



ANNUAL REPORT 2018

Alcohol and Pregnancy & FASD Research Team

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OUR RESEARCH

Fetal Alcohol Spectrum Disorder (FASD) occurs in all parts of Australian society where alcohol is consumed. No level of maternal alcohol consumption at any time during pregnancy can be guaranteed to be completely 'safe' or 'no risk' for the developing fetus. *Our research raises awareness of FASD across different regions of Australia and sections of society and builds new knowledge about the prevention of FASD.*

FASD is a form of acquired brain injury which occurs in utero and manifests as a neurodevelopmental disorder. It is characterised by impairment in multiple areas of brain functioning and, in some cases, characteristic facial features, extremely small head circumference (microcephaly) and other birth defects. *Our research is working with health professionals to understand the condition, build knowledge and capacity to assess and diagnose and investigate new technologies to assist with the diagnostic process.*

FASD is a condition that has lifelong impacts on individuals, their families, caregivers and the wider community. *Our research is investigating ways to better engage children in an education setting and working with families to manage children with FASD. Our research is also developing workforce training for staff working in the justice sector such as corrective services officers and police.*

We are also working with government and other stakeholders to *advocate, review and change policy, and identify the economic costs of FASD.*

Collaboration is key to the success of our research. We thank all our partners and the community members who share their wisdom, experience and time with us. A list of research projects, our research partners and community can be found on pages 11-15.



Dr Roslyn
Giglia



Dr James
Fitzpatrick



Prof Carol
Bower

OUR RESEARCHERS

Through dedication and high quality research, leadership and service, our researchers strive to deliver high impact and translational research to improve the lives of children and young people living with FASD and their families.



Narelle
Mullan



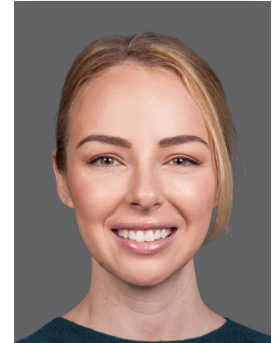
Dr Amy
Finlay-Jones



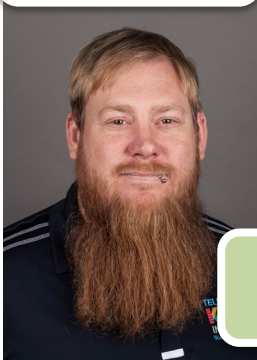
Annalee
Stearne



Bree Wagner



Candice
Browne



Dave Tucker



Emma
Adams



Elaine
Clifton



Elyssa
Strumpher



Fatuma
Hamid



Gayle Segar



Hayley
Passmore



Heather
Jones



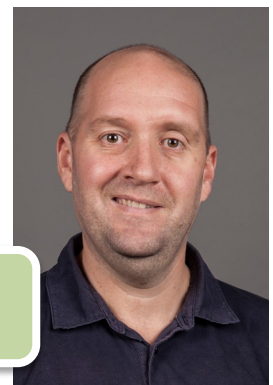
Jacinta
Freeman



Kaashifah
Bruce



Michelle Gray



Dr Martyn
Symons



Natalie
Kippin



Margaret
Ramirez



Assoc Prof
Roz Walker



Dr Rochelle
Watkins



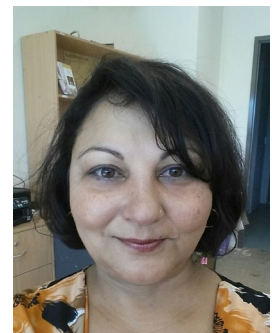
Dr Rebecca
Pedruzzi



Sharynne
Hamilton



Sue Cherel



Sangita
Daniels



Dr Tania
Gavidia



Tess
Fletcher



Tracy McRae



Dr Tracy
Reibel

HIGHLIGHTS FROM 2018

Moved to our new home



In August 2018 we moved from our home of 20 years on Roberts Road Subiaco into the Perth Children's Hospital

2nd Australasian FASD Conference Perth 21-22 November 2018



8 plenary sessions, 6 workshops & 84 presentations



374 participants



OUR SCIENCE OUR STORIES
Health professionals, researchers, parents and care givers, service providers and policy makers

You can watch videos of all plenary sessions and view some of the presentations at <https://www.fasdhub.org.au/research-and-publications/fasd-research-australia/fasd-2018-conference/>

Signed a Memorandum of Understanding (MOU) with CanFASD

CANADA AUSTRALIA FASD RESEARCH NETWORK

The purpose of this MOU is a cooperative effort between the two organisations to advance the knowledge and understanding of FASD and its link with alcohol use.



46 presentations at
international,
national &
state/territory
conferences &
seminars

15 workshops
conducted for
health & other
professionals

11 publications
& 5 reports

6 PhD candidates
& 2 Masters
students

4 submissions to
inquiries &
clinical guideline
development

5 new projects
commenced

2018 Awards

Congratulations to



Professor Carol Bower

Public Health Association Australia

Top 10 Public health successes over the last 20 years

Folate: we reduced neural tube defects

Hayley Passmore

PhD Student Paper Prize

Australian and New Zealand Society of Criminology Conference

Improving the management of young people with Fetal Alcohol Spectrum Disorder (FASD) in a Western Australian detention centre



RESEARCH PROJECTS

These projects include researchers from the Telethon Kids Institute Alcohol and Pregnancy & FASD Research Team and also Institute staff working with the FASD Research Australia Centre of Research Excellence.

