

# Making FASD History

Newsletter Number 2, December 2017

## FETAL ALCOHOL SPECTRUM DISORDER (FASD)

*is caused by drinking alcohol during pregnancy. It can affect the development of a baby's brain and body in adverse ways. Drinking alcohol during pregnancy can make kids:*



**Be born small  
and grow slow**



**Have a short  
temper**



**Have trouble  
at school**



**Not remember  
things**



**Have trouble hearing  
and speaking**



### WHAT ARE WE DOING

Raising community awareness of the risks of drinking alcohol during pregnancy, and providing support to children with FASD and their families.



### WHY ARE WE DOING IT

To make FASD history so children can live happy, healthy and productive lives

**Welcome!** *This newsletter provides an overview of the comprehensive research program we are undertaking with many diverse communities across Australia.*

*We acknowledge and pay our respects to the traditional owners and Elders past and present on the lands in which we are working together. We would also like to acknowledge the generosity of the families and stakeholders working with us. We hope you enjoy reading about our 2017 achievements and we look forward to continued success in 2018.*



# WHAT'S HAPPENING IN THE PILBARA

**WARAJANGA MARNTI WARRARNJA**  
**TOGETHER WE WALK ON COUNTRY**

**TELETHON  
KIDS  
INSTITUTE**  
Discover. Prevent. Cure.

**BHP**



'Warajanga Marnti Warrarnja - Together we walk on country' is a partnership between the Telethon Kids Institute and BHP in collaboration with Wirraka Maya Health Service Aboriginal Corporation, the Hedland FASD Network and Hedland FASD Community Reference Group (Hedland FASD CRG). Working with the community, the project has the bold goal to make FASD history in the Pilbara.

The research in the Pilbara is focused on three main areas. These include reducing rates of drinking in pregnancy in the Hedland area, diagnosis of children who might have FASD, and support for children and families affected by FASD.

## THE ROLE OF THE Hedland FASD CRG

The Hedland FASD CRG has been established with Aboriginal representatives from the local community to provide advice on the research project within Hedland and surrounding communities.

The Hedland FASD CRG was formally established in March 2016 with the following key aims:

*Supporting the Hedland FASD project* by ensuring the key goals and principles of the project are achieved at all times.

*Enhancing Community Engagement* by providing advice to the research team, research partners and the FASD Network on engaging with Aboriginal community groups and organisations in Hedland, Warralong and Yandeyarra.

*Strengthening Community Empowerment and Capacity Building* by ensuring the cultural and ethical conduct of research in Aboriginal communities with a key focus on healing, connectedness to country, spirituality and local family involvement.

## WHO ARE THE HEDLAND FASD CRG?

The group include the initial CRG members, in addition there are many community members who come to meetings when they can, to talk about specific topics of interest.

### CRG Members 2017

Ann Sibosado, Tracy Kynaston, Anika Coppin-Foley, Janet Stewart, Bonnie Liddell, Tabareena Waddaman, Margaret Moses-Martin, David Moses-Martin, Gordon Yuline, Basil Snook, Ebony Winmar, Chrissie Black.



# WARAJANGA MARNTI WARRARNJA TOGETHER WE WALK ON COUNTRY

## Prevention



Adrian Clinch and David Tucker



The BHP FASD Prevention team has had a very busy 2017 with health promotion, consultation and data collection activities throughout the year.

International FASD Awareness Day 2017 was held at the South Hedland Town Square on Friday September 8th. Co-hosted by Wirraka Maya Health Service and the Telethon Kids Institute, the day also featured stalls and activities by South Hedland Aboriginal Family Law Services, South Hedland Child and Parent Centre (CPC) and the KindiLink Program among others.

The day was the perfect opportunity to unveil three new FASD Prevention videos, which featured local Pilbara people sharing their FASD experiences. Tracy Kynaston, a Hedland Community Reference Group member shared her personal experiences of living with FASD, and her decision not to drink while pregnant with her daughter, Amy.

We applaud Tracy's courage and her commitment to preventing FASD in her community. The video can be viewed and downloaded on our website at <http://bit.ly/2AGrnGp>



FASD Prevention work was shared with international audiences at the 2017 Global Alcohol Policy Conference in Melbourne, where Research

Officer David Tucker and Community Researcher Adrian Clinch gave two presentations on the Hedland work.

