

Making FASD History

Newsletter number 1, December 2016

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 to the first edition of the 'Making FASD History' newsletter! This newsletter provides an overview of the comprehensive research program we are undertaking with the many diverse communities in the Kimberley and Pilbara regions of Western 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 2016 achievements and we wish you all a safe and happy holiday period.



ADVOCACY

By James Fitzpatrick



A major impact of the *Make FASD History* Strategy is to influence policy and practice at a local, regional, and national level in relation to FASD. Policymakers and service providers often request high quality research to identify areas of need, and to inform solutions to public health problems. Our approach to advocacy has been strategic and ‘big picture.’

At an *international level*, the following advocacy activity has been achieved:

- Initiating a global collaboration on FASD prevention intervention research, through an emerging partnership with universities and FASD agencies in the USA, Canada, the Netherlands, and South Africa. This collaboration will work on an international multi-site FASD prevention program, heavily influenced by the *Make FASD History* strategy.
- Working through the 7th International FASD Conference Expert Advisory Committee to secure a 3-hour plenary on FASD Prevention, as an opening event at the 2017 Conference in Vancouver. This has been a significant achievement, to put FASD prevention research front and centre on the global FASD research agenda. The *Make FASD History* strategy, and early results, will be presented at this plenary session.

At the *national level*, our advocacy has achieved the following:

- Through membership of the Australian National Advisory Council on Alcohol and Drugs, having a roll out of the *Make FASD History* strategy specifically named in the 2016 Federal budget. The strategy was tabled at a national FASD roundtable in Canberra (December 2016) as an evidence based approach to FASD prevention that should be funded by Government in multiple states and territories.
- Working with the Australian Government Department of Health to allow FASD diagnostic teams to access Medicare item numbers, the same as those used for Autism diagnosis. High level discussions are underway, and the Department of Health are proactively seeking to enable this Medicare item number access.

This will be a game changer in terms of increasing diagnostic activity, as teams will have a way to fund the assessment process.

- Advising the National Disability Insurance Agency, on how to include FASD within the National Disability Insurance Scheme. This is one of the most significant policy/advocacy achievements in the field of FASD, and addresses the long-held belief that FASD should be considered as a disability, and that therapy and support for FASD should be funded through mainstream programs.

At a *local and regional level*, advocacy is ongoing in the following areas:

- Ongoing discussions with the Department of Regional Development have informed their Regional Services Reform process, such that consideration is being given to funding increased FASD diagnostic capacity throughout the Kimberley and Pilbara.
- Working with multiple sites across the Kimberley and Pilbara to consider establishing their own *Make FASD History* strategy, with research support from Telethon Kids Institute.
- Supporting the strengthening of Alcohol Management Plans and existing calls for supportive alcohol policy by local government and other stakeholders in the Pilbara.
- Development and dissemination of the FASD Model of Care for the Pilbara, that assists local agencies to understand processes and stakeholders relating to FASD screening, diagnosis, and therapy/support.

These advocacy and policy efforts have been achieved through concerted relationship-building, and the use of research evidence to offer systematic and sustainable solutions to the issue of FASD. The unwavering commitment of our Aboriginal Community Controlled Health Services partners and local champions June Councillor (Pilbara), June Oscar and Maureen Carter (Kimberley) to the *Make FASD History* strategy, is critical to address this complex issue. Through our collaborative work on FASD, so many other systems can be improved so that young people, and their families, can be the best they can be.

WHAT'S HAPPENING IN THE PILBARA?



Community Engagement

By Roz Walker



FASD education & prevention

In April 2016 the partnership was awarded a Healthway Visiting Fellowship to bring Carolyn Hartness, FASD expert and educator, to Hedland to facilitate community workshops, a community forum and stakeholder workshop for different sectors (health, early years services and childcare, disability services, education, justice, and child protection).

Throughout Carolyn's visit, Roz Walker and Sylvia Lockyer undertook extensive collaboration with the Hedland FASD Network to engage with the following service providers:

- Drug and alcohol and Mental Health services
- Local primary and high schools
- Youth (including Youth Involvement Council)
- Local Government (Town of Port Hedland)
- Justice (including Legal Aid)
- Housing, Child Protection, Health (WA Country Health Service, Wirraka Maya Health Service Aboriginal Corporation, National Disability Council) and
- Aboriginal businesses, corporations and industry partners

In total, over 80 people in Hedland participated in the workshops, 15 attended the facilitator training, and 100 people attended the Community Forum.