Prevention

1. Hedland FASD Project
2. Pilbara FASD Project
3. Making FASD History: A multisite prevention program
4. Determinants of prenatal alcohol exposure among Aboriginal women in the Pilbara (PhD project)
5. Using participatory design to create impactful health promotion messages regarding alcohol use in pregnancy (PhD project)
6. Reducing harms related to alcohol use in pregnancy - policy and practice recommendations
7. Working towards a best practice framework for FASD prevention in Australia
8. Parent Child Assistance Program - A Pilot Study in Perth
9. AUDIT-C for health professionals
10. Estimating the economic burden of FASD in Australia (Masters project)

Diagnosis

1. Normative eye tracking data for Australian children on four tasks
2. Working towards a shared framework in the diagnosis of neurodevelopmental disorders in Australia: A gap analysis
3. Dissemination and evaluation of the Australian Guide to the diagnosis of FASD and eLearning modules
4. Fetal alcohol exposure, nutritional status and epigenetic disruption - exploring the links

Therapy and Management

1. Alert Program®
2. The Alert Program Study: development and evaluation of an intervention to improve self-regulation and executive functioning skills of Australian Aboriginal primary school children with a focus on FASD (PhD project)
3. Precision pathways for young children at risk of Neurodevelopmental Disorders
4. FASD in the Australian Education System: Knowledge, Attitudes, Needs and Practices

Justice

1. Banksia Hill Detention Centre Project
2. Improving the management of young people with FASD in detention (PhD project)
3. Talking, Hearing, Understanding, Knowing: A qualitative exploration of the experiences of justice-involved youth undergoing assessment for FASD in a juvenile detention centre (PhD project)
4. Communication, fetal alcohol spectrum disorder and youth justice (PhD project)
5. Young people in detention in Western Australia: An examination of motor skills and the effect of prenatal alcohol exposure

Cross theme projects

1. FASD Hub Australia
2. Estimating the economic burden of fetal alcohol spectrum disorder in Australia: An economic modelling approach

Information on these projects is available at:

<https://alcoholpregnancy.telethonkids.org.au/our-research/research-projects/>

CONNECTING WITH OUR COMMUNITY

All research project Advisory Groups and Steering Groups include consumer and community representation. Information on these groups is available on each project page on our website.

<https://alcoholpregnancy.telethonkids.org.au/our-research/research-projects/>

Much of the research with Aboriginal communities has been community-initiated and there is genuine community leadership, and ownership of issues related to the projects.

The FASD Research Australia Centre of Research Excellence has a national Community Reference Group. The Reference Group aims to help focus future research funding on the questions that matter to people who are interested in alcohol consumption during pregnancy and people with lived experience of FASD. In 2017 this group led a national project to establish a list of the top ten research priorities. These priorities are being used to guide new grant applications and future funding applications. More information of community involvement in FASD research is available at <https://www.fasdhub.org.au/research-and-publications/fasd-research-australia/community-involvement/>



Thank you

To our amazing partners
We couldn't do it without you

Western Australia

Hedland FASD Project

- Wirraka May Health Service Aboriginal Corporation
- Hedland FASD Network
- Hedland Community Reference Group

Pilbara FASD Project

- Mawarnkarra Health Service Aboriginal Corporation
- Puntukurnu Aboriginal Medical Service
- Wirraka Maya Health Services Aboriginal Corporation
- WA Country Health Service
- Mental Health Commission (Drug and Alcohol Office)

National FASD Project

- Central Australian Aboriginal Congress (Alice Springs NT)
- Mercy Services (Newcastle NSW)
- Newcastle Local Drug Action Team (NSW)

Alert Program®

- Nindilingarri Cultural Health Service, Western Australia
- Fitzroy Valley primary schools, Western Australia
- Kimberley Education Regional Office, Western Australia
- Department of Health, Western Australia
- University of Washington, USA

Banksia FASD Project

- Banksia Hill Juvenile Detention Centre
- WA Government Department of Corrective Services
- WA Government Department of the Attorney General
- WA Police

National activities and projects

FASD Research Australia Centre of Research Excellence (CRE)

- University of Sydney
- Telethon Kids Institute
- Menzies School of Health Research
- NOFASD Australia
- Murdoch Children's Research Institute
- George Institute for Global Health
- The University of Queensland
- Marninwarntikura Fitzroy Women's Resource Centre



STUDENTS AND VOLUNTEERS

Thank you to our volunteers who worked with us in 2018. Your support and assistance to our projects is greatly appreciated by the project teams.

- Amara Du Laz
- Brian McRae
- Kate Woolhouse

We are pleased to be supporting the next generation of researchers:

- Tess Fletcher - PhD
- Dr Amy Finlay-Jones - Masters
- Sharynne Hamilton - PhD
- Natalie Kippin - PhD
- Renee Mellor - Masters
- Hayley Passmore - PhD
- David Tucker - PhD
- Bree Wagner - PhD

You can read about their research on our website

<https://alcoholpregnancy.telethonkids.org.au/our-research/research-projects/>





ALCOHOL AND PREGNANCY & FASD RESEARCH

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