org)

National Health & Medical Research Council (NHMRC) Grant Success

Congratulations to the collaboration of Australian researchers, and consumer and community representatives who were successful in obtaining a NHMRC Grant to set up the **Reducing the Effects of Antenatal Alcohol on Child Health (REAACH) Centre for Research Excellence**.

The CRE will be led by **Professor Carol Bower** from the **Telethon Kids Institute** and **Professor Elizabeth Elliott** from **the University of Sydney**.

We acknowledge all investigators and the team who participated in the intensive interview process.

Chief Investigators

- Professor Carol Bower
- Professor Elizabeth Elliott
- Dr James Fitzpatrick
- Dr Rochelle Watkins
- Ms Heather D'Antoine
- Ms June Oscar
- Dr Roslyn Giglia
- Professor Steve Zubrick
- Professor Jonathan Carapetis



Associate Investigators

- Magistrate Catherine Crawford, Professor Jane Halliday, Ms Lorian Hayes, Professor Jane Latimer, Associate Professor Raewyn Mutch, Mr Glenn Pearson, Dr Tracy Reibel, Ms Vicki Russell, Professor Sven Silburn

The aim of the REAACH CRE is to:

- Prevent alcohol use in pregnancy and its effects on child health
- Decrease the incidence of FASD
- Improve national diagnostic capacity and management through effective interventions

The REAACH CRE research program will be underpinned by our **four current and ongoing FASD research areas:**

- epidemiology and surveillance
- prevention and diagnosis
- Indigenous communities
- juvenile justice

Through collaborative continuing research REAACH will create new knowledge and accelerate its effective translation for the prevention, diagnosis and management of FASD in Australia.

NHMRC Grant Success

The **Making Fetal Alcohol Spectrum Disorders History in the Pilbara: An evidence-based prevention intervention** application for a project grant was also successful.

The grant is a partnership between the Telethon Kids Institute and Pilbara communities and organisations:

- Mawarnkarra Health Service
- Puntukurnu Aboriginal Medical Service
- Wirraka Maya Health Service
- WA Country Health Service
- WA Drug and Alcohol Office

The goal of this project is to evaluate the effectiveness of an evidence-based FASD prevention intervention to reduce the rates of alcohol use in pregnancy among Aboriginal women in three communities in the Pilbara region of WA.



Chief Investigators:

- Dr James Fitzpatrick
- Associate Professor Roz Walker
- Professor Rhonda Marriott
- Mr Glenn Pearson
- Professor Sven Silburn
- Professor Mike Daube

Associate Investigators

- Ms Margaret Abernethy, Ms Heather D'Antoine, Mr Gary Kirby, Ms Nancy Poole, Dr Martyn Symons

New Projects

Hedland FASD Project: Building an evidence base on what works in FASD prevention and improving the support available for children with FASD and other neurodevelopmental delays

We acknowledge the significant contribution and funding from *BHP Billiton* towards the *Pilbara Health Strategy*. One component of this strategy is the Hedland FASD Project. The Telethon Kids Institute is also pleased to announce that they have received funding for this project in the *NHMRC 2015 Project Grant* round.

We will work with:

- Wirraka Maya Health Service Aboriginal Corporation
- Hedland community
- Hedland FASD Network

Together we will:

- design and implement strategies and activities to reduce the rates of women drinking alcohol in pregnancy
- increase the knowledge of service providers and families about how to support children with FASD

By working with the community we can develop and put in place local, culturally appropriate solutions for encouraging women not to drink and their partners and families to support them.

For those children already born with FASD, we can help increase understanding of families and services about their problems and behaviours and develop plans to support these children and the families who are caring for them.

We recognise that many families and services already have considerable wisdom and experience and it is important that they can share these experiences, both good and bad.

For further information contact [Kristen White](#)

Career opportunity

Research Officer – Therapy & Support Interventions

This position will work with the project team, communities and stakeholders in Hedland and surrounding communities

To apply please read the [selection criteria and job description](#) and submit your application by 23 November

For further information on this position contact [Heather Jones](#)



True Blue Dreaming (TBD) is a youth and community development-mentoring program, engaging young people aged 12-18 in rural and remote Western Australia. The aim is to build relationships with students and assist them in identifying their future aspirations. [Read more](#)

TBD has engaged the Telethon Kids Institute to conduct a review of current programs and evaluate the outcomes. The review will also look at current processes with the aim of ensuring continuous quality improvement.