The Healthway fellowship has been a fantastic and highly effective way to increase the number of community members and professional stakeholders involved in a range of education and training activities focused on preventing FASD. It has also been a great way to provide information to carers and families supporting children with FASD.

Engaging with community & stakeholders

Throughout the year the Community Reference Group and Community Researchers have emphasised the importance of meetings on country to increase community awareness about FASD.

In September, our team was invited to attend the Yule River Bush Meeting which was mainly focused on how the Aboriginal Heritage Act will affect the rights of Aboriginal people in WA. On Day One, Community Researcher and CRG member Adrian Clinch attended the meeting in his capacity as a Traditional Owner. On day two he was joined by FASD Coordinator Sylvia Lockyer and Research Officer David Tucker.

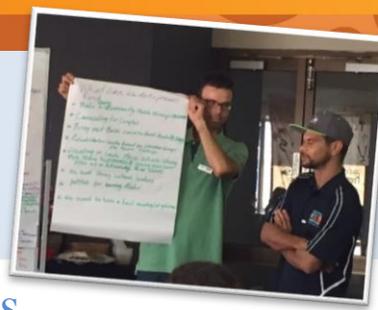
Several Hedland community members used this opportunity to speak about their concerns related to alcohol misuse with key politicians including Ben Wyatt, Pat Dodson, Stephen Dawson and Robin Chappell.



Yule River Bush Meeting, 21-22 September 2016.

Capacity Building

By Roz Walker



Building the capacity of carers, community & professionals

An important aspect of the Healthway visiting fellowship has been to develop a 4 day Facilitator Training Program and resources manual to support future training and sustain the model of care developed to help make FASD history.



Roz, Sylvia, and Carolyn working together to develop a facilitator training package.

Training outcomes

Roz Walker and Sylvia Lockyer facilitated a large number of workshops with Carolyn Hartness and various community and stakeholder groups in Hedland, Warralong and Yandeyarra.

Evaluations highlighted that the majority of people found the workshops increased their:

- Knowledge and understanding of FASD and the harmful effects of drinking alcohol in pregnancy.
- Recognition of the importance of prevention.
- Commitment to work to change attitudes at a community level to support women to stop drinking during pregnancy and throughout breastfeeding.

Employing local community researchers

A key aspect of the project this year has been to understand community knowledge, attitudes and practices around drinking during pregnancy so that the effectiveness of prevention efforts can be assessed over time. This has provided an excellent opportunity for local capacity building, with 11 casual Community Researchers being employed to date to undertake data collection.



Olivia Joseph (Community Researcher) conducting interviews with community.

Training for the Alert Program®

Piloting the Alert program® in Hedland this year as part of the Therapy and Support component of the project has offered a lot of exciting opportunities for capacity building of local people. Three of our team members (Emma Douglas, Janelle Clifton and Margaret Ramirez) have completed the 20 hour Alert Program® online training course. Janelle has also delivered Alert Program® teacher training and Community Researcher Adrian Clinch also attended. In addition Elaine Clifton has been employed as a local Community Researcher.

Hedland FASD CRG



THE ROLE OF THE CRG

The Hedland FASD Community Reference Group (Hedland FASD CRG) has been established with Aboriginal representatives from the local community to provide advice on the research project aimed at reducing Fetal Alcohol Spectrum Disorder (FASD) within Hedland and surrounding communities. This project is being driven by the community and aims to make FASD history in the Pilbara.

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 2016

- 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



Key Responsibilities of the CRG

- Provide advice to the Hedland FASD Network, research team and Wirraka Maya Health Service Aboriginal Corporation
- Talk to the community about the Hedland FASD project

Actively support

- Events promoting the FASD project
- Bush meetings, women's and men's gatherings to promote FASD awareness
- Aboriginal community research recruitment

Actively encourage and assist

- Policy development around Alcohol restrictions and legislation
- Activities to increase community-wide FASD promotion and prevention around FASD



Rebecca Samulski (BHP Billiton), James and Roz talked with the CRG about priorities at the project launch.

CRG Milestones in 2016

Since March 2016 the group have worked with the research team members, Associate Professor Roz Walker, Sylvia Lockyer and Adrian Clinch (also CRG).

Establishing Terms of Reference: These were endorsed in June 2016.

Naming the Project: The research team worked with the Hedland FASD CRG to decide on the project name 'Warajanga Marnti Warrarnja - Together we walk on country.'