Adrian was also awarded the GAPC2017 Ian Webster Conference Scholarship Program, funded by the Foundation for Alcohol Research and Education (FARE), an independent, not-for-profit organisation working to stop the harm caused by alcohol ([www.fare.org.au](http://www.fare.org.au)). Further congratulations to Adrian for being awarded the 2017 Port Hedland NAIDOC Scholar of the Year (pictured below). Adrian also began TAFE Business Studies earlier this year.

The FASD prevention team spent the month of October conducting the annual community FASD survey, and were able to collect more than 400 responses across Hedland, Yandeyarra and Warralong communities.

A huge effort, with very special mention to the many volunteers (Geoff Tucker, Helen Tucker, Brian McRae, Jesse White, Fatuma Hamid) and staff (Sangita Daniel, Zabia Chmielewski, Gayle Segar, Adrian Clinch, Sissy Ramirez, Tracy McRae) who worked tirelessly to achieve this.





## Therapy and Support



Tracy McRae, Margaret (Sissy) Ramirez, & Sangita Daniel

### The Alert Program®

The Alert Program® teaches children and their caregivers about self-regulation using the metaphor of a car engine (see diagram below) and asks them to imagine 'how fast their engine is running.' It provides a toolbox of strategies (move, touch, look, listen, put something in the mouth) so that children are empowered to self-regulate.

In 2017 we welcomed Tracy McRae to the team! Tracy is co-ordinating our Therapy and Support program in Hedland with local team members Sissy and Sangita. Tracy previously provided support in implementing the Alert Program® in the Kimberley.

Implementation of the Alert Program® has been completed in four schools in the Pilbara region; South Hedland Primary School, Cassia Primary School, Yandeyarra Community School and Strelley Community School. A big thank you to all the schools and communities involved for their support.

Emma Adams (Data and Statistics Manager) has been working with the team to commence analysis of the study data and the team is looking forward to presenting the study results in 2018.

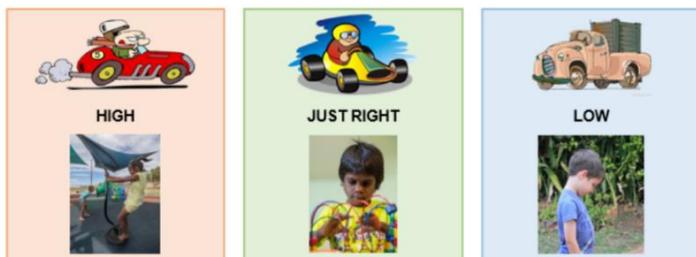
### Parent/Carer Support Program

Development of a Carers Support Program will commence in early 2018 with Elaine Clifton coming aboard as a Community Researcher.

Elaine will assist with interviews of carers of children with FASD to understand their lived experience and identify their support needs.

Elaine retired from the Department of Prime Minister and Cabinet in 2016 after 35 years working in various public service roles and is excited to be involved in the Pilbara FASD Strategy.

We also wish to congratulate Community Researcher Margaret Ramirez (Sissy) who attended the Telethon Kids Institute Scientific Retreat in November and presented her work with the Alert project team. Sissy has also commenced Certificate II in Business at the North Regional TAFE and is hoping to attend an Aboriginal Leadership course in 2018.



Data and Statistics Manager  
Emma Adams

*"Now I have the opportunity to be a part of Telethon Kids Institute and am part of a great team doing their utmost to help our community."* Community Researcher Elaine Clifton (pictured right)





PATCHES Director James Fitzpatrick

# Diagnosis



PATCHES continued delivery of multidisciplinary FASD diagnostic clinics in 2017. The clinics were delivered at the Youth Involvement Council in South Hedland. At these clinics PATCHES saw children from throughout the Pilbara area including Karratha, Roebourne and communities such as Jigalong.

The clinics enabled diagnoses and referrals to the WA National Disability Insurance Scheme eligibility team with a number of children being granted funds for ongoing assistance.

Assessments were contributed to by local paediatricians, school psychologist reports and allied health clinicians. PATCHES worked closely with the Department of Communities district psychologist and other local stakeholders to run an efficient service for families.

Early in 2017, documentation of referral pathways for diagnosis of FASD and other neurodevelopmental disorders was finalised for the Hedland area.

The process involved extensive consultation with key stakeholders and health professionals. A series of visual maps were developed. These maps identify reasons for referral, screening, support/assessment service providers and teams, potential diagnoses, service funding for disability support and local services available for support.

