



## VIEWPOINT

## There's hope in the valley

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**Abstract:** Aboriginal women in the remote Fitzroy Valley region in Western Australia's Kimberley were concerned about high rates of alcohol use in pregnancy and its possible impact on child development. They successfully lobbied for restricted access to alcohol in 2007. In 2009 they developed a strategy for the diagnosis and prevention of Fetal Alcohol Spectrum Disorders (FASD) and the support of parents and carers of affected children. Aboriginal organisations then partnered with research and clinical groups from Sydney to conduct a FASD prevalence study. This commenced in 2010 following extensive community consultation and receipt of community consent. Data from this study are still being collected and will be used by the community to advocate for improved services and new models of health care. Prevention of FASD is important to optimise health and development for future generations of Aboriginal children and to ensure the transfer of culture and language from one generation to the next.

**Key words:** Aboriginal, alcohol, fetal alcohol spectrum disorders, pregnancy.

In the remote Fitzroy Valley in the Kimberley region of Western Australia, Aboriginal women have led the way in developing a strategy to deal with Fetal Alcohol Spectrum Disorders (FASD) – the legacy of alcohol use in pregnancy. They have now formed a partnership with clinicians and researchers from the Discipline of Paediatrics and Child Health at the University of Sydney and the George Institute for Global Health to address the diagnosis, management and prevention of FASD and to provide support for parents and carers of affected children.

At the centre of the Fitzroy Valley lies Fitzroy Crossing town, some 400 km east of Broome and surrounded by more than 40 small communities located up to 190 km from town. The valley is home to just over 4000 people, predominantly Aboriginals belonging to five language groups (Bunuba, Walmajarri/Wangkatjungka, Nyikina and Goonandi) with strong connections to their land. The region is renowned for its gorges, ancient

reefs, boab trees, strong culture and vivid art. The community has been praised for the innovative governance structure they have developed to enable self-determination in prioritising and addressing issues of concern for Aboriginal people.<sup>1</sup>

In 2007, the communities of the Fitzroy Valley were in turmoil: alcohol misuse was widespread and contributed to alcohol-related deaths and suicides, violence and crime. Under the strong leadership of women such as June Oscar and Emily Carter, the Aboriginal communities successfully lobbied the WA liquor licencing board for restrictions on the sale of full-strength take-away alcohol. The benefits have been well documented.<sup>2</sup> The story of the alcohol restrictions was told in the film 'Yajilarra' (produced by Jane Latimer and directed by Melanie Hogan)<sup>3</sup> which was received with acclaim by audiences throughout Australia and internationally, including at the United Nations, in the Australian Federal parliament and at the Governor General's residence in Australia.

At a Women's Bush Meeting in 2008, the women of the Fitzroy Valley communities identified the need to address Fetal Alcohol Spectrum Disorders (FASD) – the legacy of alcohol use in pregnancy. They were particularly concerned about the effect that alcohol has on the transfer of culture – stories, art and ceremony – from one generation to the next. In October 2008, a FASD leadership team was convened, and in November 2008, they embraced a 'circle of friends' – partners in government, business and community organisations – and developed a strategy to address FASD (Fig. 1). The strategy, called Marulu, includes diagnosis and prevention of FASD, community education and support for parents and carers of affected children. Marulu is a Bunuba word meaning 'precious, worth nurturing'. A short film, Marulu, highlights the importance of FASD as an issue for the community.<sup>4</sup>

## Key Points

- 1 Alcohol use in pregnancy is common worldwide, may cause Fetal Alcohol Spectrum Disorders (FASD), and should be avoided.
- 2 The Liliwan project will provide the first population-based data on FASD prevalence in Australia.
- 3 Aboriginal women from the remote Fitzroy Valley in Western Australia have developed a strategy to address prevention and management of FASD which may be applicable to other settings.

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Accepted for publication 1 December 2011.

In 2009, Indigenous leaders in the Fitzroy Valley invited a group of clinicians and researchers with whom they had an established relationship to collaborate to progress their FASD strategy. A partnership was formalised between Nindilingarri Cultural Health Services (Maureen Carter, CEO) and Marninwarntikura Women's Resource Centre (June Oscar, CEO) in Fitzroy Crossing, The University of Sydney Medical School (Professor Elizabeth Elliott and Dr James Fitzpatrick) and The George Institute for Global Health (Associate Professor Jane Latimer) (Fig. 1 & 2). Following a community consultation,<sup>5</sup> the group agreed to conduct the first Australian study of FASD prevalence. They called the study the Lililwan Project. Lililwan is a Kimberley Kriol (Aboriginal English) word meaning 'all the little ones'. Dr James Fitzpatrick is a Chief Investigator on this project; the project is the subject of his PhD work.