This has been an important step - 'everything is in the name.' Deciding on the right name took several weeks and very wide consultation with all of the local language groups to agree on using **Nyangumarta** language.

It was very important to everyone that the name was able to capture the essence of the project – the notion of Aboriginal families, mothers, fathers, children and communities, and Aboriginal and non-Aboriginal people all working and walking together to find solutions to very complex issues.

The idea of **Walking together on country** was important as **country is the mother**. It is country that people draw their strength and sense of identity and connectedness from - Warajanga Marnti Warrarnja.

Providing input into the video for the launch

Providing input into events including the Community Forum, Carolyn Hartness community workshop, and many others.

Promoting the story of the 1946 strike: By linking this 70th anniversary as a platform for health promotion and community participation and research to strengthen communities and strong culture through revisiting the role of Elders in securing rights.

Assisting the FASD network by supporting collaborative partnerships between various groups to address alcohol and addiction related issues to reorient health and community and disability services in Hedland.

Project Launch:

WARAJANGA MARNTI WARRARNJA TOGETHER WE WALK ON COUNTRY



'Warajanga Marnti Warrarnja - Together we walk on country' is a partnership between the Telethon Kids Institute and BHP Billiton in collaboration with Wirraka Maya Health Service Aboriginal Corporation and the Hedland FASD Network.

Working with the community, the project has the bold goal to make FASD history in the Pilbara and builds upon the successful FASD prevention model in the Kimberley, the Marulu Strategy. The project was officially launched on October 10, 2016 at the Spinifex Hill Studio in South Hedland.

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

The launch of the project was attended by community members, the Hedland Community Reference Group, BHP Billiton representatives, Telethon Kids Institute staff and representatives from local health, education and justice organisations.

CEO of Wirraka Maya Health Service Aboriginal Corporation, June Councillor (pictured above), reflected on the importance of the Hedland FASD project, and shared her dream for the community, "My hope for our kids and our community is that they will grow up strong knowing and believing in themselves and that they will become our future leaders. Wirraka Maya is in a strong position to lead the strategy to achieve these outcomes."

Project lead, Telethon Kids Institute paediatrician Dr James Fitzpatrick, said that FASD represents a community crisis and needs to be addressed urgently. The project will measurably and sustainably improve the health of Aboriginal children in the Pilbara by supporting the development and implementation of a Hedland FASD strategy.

Dr Fitzpatrick acknowledged the incredible investment from BHP Billiton in this project - \$1 million a year for five years - to help communities make FASD history.

Michael Bailey, General Manager Rail for BHP Billiton Iron Ore, highlighted the importance of this project in giving children a better start to life.

"Through our partnership with the Telethon Kids Institute we are hoping to improve a child's quality of life, by reducing the prevalence of FASD and improving the outcomes of children who are diagnosed with FASD."

Head of Aboriginal Health Research at Telethon Kids Institute, Mr Glenn Pearson, said the launch confirms this project as the Institute's flagship in the Pilbara.



Prevention



Adrian Clinch, Beatriz Cuesta-Briand, and Dave Tucker

‘Warajanga Marnti Warrarnja’ Together we walk on country

Much has been achieved by the FASD Prevention Team in 2016 in the areas of data collection, development of health promotion resources, and participation and engagement in community events.

Approximately 700 community surveys were conducted in South Hedland, Port Hedland, Warralong and Yandeyarra to understand knowledge, attitudes, and practice around alcohol use in pregnancy. We have also obtained data to investigate rates of drinking during pregnancy over the last 5 years. Preliminary results are expected early next year.

Another highlight has been the development of FASD health promotion resources in collaboration with the Hedland Community Reference Group and community members. These resources include pamphlets, posters and a project banner. Approximately 750 pamphlets have already been distributed and our resources are now available at many service providers in Hedland.

The Prevention Team has continued to work closely with our Project Partner Wirraka Maya Health Service Aboriginal Corporation. As part of our project’s broad awareness initiatives, we joined forces to hold a community event in South Hedland to mark International FASD Awareness Day on September 9, 2016.

The event was well attended, and community members of all ages had the opportunity to enjoy the sausage sizzle and damper, have a yarn about issues affecting their communities, and engage with service providers.



Community Researcher Adrian Clinch (far right) conducting surveys in Yandeyarra – April 2016.