The maps (example below) provide an important tool for engagement and capacity building with health services and non-government organisations in each of the three sites in the Pilbara. These maps can be accessed on our website at <http://bit.ly/2AGrnGp>

A paper documenting this process is currently being finalised for submission in 2018 so that the work can be shared more widely.

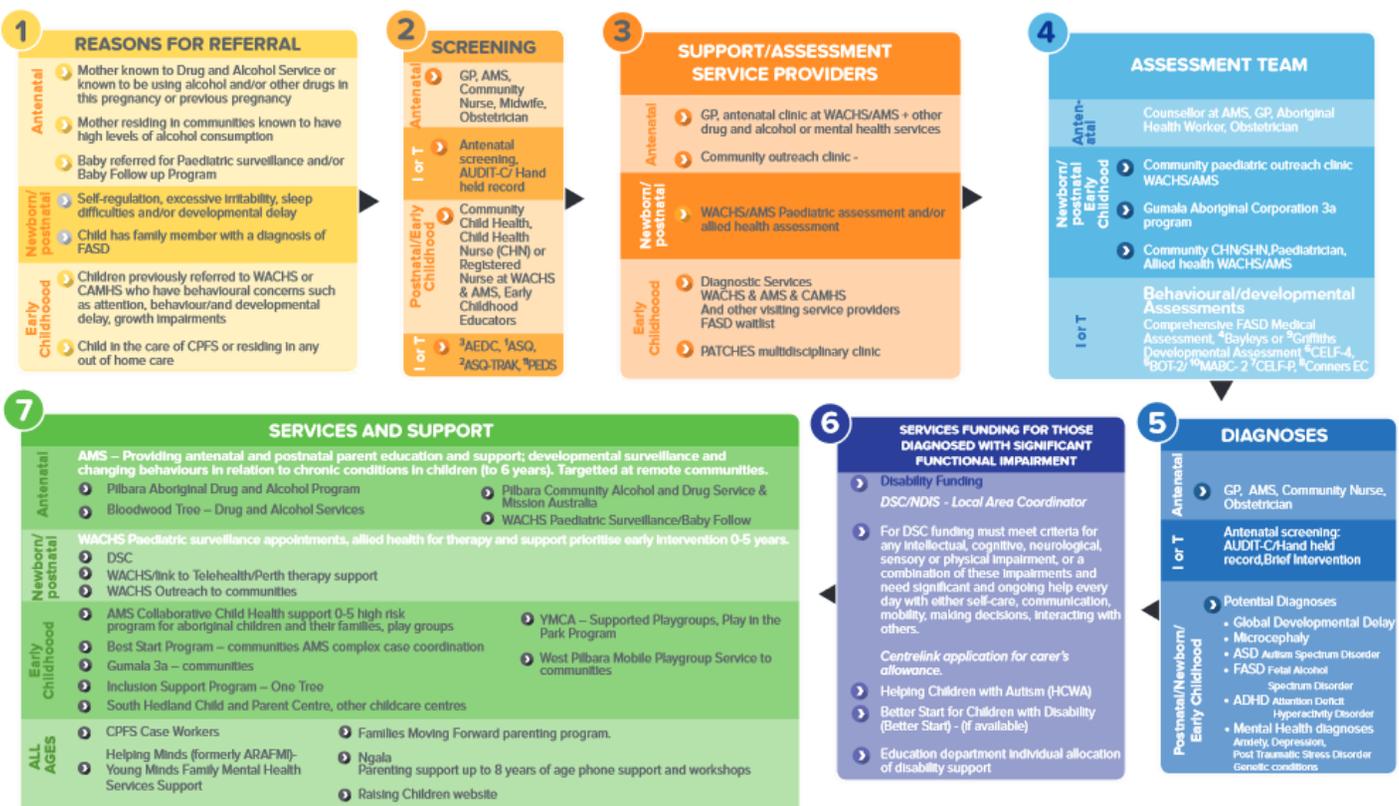
## Pilbara Model of Care: Health System

Dudley, A; Fitzpatrick, J; Walker, R

November 2016



A mother and child's Integrated Journey:  
 Fetal Alcohol Spectrum Disorder (FASD)  
 0 - 4 years



# NHMRC Pilbara FASD project



Government of Western Australia  
WA Country Health Service



Government of Western Australia  
Mental Health Commission  
Drug and Alcohol Office



*David Tucker, Roz Walker, and Michelle Gray*

2017 was the year of travel for the NHMRC FASD Prevention team, with multiple visits to the Western Desert communities Jigalong, Parnngurr and Punmu.