The program of work will also include the development of a formal 'intervention trial' model – for example to measure improvements in self-regulation and school attendance among participants in the TBD program with complex behavioural problems including FASD.

For more information contact [Joanna Nicholas](#)



Project Updates

Marulu FASD Prevention Strategy

The *Marulu FASD Prevention Strategy* Team conducted community consultations during August and October 2015 to administer an evidence-based knowledge, attitudes and practices (KAP) quantitative questionnaire. The KAP was used to determine Fitzroy Valley community-level knowledge, attitudes and practices related to alcohol use in pregnancy and FASD. The questionnaires were administered before and after a coordinated FASD Prevention campaign conducted in September. The questionnaires administered in October also collected information about the campaign including levels of exposure and community feedback on the various campaign components.



The FASD prevention campaign consisted of mass media television advertisements and local Fitzroy Valley community messages. The *Strong Spirit Strong Future - Healthy Women and Pregnancies* mass media television advertisements is a collaborative initiative between the Western Australian Drug and Alcohol Office/Mental Health Commission, Telethon Kids Institute, and McCusker Centre for Action on Alcohol and Youth.



Local FASD awareness activities in the Fitzroy Valley included a FASD Awareness Day community event, radio advertisements and the distribution of posters and flyers.

The forty-five minute KAP questionnaires were conducted with over 400 participants including both male and female community members from more than 20 Fitzroy Valley communities. Electronic data collection forms on iPads and pictorial aids were used to improve data collection accuracy in the culturally diverse and remotely located communities. Analysis of questionnaire data is currently underway in anticipation of community feedback commencing in early 2016.

Special thanks to our local community researchers, in particular Harlen Bedford, Hozaus Claire and Sherina Malo who worked alongside Telethon Kids Institute researchers to explain and deliver the questionnaires; Fitzroy Valley community members who participated in the research; and staff from Fitzroy Valley partner organisations as well as research collaborators who contributed to the development of the KAP questionnaire.

For further information contact [Kaashifah Bruce](#)

Best wishes from the *Marulu FASD Prevention Strategy Team*



Project Updates

Understanding FASD – a guide for justice professionals

The final report for this project has been submitted to the WA Department of the Attorney General.

The resources developed as part of this project include:

Videos

Videos available from the [Professional Development subsite](#)

- 1164 plays across Australia and 14 other countries (30 April – 10 September 2015)



Website

- 325 visits to the [FASD & Justice page](#)
- 348 visits to the [Professional Development subsite](#) (30 April – 10 September 2015)



On-line CPD module for lawyers

The module is hosted on Legal Aid WA's [Train-N-Track website](#)

WA lawyers who are not Legal Aid employees can get free access by contacting Rhys McVicker via [email](#) or phone 9261 6384. This module will be evaluated in 2016 and opportunities for access by lawyers across Australia will be investigated.

For further information contact [Heather Jones](#)

Banksia Hill FASD Study

The Banksia Hill team greatly appreciates all the people and organisations who have contributed to the FASD in the juvenile justice system project – so much has been learned since starting the pilot study in May 2015.

Partnerships are vitally important as the project connects with the Department of Corrective Services, the Department for Child Protection and Family Services, young people 10-17 years old in detention, their families and communities.

By working together, the staff at the Banksia Hill Detention Centre and clinicians and project team members from Telethon Kids Institute have identified challenges on-site and developed solutions with guidance from the Consumer and Community Reference Group, Steering Group and Project Reference Group.

Young people are participating in medical, speech and language, sensory and movement, and psychological assessments aimed at identifying impairment, FASD or other conditions. A report outlining the young person's strengths and difficulties with recommendations for strategies is prepared and tailored for each person. Sharing the information from the assessments can be a catalyst for change when a greater understanding is gained of the capacities of the young person.

Another aspect of this study is exploring how the recommended strategies match with existing communication and management pathways at Banksia Hill. Professional development and training programs will be developed to help staff maximise the young person's outcomes.