No Gurry (grog) for Healthy Babies
Having alcohol any time in your pregnancy can hurt your baby

What is FASD?
FETAL ALCOHOL SPECTRUM DISORDER (FASD)
FASD is caused by drinking alcohol during pregnancy. It can affect the development of a baby’s brain and body in different 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

These troubles are sometimes called FASD.

If you would like to know more about the project or get involved:
Email: PilbaraFASD@telethonkids.org.au
Call: Dave Tucker | 0422 440 724
Roz Walker | 0427 011 023

Making FASD History in the Pilbara
The Telethon Kids Institute is working with Wirraka Maya Health Services and BHP Billiton to help make FASD History in the Pilbara:

- Stop kids being born with FASD
- Diagnose kids who might have FASD
- Support kids and families affected by FASD

WARAJANGA MARNTI WARRARNJA TOGETHER WE WALK ON COUNTRY

TELETHON KIDS INSTITUTE | bhpbilliton | WIRRAKA MAYA HEALTH SERVICE

In partnership with the Hedland FASD Network and acknowledging the contribution and guidance of the Hedland FASD Community Reference Group



Philip and Donna Wright (left), and CRG Member Ann Sibosado at the International FASD Awareness Day event.

Therapy and Support



Emma Douglas, Margaret (Sissy) Ramirez, and Janelle Clifton

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.

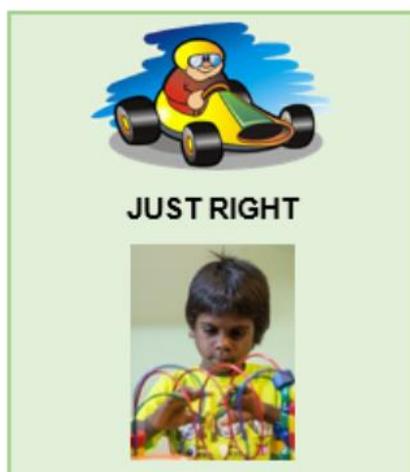
Our team has been working with a local school in Hedland to pilot the Alert Program® in term 4, 2016. With the help of our Community Researcher, Sissy, we have taken the model of the Fitzroy Valley Alert Program® Study and adapted it to be culturally and contextually appropriate for the Pilbara region. The pilot study has allowed us to trial these changes in the local context. The teachers have all been very enthusiastic about the program and have told us the kids love using the sensory tools introduced by the program. The tools are working really well for some students in particular.

In the first few months of 2017 we will be gearing up to implement the Alert Program® with four schools across Hedland and surrounding communities in terms 2 and 3, 2017. We will be applying the lessons learned from the pilot study and continuing to build relationships with schools and stakeholders.

Parent/Carer Support Program

We are also starting to plan for the Parent/Carer Support Program which will be implemented in 2017. The first step is to do some yarning sessions with families who have a child with FASD so we can understand the lived experience, strengths and weaknesses of these families.

Key aims of the Parent/Carer Support Program are to reduce problem behaviours in children, increase caregivers' overall wellbeing and reduce caregiver stress. The yarning sessions with families will help us understand their needs and therefore help us offer a program that is tailored to meet these needs.



FASD Model of Care



Angela Dudley



A FASD model of care has been identified as important in providing best practice care and services within health, education and justice systems for a person with FASD or neurodevelopmental delays.

The Model of Care for FASD in the Pilbara established the documentation of referral pathways for diagnosis of FASD and other neurodevelopmental disorders. The process involved extensive consultation with key stakeholders and health professionals. Consequently, a series of visual maps for the health, education and justice systems were developed. The visual 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 visual maps have been presented to the Hedland FASD Network with feedback invited and received from service providers and stakeholders.

This model of care will 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.

Diagnosis

Throughout 2016, multidisciplinary diagnostic clinics were conducted by PATCHES Paediatrics in the Pilbara. The PATCHES team, which includes a paediatrician, neuro/clinical psychologist, speech therapist, occupational therapist and clinic coordinator delivered these clinics in Hedland (which also included referrals from Roebourne and Karratha).

A number of child development – related diagnoses were reached as a result of the clinics, with education and therapy a focus for families, carers and teachers. Ongoing robust partnerships with local agencies including local schools, WA Country Health Services and Hedland Health Campus were integral to the success of these clinics. Our collaborative working relationship ensured the best possible pre-clinic preparation, meaning that families/carers received feedback and recommendations on the clinic day.