Extensive research and consultation was undertaken with project partners including the three Aboriginal Controlled Health Services - Puntukurnu Aboriginal Medical Services (PAMS) in Newman, Wirraka Maya in Hedland and Mawarnkarra in Roebourne and stakeholders early in the year, with field trips to Newman, in the Western Desert, and Warralong and Yandeyarra in Hedland and Roebourne.

Members of the team travelled to Parnngurr during the Western Desert Football Carnival, where Punmu took home the cup. It was an opportunity to re-establish relationships, share information about the project and to build on existing work being driven by community and stakeholders in each of the sites.

In Newman an exciting opportunity to work with Kanyirninpa Jukurrpa (KJ) was established. In early 2018 the team will be assisted by the KJ Rangers and Women's Leadership programs to develop and translate a community FASD survey appropriately for use in Western Desert Martu Communities.

A highlight of 2017 was taking Canadian practitioners Nancy Poole and Lorraine Greaves to Hedland to deliver a workshop and community forum on gender and trauma-informed care and services.

The Making FASD History team was delighted to welcome new members to the team this year. Michelle Gray came on board as the Project Manager of Pilbara FASD Prevention in October 2017. Michelle previously worked at the Mental Health Commission where she was instrumental in the development of the Strong Spirit Strong Future FASD Prevention campaign, and the creation of local drug and alcohol action plans with Pilbara communities.

David Tucker also joined the NHMRC team in early 2017 as a PhD student to examine the predictors of prenatal alcohol consumption in Pilbara Aboriginal communities and the development of evidence based prevention interventions.

Community and stakeholder led forums throughout the year highlighted local commitment and focus on FASD prevention. Roz Walker and James Fitzpatrick presented to the Pilbara Aboriginal Health Planning Forum throughout the year. Roz and Michelle also presented at a 'Pilbara 4 Purpose' forum in November where Roz was an invited member of an expert Q&A panel and recommendations were presented to the Hon. Stephen Dawson (Minister for Environment).



*David Tucker and Roz Walker in Newman*



# WHAT'S HAPPENING IN THE KIMBERLEY

## Therapy and Support

### The Alert Program®



*Bree Wagner  
and Sue Cherele*

It has been a busy second half of the year for the Kimberley Alert Program® project. The team has continued visits to Fitzroy Valley schools and communities to collect data and support schools to implement the Alert Program®.

The data collection phase of this four-year project was completed in December 2017. Work in the Fitzroy Valley has been supported by Community Researchers Sue Cherele, Samantha Ahfat, Irene Passenger and Marissa Williams. Bree Wagner (Study Coordinator), Emma Adams (Data and Statistics Manager) and Gayle Segar (Research Assistant) have been working hard to enter, check and clean data.

Data analysis will begin in early 2018. Bree is currently working with the Kimberley Education Regional Office to discuss future steps for the schools who received the program in 2016 and 2017.

We congratulate Sue Cherele who was announced as a semi-finalist in the WA Regional Achievement and Community Awards for her work on the Alert Program® project. We also congratulate Sue and Bayulu community researcher Rebecca Smith for completing their Certificate II in Community Services through North Regional TAFE.

We wish to thank Maureen Carter, CEO of Nindilingarri Cultural Health Services for her continued guidance and support. Our thanks are also extended to our chief investigators, collaborators from the Departments of Education and Health, the Fitzroy Valley communities and schools participating in the project and our team colleagues here in Perth. We look forward to sharing results of this project with you in the second half of 2018!



*Clockwise from bottom left: School resources, Community Researcher Irene Passenger, end of year celebrations, and flying to Ngalapita.*

# Marulu Prevention Project Update



*Kaashifah Bruce and Martyn Symons*

After three years, the Marulu FASD Prevention Project wrapped up on 30 June 2017. Key activities for the final year (July 2016 to June 2017) included the completion of seven FASD Awareness videos developed by Paul Bell from Feral Films in consultation with community groups across Australia, Telethon Kids Institute's research team and Communication and Engagement Team.