Teachers, custodial officers and other staff at the Banksia Hill Detention Centre and educators at the WA Corrective Services Academy are generously sharing their experience and expertise.

For further information contact [Noni Walker](#)



Project Updates

What's the difference between a diagnostic instrument and a screening tool?

Diagnostic instrument

The Australian FASD Diagnostic Instrument is a tool that will be used by clinicians to formally diagnose a person with FASD.

The diagnostic instrument is a form that includes information on:

- How and what to measure or test
- How to record the results
- How to use this information to make a diagnosis

Although FASD has been diagnosed in Australia using overseas diagnostic criteria for many years, the Australian instrument has been developed by Australian clinicians for the Australian context.

When the Australian Diagnostic Instrument is released, on-line training in its use will be available for all health professionals to improve diagnostic capacity in Australia. Clinicians experienced in FASD diagnosis are also conducting training programs across Australia.

Screening tool

A screening tool does not diagnose FASD. It simply identifies people at high risk of FASD who would then be recommended for a diagnostic assessment.

Telethon Kids Institute researchers are working to develop a screening tool that is based on information that is readily available, and that is simple and easy to use in the Australian justice context.

It is hoped that in the future all children in detention will be screened for FASD using this tool. Those who identify as at high risk would be sent for a diagnostic assessment.

Why did you develop a diagnostic instrument before a screening tool?

There is no point in screening people at high risk of FASD if there are not the means to diagnose FASD in this high risk group.

When will the diagnostic and screening tools be available?

The Australian diagnostic instrument for FASD

This resource, together with an on-line training module, will be submitted to the Commonwealth Department of Health on 15 December 2015 and once accepted by DoH will be disseminated.

FASD Screening tool for young people entering the juvenile justice system

This tool is expected to be ready by 2017.

Alert Program® Study

The Alert Program® Study commenced in July 2015 at Muludja School in the Fitzroy Valley. The community, families and school staff have actively participated and the role of community researchers has been essential to the project. They helped support the Perth based researchers understand the cultural protocols of working within the community and used their language expertise to ensure families could access information about the project in their first language. Teachers underwent training on the Alert Program®, parents and caregivers completed questionnaires and children completed assessments. 100% of questionnaires for students were completed by teachers and their commitment to this project is greatly appreciated.

Teachers finished teaching the Alert Program® curriculum in Term 3 and provided lots of feedback. Together with feedback from families and local OTs this feedback will be incorporated into the second version for wider implementation in 2016.

For more information contact [Bree Wagner](#)



Project Updates

Breastfeeding and alcohol

Did your health professional talk to you about alcohol when you were having a baby, and even after you had given birth? Did you know that alcohol in breastmilk can disrupt the hormones needed to successfully breastfeed? It causes the baby to receive less breastmilk which then makes the baby hungry and cranky.

In Australia there are national guidelines which outline how to safely breastfeed and consume alcohol but are our maternal health professionals aware of these? Research into this topic has been underway at the Telethon Kids Institute for just over six months now. Researcher, Dr Roslyn Giglia is working with midwives, child health nurses, GPs, paediatricians and obstetricians to find out if they are talking to pregnant women and new mothers about alcohol and breastfeeding.



Midwives and Audit C Intervention Project

This project aims to develop a comprehensive resource for midwives to support them in their day-to-day practice with women. While most midwives do ask pregnant women about their alcohol use, this is not always done using a screening tool, and it has been recognised that midwives are not always confident in their knowledge of what to do if women are drinking alcohol at risky levels.

Promoting routine screening of all pregnant women (using the Audit C tool) and providing guidance for a brief intervention is a key aspect of this project, together with understanding how to manage or refer women who require assistance to stop drinking. This aligns with the inclusion of the Audit C in the new National Hand Held Pregnancy Record, which requires an Audit C score to be recorded three times during pregnancy. The WA Department of Health implemented the Hand Held Pregnancy Record in April of this year.

The project also aims to canvass women's opinions on the acceptability of the screening tool, by 'road testing' different versions with women in community based focus groups. These groups are planned for November and December and recruitment is currently taking place.