WHAT'S HAPPENING IN THE KIMBERLEY

Therapy and Support

Bree Wagner and Sue Cherel



The Alert Program®

This year has been a big one for the Alert Program® team! Building upon the success of a pilot study undertaken in 2015, study coordinator, Bree Wagner and lead community researcher, Sue Cherel worked together to start a two year project to train school staff across nine Fitzroy Valley communities to deliver the Alert Program® to primary school students.

To find out if the program helps students in the Fitzroy Valley manage their alertness levels and improve skills like concentration, short term memory and planning, we are inviting parents/caregivers, teachers, and students to answer questions about children's learning and behaviour before and after they participate in the program. Students are also being invited to play computer games to find out if the program has helped their learning and behaviour. So far parents/caregivers have given permission for 217 students across seven Fitzroy Valley schools to be involved in the research project. It is hoped an additional 70 students will receive permission to be involved in 2017.

Capacity building

The Alert Program® team has expanded this year to include 10 new community researchers - Kerry Anne Hobbs, Francine Jack, Cynthia Cox, Maria Cox, Lurlene Dawson, Janice Moora, Jennifer Jacky, Tamika Shaw, Rebecca Smith and Danielle Munday. These women have been integral to the

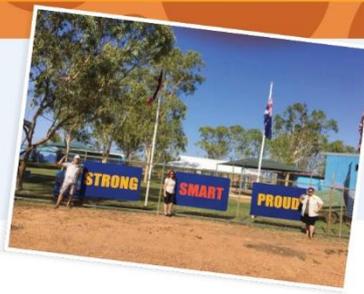
success of the project to date, by introducing families to researchers and ensuring researchers work in culturally and linguistically appropriate ways. Funding has been awarded from the 100 Women Foundation to provide training to community researchers in Certificate II in Community Services through North Regional TAFE in 2017. Also joining our team this year were research assistants Tracy McRae, Emma Douglas and Anika Collison. A large group of volunteers and students from across Australia have supported our field trips too.

A workshop is planned for early 2017 to upskill Kimberley Education Regional Office (KERO) staff to become Alert Program® leaders and to develop a method for sustaining the Alert Program® in schools after the research has finished. We are thankful to Edie Wright, Jo Fox and Greg Robson from KERO for their ongoing support and guidance with this endeavour.

As we end this this year our sincere thanks for involvement in the project is extended to the families, students and school staff from Wangkatjungka, Djugerari, Ngalapita, Bayulu, Yakanarra, Yungngora and Yiyili schools. We are also grateful for support and guidance provided by our chief investigators, Kimberley/Pilbara FASD team members, CEO of Nindilingarri Cultural Health Service Maureen Carter, WA Country Health Service occupational therapist Kristen Campbell, Alert Program® developers/staff Mary Sue Williams, Sherry Shellenberger and Molly McEwen, and Marulu FASD and Early Life Trauma Strategy Coordinator Sue Thomas.



Diagnosis



PATCHES Paediatrics delivered multidisciplinary diagnostic clinics in the Kimberley in February, July, August and November this year with expanded clinical activity in Derby, Broome and East Kimberley to assess clients in Kununurra/Halls Creek. The ages of the children assessed ranged from 4 to 11 years old with family and carer involvement playing a pivotal role in ensuring the clinics were a positive experience for children.

Early community liaison enabled clinics to be conducted at local schools which provided a familiar setting for the children and families/carers. Delivering clinics at local schools also provided an opportunity for teachers to receive post-clinic feedback.

Local efforts from dedicated teachers, staff, the WA Country Health Services teams in Kununurra (Allied Health and Paediatric and Child Health Nurse teams), Broome Regional Aboriginal Medical Service (BRAMS), Kununurra Medical Centre, Ord Valley Aboriginal Health Services and Derby Aboriginal Health Service (DAHS) were vital in ensuring the clinics were successful. The PATCHES Paediatrics team also provided a professional development opportunity for local East Kimberley agencies in November. Positive feedback was received from attendees at this therapy-focused workshop, with overwhelming interest for future training opportunities.



Marulu Prevention Project Update



Martyn Symons and Kaashifah Bruce

In 2016 the Prevention team continued to analyse and share the 2015 prevention survey results with Fitzroy Valley community members and local partner organisations. The survey conducted with over 400 men and women across 20 communities aimed to understand community members' knowledge, attitudes, and practices around FASD and drinking in pregnancy.