The videos were developed to raise awareness of the effects of alcohol use in pregnancy and the world leading research Telethon Kids is conducting with communities. The videos are downloadable and can be found at the following web address <http://bit.ly/2yQNsK2>

In addition, data from 2016 AUDIT-C records has been analysed. Two draft papers have been developed so that the team can share the community Knowledge, Attitudes and Practices

and AUDIT-C results more widely. These papers will be ready for submission in early 2018.

We have also been able to share these learnings in the new FASD Prevention work in the Pilbara, and soon in Newcastle and Alice Springs.

As always, we thank the Fitzroy Valley communities for allowing the team to conduct this important work. The support of community members, community leaders and local organisations has enabled us to document the strengths and needs of the community, as well as build an evidence base for FASD prevention.



# MAKING FASD HISTORY

## Future work



*Kaashifah Bruce, James Fitzpatrick and Rebecca Pedruzzi*

Recently, our team at Telethon Kids worked with Central Australian Aboriginal Congress Aboriginal Corporation (Congress) in the Northern Territory and Mercy Services in New South Wales to secure \$2.7 million in funding from the Commonwealth Department of Health (2017-2020).

The purpose of this funding is to initiate FASD prevention programs in Alice Springs and Newcastle. James Fitzpatrick, Kaashifah Bruce, and Rebecca Pedruzzi worked in collaboration with the Telethon Kids Institute Research and Development team, Consumer and Community Involvement Program team, the Australian FASD Centre for Research Excellence, Congress and Mercy Services to develop the grant. Thanks to all who contributed to the development of this grant!

The work aims to ensure sustainability and capacity building for local health services so that communities can continue to lead FASD prevention activity. As a result of this funding, a FASD coordinator will be recruited in both Alice Springs and Newcastle in early 2018 to facilitate community-led activity. Additionally we welcome Program Manager Annalee Stearne and Senior Research Officer Tania Gavidia to the team! Annalee and Tania will be based at Telethon Kids but travelling regularly to work with our stakeholders in Alice Springs, Newcastle, and the Pilbara.

Over the last year we have had regular meetings with our international networks in Canada and Europe. In July, Senior Research Officer Rebecca Pedruzzi obtained a grant allowing her to work with our collaborators at Maastricht University in the Netherlands.

Her project aims to understand what we know and what we don't know about FASD prevention in Australia. As part of her grant award, Rebecca travelled to Maastricht to receive training in evidence based prevention methods. Rebecca will be drawing on the expertise of our Netherlands collaborators to ensure that as researchers we are working in the best ways possible to Make FASD History.

The team is looking forward to further developing these national and international collaborations and sharing the collective knowledge of our community and research partners.



*Clockwise from bottom left: New team members Annalee Stearne and Tania Gavidia; Rebecca with our European collaborators in Maastricht; and Kaashifah with Elvira Johnson from Mercy Services.*



# TEAM UPDATES

## Team achievements in 2017

2017 was a busy year for our team with the hard work of our staff being recognised both locally and internationally. Some of these achievements include:

### Development of FASD resources

- A video outlining the lived FASD experience of Community Reference Group member Tracy Kynaston developed and launched in Hedland on International FASD Awareness Day.
- Two videos discussing the impact of FASD at a community level, and the role of local men and women in helping to prevent FASD and support those individuals and families affected by the disorder.
- Seven FASD Awareness videos developed by Paul Bell from Feral Films in consultation with community groups across Australia, Telethon Kids Institute's research team and Communication and Engagement Team.
- James Fitzpatrick and Rebecca Pedruzzi developed a chapter on FASD for inclusion in the NACCHO/RACGP National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people (3rd edition).

### Awards

- Adrian Clinch was awarded the Hedland NAIDOC Scholar of the Year award.
- Adrian Clinch was awarded a Foundation for Alcohol Research and Education (FARE) Scholarship to attend the 2017 Global Alcohol Policy Conference in Melbourne.
- James Fitzpatrick received the Professional award for West Australian of the Year 2017.

### Grants

- Rebecca Pedruzzi was awarded a Friends of the Institute Sabbatical award to work in collaboration with Maastricht University on developing best practice for FASD prevention programs.
- Funding of \$2.7 million for FASD prevention programs from the Commonwealth Department of Health (2017-2020) awarded to Telethon Kids in collaboration with Central Australian Aboriginal Congress Aboriginal Corporation in the Northern Territory and Mercy Services in New South Wales.