Read more on our [recruitment poster](#)

PARTICIPATE IN OUR STUDY

Dr Giglia would like to speak with women who are pregnant or have a baby less than 18 months old to find out what they know and think about drinking alcohol during breastfeeding.

If you are a pregnant woman, new mum or health professional and interested in having your voice included then Dr Giglia would like to hear from you.

Please email or phone

[Roslyn Giglia](mailto:roslyn.giglia@telethonkids.org.au)

08 9489 7726

As there is quite a lot of work being done across the country in relation to alcohol screening and brief intervention in pregnancy and resource development for both professional and community use, a **national videoconference link up** is planned for 26 November.

This will bring together researchers who are currently undertaking projects and establish if there are areas where collaboration may be possible.

Date: 26 November 2015

Time: 12.00pm (WST)

Any researcher who would like to join the video conference please email or phone

[Tracy Reibel](mailto:tracy.reibel@telethonkids.org.au)

08 9489 7913

Project Updates

Report to the National Disability Insurance Agency

The National Disability Insurance Agency (NDIA) has identified FASD as an important category of disability for consideration within the National Disability Insurance Scheme (NDIS). NDIA contracted Telethon Kids Institute to conduct a critical review of the available published and unpublished literature relating to impairment and interventions for FASD. A structured review and synthesis of literature has been provided, with oversight and input from an Expert Review Panel of leaders in the field of FASD and Disability.

The purpose of the review was to describe the types of disability supports, services and interventions that individuals with FASD require across their life course. This information will inform an approach to assessment and documenting impairment associated with FASD that will enable support and intervention planning within the NDIS.

The review provides a detailed summary of current knowledge of impairments seen in FASD across the life course, and interventions and supports that have been shown, or are likely, to ameliorate the impact of these impairments. Based on the available literature and deliberation by an Expert Review Panel, guidance is provided on the level of intervention and support required for individuals with varying levels of impairment severity.

It is anticipated that the review will provide an evidence base for the impairments associated with FASD to be considered within the NDIS, so that effective interventions and supports may be provided within an appropriate funding framework. As with other disabilities, outcomes for people with FASD can be improved through early diagnosis, early intervention, and a life course approach to improving function and participation.

The completed review has been provided to the NDIA and Telethon Kids Institute is currently awaiting advice on when the published report will be available in the public domain.

Statement from NOFASD Australia

National Disability Insurance Scheme

NOFASD Australia strongly supports the development of the National Disability Insurance Scheme and recognises that a nationalised disability care scheme is long overdue.

We particularly welcome the scope of the scheme in covering a breadth of disabilities that exist in the Australian community and a wide range of support needs. In particular, the inclusion of intellectual and cognitive disabilities is of major importance to individuals and families living with FASD

[Read more](#)



[National Disability Insurance Agency](#)

[National Disability Insurance Scheme](#)

FASD Clinical Network

Purpose

To coordinate, expand capacity and standardise our approach relating to FASD referral, diagnosis and management in Australia.

Terms of reference

- To provide collegiate support in establishing and expanding FASD diagnostic services.
- To standardise our approach to assessment, diagnosis, data management and therapy.
- To provide opportunity for national and international collaboration in clinical research.
- To standardise the definitions of training related to FASD education and continuing professional development.
- To provide support for the development of continuing professional education tools for use by health professionals in Australia.
- To support the national accreditation of continuing professional development in FASD.
- To support workforce development in FASD assessment, diagnosis and therapy.
- To contribute to research in FASD assessment, diagnosis and therapy.
- To contribute to the development and maintenance of regional and national FASD databases.