In May and September 2016, Kaashifah Bruce and Martyn Symons visited the Fitzroy Valley to hold presentations at health organisations, community meetings, and a cultural camp. Community feedback reports and flash drives with electronic health promotion videos and documents were distributed to support local services with their

continued FASD prevention and awareness activities. The results have been very encouraging with most people reporting that 'no alcohol in pregnancy is the safest option.'

A highlight for the team in 2016 was our attendance at the Fitzroy Valley FASD Awareness Day (September 9) community event to celebrate community members, local organisations and researchers coming together and walking together to make FASD history. The 'Strong Spirit Strong Future' campaign including television advertisements and promotional posters were also run in September to coincide with FASD Awareness Day. This campaign is a collaborative initiative between the WA Mental Health Commission, Telethon Kids Institute and McCusker Centre for Action on Alcohol and Youth.

The next steps for the project will be to write up and share more of the results including those about rates of drinking in pregnancy. The team is also working with Paul Bell from Feral Films to produce promotional videos to share important stories about FASD and the work undertaken to address this problem. We look forward to sharing this with everyone in mid-2017 when the project will officially wrap up.

We thank the many communities, key stakeholders and partner organisations (including Nindilingarri Cultural Health Services) involved with FASD prevention for their ongoing support. Wising everyone a happy and safe holiday period!





PROJECT TEAM UPDATES

Team achievements in 2016

2016 has been a very successful 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

- Pilbara model of care for FASD: Visual maps for the Health, Education and Justice System developed by Angela Dudley in partnership with the Pilbara FASD Strategy team, Hedland FASD Network, WA Country Health Service, and Wirraka Maya Health Service Aboriginal Corporation.
- Protocol documenting the Model of Care process for FASD in the Pilbara.
- *No Gurry for Healthy Babies* suite of resources developed in partnership with members of the Community Reference Group and community members in Hedland, Yandeyarra and Warralong.

Awards

- June Oscar AO received the 2016 Desmond Tutu Reconciliation Fellowship award.
- June Oscar AO awarded the 2017 WA Local Hero award for her commitment to lobbying for alcohol restrictions in the Fitzroy Valley.
- James Fitzpatrick named as a finalist in the WA Australian of the Year awards for his work to reduce alcohol related harm in babies.
- Associate Professor Roz Walker awarded a lifetime achievement award by the Public Health Association WA branch recognising her significant contribution to community empowerment and development, research and policy translation and public health to improve Aboriginal maternal health and child development outcomes in WA over the last 30 years.
- Bree Wagner awarded the Aboriginal Health Award by the Public Health Association WA branch. The award celebrates the achievement of a public health professional that has made a significant contribution to Aboriginal communities in WA.
- Bree Wagner winner of the Kudos Early – Mid Career Research Excellence Award by Telethon Kids Institute.
- Bree Wagner winner of the Kudos People Excellence Award 'Engage and Inspire' by Telethon Kids Institute.
- Margaret Ramirez winner of the Kudos People Excellence Award 'Community Spirit' by Telethon Kids Institute.
- David Tucker presented with a Certificate of Appreciation by the Department of Local Government and Communities for his 'contribution to the wellbeing of children, families and communities through supporting the delivery of Aboriginal Early Years – Best Start Port Hedland.'

Grants

- James Fitzpatrick received an NHMRC Career Development Fellowship: Implementing and evaluating pragmatic strategies to prevent Prenatal Alcohol Exposure (PAE), and treat Fetal Alcohol Spectrum Disorders (FASD).
- James Fitzpatrick received a state government New Independent Researcher Infrastructure Support (NIRIS) award.

- Roz Walker and Tracy Reibel in partnership with Rural Health West received a Commonwealth Tackling Indigenous Smoking Award to develop an innovative woman centered approach to Aboriginal women's smoking in pregnancy in Hedland and the Western Desert communities. This project will directly complement the work with midwives and community care workers in reducing alcohol in pregnancy.
- James Fitzpatrick received a Supporting Research Leaders grant through Telethon Kids Institute to expand the Make FASD History Strategy to other sites.
- Bree Wagner received a grant from 100 Women to provide training in Certificate II Community Services for Aboriginal community researchers in the Fitzroy Valley.