### Reports & Publications

- Report by David Tucker, Beatriz Cuesta-Briand and Roz Walker: Knowledge, attitudes and practices related to FASD: Stages 1 and 2 Baseline and End-line descriptive data analysis. Telethon Kids Institute Report 2017.
- Report by David Tucker, Beatriz Cuesta-Briand and Roz Walker: Self-reported alcohol consumption during pregnancy: A baseline investigation in Port Hedland, Yandeyarra and Warralong. Telethon Kids Institute Report 2017.
- Report by Kaashifah Bruce and colleagues: Making FASD History: Marulu Fetal Alcohol Spectrum Disorder Prevention Strategy. Final Report to Western Australian Government Department of Health. Telethon Kids Institute, August 2017.
- Annual report to BHP: Pilbara FASD Research Project, June 2017.

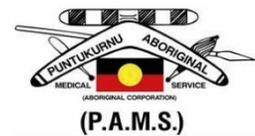
- James Fitzpatrick and colleagues (2017) published a paper in the Australian and New Zealand Journal of Public Health: The Marulu Strategy 2008–2012: overcoming Fetal Alcohol Spectrum Disorder (FASD) in the Fitzroy Valley <http://onlinelibrary.wiley.com/doi/10.1111/1753-6405.12689/references>
- James Fitzpatrick and colleagues (2017) published a paper in Research in Developmental Disabilities: Prevalence and profile of Neurodevelopment and Fetal Alcohol Spectrum Disorder (FASD) amongst Australian Aboriginal children living in remote communities <http://www.sciencedirect.com/science/article/pii/S0891422217300975>

## Conference presentations

- Kaashifah Bruce, Roz Walker and June Councillor presented 'Making FASD History: Community and research partnerships in remote Western Australia' at the 15th World Congress on Public Health, Melbourne, Victoria.
- Bree Wagner presented 'The Alert Program® Pilot Study: a Classroom Based Intervention to Support Children with FASD to Improve Self-regulation and Executive Functioning Skills' at the 7<sup>th</sup> International Conference on FASD Research, Vancouver, Canada.
- Martyn Symons presented 'Evaluating the Effectiveness of FASD Prevention in a Remote Indigenous Community in Australia: Alcohol Consumption During Pregnancy' at the 7th International Conference on FASD Research, Vancouver, Canada.
- 'Building an Evidence Base for FASD Prevention Strategies in North West Australian Communities: An Assessment of Knowledge, Attitudes and Practices' by David Tucker, Martyn Symons, and Kaashifah Bruce at the 7th International Conference on FASD Research.
- Team presentation 'Making FASD History: FASD Diagnosis, Prevention and Interventions – Evaluating and Scaling Up Successful Models in Remote Australian Communities' at the 7th International Conference on FASD Research, Vancouver, Canada.
- James Fitzpatrick, Kaashifah Bruce, June Councillor, and Anne Russell presented 'FASD Prevention with Indigenous Communities' at the 7<sup>th</sup> International Conference on FASD Research Vancouver, Canada.
- David Tucker, Adrian Clinch, and Roz Walker presented 'Tackling Fetal Alcohol Spectrum Disorder from within: Building capacity for sustainable change' at the Global Alcohol Policy Conference 2017 Melbourne, Victoria.
- David Tucker presented 'Targeted Alcohol Interventions: Understanding vulnerabilities to alcohol consumption during pregnancy' at the Global Alcohol Policy Conference 2017 Melbourne, Victoria.



NHMRC  
PILBARA  
FASD  
PROJECT



Government of Western Australia  
WA Country Health Service



Government of Western Australia  
Mental Health Commission

Drug and Alcohol Office

In partnership  
with the Hedland  
FASD network  
and community  
reference groups

WARAJANGA MARNTI WARRARNJA  
TOGETHER WE WALK ON COUNTRY



McCusker  
Charitable  
Foundation



Department of  
Education

KIMBERLEY  
MARULU  
FASD  
STRATEGY



McCusker  
Charitable  
Foundation



Government of Western Australia  
Mental Health Commission



Government of Western Australia  
Department of Health



Government of Western Australia  
Department of Aboriginal Affairs



Government of Western Australia  
WA Country Health Service

Making FASD History:  
A multi-site prevention program



Australian Government  
Department of Health

If you'd like to know more about the project or to be involved:



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