Criteria for membership of the Australian FASD Clinical Network

3 membership categories

- Clinicians who are active in FASD diagnosis
- Researchers who are actively involved in FASD diagnostic research activity
- Consumer/community/policy members

Administration/Coordination 2015-2016

- **Chair:** Dr James Fitzpatrick (Paediatrician and McCusker Clinical Research Fellow in Aboriginal Health) Telethon Kids Institute WA
- **Co-Chair:** Dr Kerryn Bagley (Social Worker) Better Life Centre QLD
- **Coordinator:** Angela Dudley (Telethon Kids Institute WA)

For more information contact [Angela Dudley](#)
08 9489 7913

FASD Clinicians Forum

Date: Tuesday 1 December 2015

Time: 9.00am – 11.00am

Venue: Telethon Kids Institute

Purpose of the FASD Clinicians Forum

To provide an opportunity for health professionals across WA to discuss current issues related to FASD diagnosis and therapy interventions

Items for discussion:

- FASD Diagnosis
Implementation of the Australian diagnostic instrument & on-line training program (December 2015)
- FASD Interventions
Report to the National Disability Insurance Agency – literature review of evidence-based interventions

Who should attend: Health professionals interested in FASD assessment – paediatricians, geneticists, psychiatrists, psychologists, occupational therapists, speech pathologists, physiotherapists

Join us in person, by phone or GoToMeetings

Details will be provided on RSVP

RSVP: Wednesday 25 November

[Heather Jones](#)

08 9489 7724

Focus on our team



Jacinta Freeman – Research Officer Banksia Hill FASD Project

Jacinta has an academic background in nursing, midwifery, health promotion and public health.

She worked in regional and remote locations as a nurse/midwife for 8 years and then as a health promotion officer in the Pilbara region. While living overseas Jacinta completed her Masters in Public Health and on her return to Australia worked on tobacco controls, road safety projects and community advocacy training.

Jacinta joined the Telethon Kids Institute as the Research Officer for the Banksia Hill FASD Project. She is the linchpin for this project working with young people in Banksia Hill, their families, Banksia Hill staff and the community.



Alcohol, Pregnancy & FASD Research Program



Bree Wagner – Alert Program® Study Coordinator

Bree has qualifications in education, social science, training & assessment and leadership coaching.

After undertaking studies to become a home economics teacher, Bree moved to the remote Kimberley community of Fitzroy Crossing and shifted her experience to the primary school sector as a numeracy and literacy teacher. She progressed her career by taking on the roles of primary school deputy principal and student services coordinator. Bree furthered her passion for working in partnership with the local community by leading the establishment of the Baya Gaway Children and Family Centre in Fitzroy Crossing. In this role, Bree built her capacity to work with a range of stakeholders to develop programs and lead initiatives to close the gap of disadvantage between Aboriginal and non-Aboriginal children in education and health. She will continue working closely with the Fitzroy Valley community to coordinate a trial which will evaluate the effectiveness of the Alert Program for primary school children (with and without FASD) self-regulation and executive functioning skills.

Alcohol, Pregnancy & FASD Research Program Reports and Publications 2015

1. **Fitzpatrick JP**, Carter M, Oscar J, Ferreira ML, Carmichael Olson H, Lucas BR, Doney R, Slater C, Try J, Hawkes G, Fitzpatrick E, Hand M, **Watkins RE**, Martiniuk AL, **Bower C**, Boulton J, Elliott EJ. Prevalence of Fetal Alcohol Syndrome (FAS) in a population-based cohort of children living in remote Australia: The Lililwan Project. *Journal of Paediatrics and Child Health*. 2015. doi:10.1111/jpc.12814
2. **Fitzpatrick JP**, Ferreira ML, Carter M, Oscar J, Martiniuk AL, **Watkins RE**, Elliott EJ. Prevalence and patterns of alcohol use in pregnancy in remote Australia. *Drug and Alcohol Review* 2015. May;34(3):329-339



Strong women leading the way



Emily Carter & June Oscar AO

Deputy & CEO
Marninwarntikura
Women's Resource
Centre



Maureen Carter

CEO
Nindilingarri
Cultural
Health
Service



Vicki Russell

CEO
NOFASD
Australia



Sue Miers AM

Chairperson
NOFASD
Australia



Elizabeth Russell

Founder Russell
Family Fetal
Alcohol
Disorders
Association



Lorian Hayes

Founder of the
National
Indigenous
Australian Fetal
Alcohol
Education
Network &
Indigenous
spokesperson
NOFASD
Australia Board

The Alcohol, Pregnancy & FASD Research Group acknowledges the drive & determination of these women (and many others) to make a difference to the lives of children living with FASD and their families.