Reports & Publications

- James Fitzpatrick invited to author a chapter on FASD in the National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people (3rd edition).
- A paper authored by Bree Wagner & colleagues was published by the *Australian Occupational Therapy Journal*: The development of a culturally appropriate school based intervention for Australian Aboriginal children living in remote communities: A formative evaluation of the Alert Program® intervention. *Aust Occup Ther J*. doi:10.1111/1440-1630.12352.
- Bree Wagner's article on Consumer and Community Participation in Fetal Alcohol Spectrum Disorder (FASD) Intervention Research was featured on the WA Council of Social Services: Early Years Network website.
- Report by David Tucker: Making FASD History in the Pilbara – Service provision and FASD in Port Hedland: An environmental scan.
- Report by David Tucker, Roz Walker, and Kristen White: Making FASD History in the Pilbara – Consultation Report: Community and Stakeholder consultations 2015.
- Report by David Tucker, Kaashifah Bruce, and James Fitzpatrick. Making FASD History in the Pilbara – knowledge, attitudes and practices related to FASD and levels of self-reported alcohol consumption during pregnancy: A baseline investigation in Port Hedland, Yandeyarra and Warralong.
- Report by Kaashifah Bruce and colleagues: Making FASD History: Fetal Alcohol Spectrum Disorder Prevention Strategy Report 2015-2016.
- Report by Kaashifah Bruce and colleagues: Making FASD History: Marulu Fetal Alcohol Spectrum Disorders Prevention Strategy. 2015 Annual Report to Western Australian Government Department of Aboriginal Affairs. Telethon Kids Institute, January 2016.
- Annual Report to BHP Billiton: Pilbara FASD Research Project, June 2016.
- Roz Walker was a senior author on five published papers which have direct relevance to complex issues surrounding FASD prevention including effective engagement and support for women and their families and the importance of qualitative methodologies in Aboriginal research contexts.
 - Reibel, T., Wyndow, P., & Walker, R. (2016). From Consultation to Application: Practical solutions for improving maternal and neonatal outcomes for adolescent Aboriginal mothers at a local level. *Healthcare*, 2016 (4). (In press).
 - Fairthorne, J., Walker, R., de Klerk, N., & Shepherd, C. (2016). Early mortality from external causes in Aboriginal mothers: a retrospective cohort study. *BMC Public Health*, 2016 16:461.
 - Dudgeon, P., Scrine, C., Cox., A., & Walker, R. (2016). Facilitating empowerment and self-determination through participatory action research: Findings from the National Empowerment Project. *International Journal of Qualitative Methods* (In press).
 - Munns, A., Watts, R., Hegney, D., & Walker, R. (2016). Effectiveness and experiences of families and support workers participating in peer led parenting support programs delivered as home visiting programs: A comprehensive systematic review. *The Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports*.

Presentations

- Roz Walker invited to present *Sampling and Recruitment: Getting it right in qualitative research in Aboriginal contexts* at the Qualitative Health Research for Aboriginal and Torres Strait Islander Peoples Forum, Telethon Kids Institute.
- Roz Walker invited to present *Building capabilities in doing research in the Kimberley* at the Kimberley Child and Family Health Forum in Broome, September, 2016.
- Roz Walker invited to present *An Overview of Pilbara Research Projects and Partnerships*, Pilbara Aboriginal Health Planning Forum Karratha WA. 23 March 2016.
- Emma Douglas, Janelle Clifton & Margaret Ramirez presented their work on the Alert Program at the Telethon Kids Institute, Scientific Retreat 2016.
- Kaashifah Bruce, Martyn Symons, Adrian Clinch & David Tucker presented their work on preventing FASD in the Kimberley and Pilbara at the Telethon Kids Institute, Scientific Retreat 2016.
- Martyn Symons presented a framework for mapping influences on alcohol consumption during pregnancy and also introduced us to machine learning at the Telethon Kids Institute, Scientific Retreat 2016.
- Roz Walker and Beatriz Cuesta-Briand presented *Making FASD History in the Pilbara*, Pilbara for Purpose Forum Newman, November 2016.
- Roz Walker presented *Making FASD History in the Pilbara* to the Marwarnkarra Aboriginal Health Service Board, Roebourne, November 2016.
- Roz Walker presented *An overview of Making FASD History in the Pilbara* to the FASD Network, Wirraka Maya Wellbeing Centre, Hedland, 23 May 2016.
- Roz Walker presented on the *FASD Research Strategy* in Hedland to the Hedland Community Forum, Ibis Hotel, Port Hedland, 6 May 2016.



In partnership
with the Hedland
FASD network
and community
reference groups

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**KIMBERLEY
MARULU
FASD
STRATEGY**



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



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