Stage 1 of the project (2009–2011), which was funded by the Yajilarra trust, included development and use of a medical history checklist to obtain information about antenatal exposures, early life trauma, health and development from parents and carers of all children born in 2002 or 2003 (Fig. 3). Stage 2 (currently underway) involves multidisciplinary assessment of the health and

development of these children and is funded by the Commonwealth Departments of Health and Ageing and Families, Housing, Community Services and Indigenous Affairs, Save the Children and the Foundation for Alcohol Research and Education. Pro bono support is being provided by Blake Dawson Solicitors, M&C Saatchi and the Australian Human Rights Commission.

Alcohol consumption is common among Australian women, including women of childbearing age. Alcohol is teratogenic and its use in pregnancy may result in miscarriage, stillbirth, prematurity, small for gestational age babies, birth defects and FASD (a group of lifelong disorders including Fetal Alcohol Syndrome and Alcohol-Related Neurodevelopmental Disorders).<sup>6,7</sup> The project will enable us to estimate the prevalence of FASD and other health problems and to develop individual treatment plans for affected children. The project includes community education, support for parents and carers and advice for teachers. It provides opportunities for capacity building in the community, including training and employment of local Aboriginal



**Fig. 1** James Fitzpatrick. (photo E. Elliott)



**Fig. 2** The four women representing the collaborators in the Lililwan project (left to right): Elizabeth Elliott (University of Sydney), Maureen Carter (Nindilingarri Cultural Health Services in Fitzroy Crossing), June Oscar (Marninwarntikura Women's Resource Centre), Jane Latimer (The George Institute for Global Health). (photo C. Constantine)



**Fig. 3** One of the campsites during the study. (photo E. Elliott)



**Fig. 4** Three sisters – healthy, happy children in the Fitzroy Valley (photo by E. Elliott).

people. The unique data derived from the project will enable the community to advocate for improved health, community and education services.

The project demonstrates the importance of Aboriginal-led research. Australia's Aboriginal and Torres Strait Islander Social Justice Commissioner, Mick Gooda, described the project as 'a genuine partnership – one where research is done with the community and not just about the community', saying it is 'setting an example to the rest of Australia' being a process 'guided by a relationship underpinned by meaningful, respectful engagement and collaboration' (Fig. 4).<sup>1,5</sup>

As James Fitzpatrick so eloquently states in his winning poem, there is now 'Hope in the Valley'.

#### Hope in the Valley

**James Fitzpatrick, winner, Derby Bush Poetry Competition, 2011**

There's hope in the Valley, it flows slow and deep  
a river of life floods the plains  
It softens the tears that the grandmothers weep  
like a desert refreshed by the rains  
There's pride in the Valley, those women stood strong  
to stop that damned river of booze  
While businessmen, countrymen swore they were wrong,  
but the women had too much to lose  
See the children were damaged before they were born  
the alcohol poisons the brain  
The grandmothers grew them up, tired and forlorn  
while the parents went drinking again  
Now the river of grog is a trickle out there  
and the young people hunt through the skies  
For the spirits of old men with wild untamed hair  
and that wise, patient gleam in their eyes  
There's hope in the Valley, it flows deep and slow

like culture – where life finds its themes  
The river of hope has a long way to go  
but it's flowing, and so are their dreams.

#### Listen to the podcast of James reading his poem at:

A morning of laughs and strong messages at the Derby Bush Poets breakfast. <http://www.abc.net.au/rural/content/2011/s3254001.htm>

**Watch Marulu, a free 5-min DVD about the Lililwan project at:** [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60884-2/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60884-2/fulltext)

## Acknowledgements

We acknowledge philanthropic support from a generous Australian Family and funding from the National Health and Medical Research Council (NHMRC), Department of Health and Ageing; the Department of Families, Housing, Community and Indigenous Affairs; Save the Children Australia; and The Foundation for Alcohol Research and Education. *Pro bono* support has been provided from the Australian Human Rights Commission; M&C Saatchi and Blake Dawson Solicitors. Elizabeth Elliott is supported by an NHMRC Practitioner Fellowship (457084) and Jane Latimer is supported by an ARC Future Fellowship (FT0991861).

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