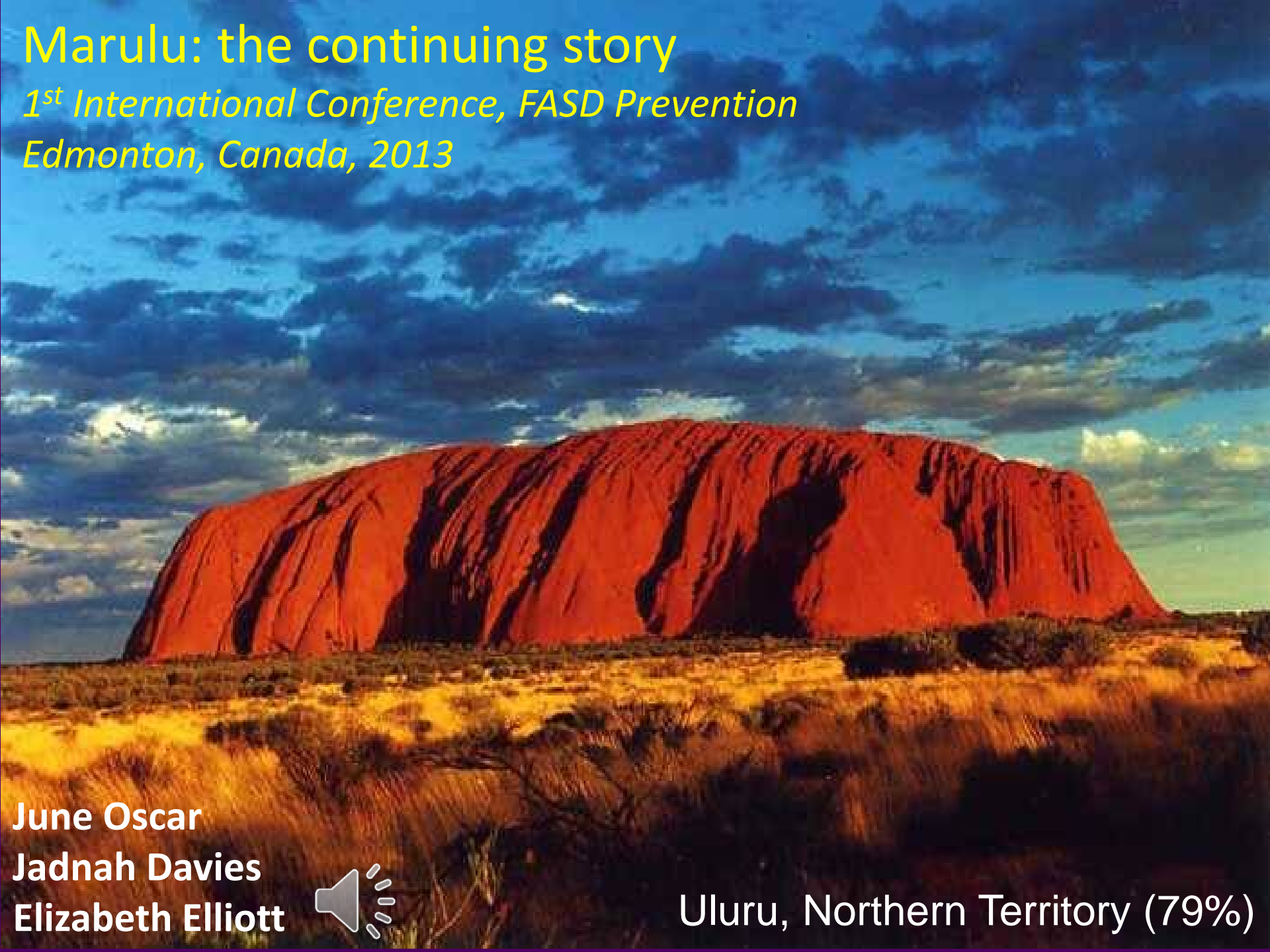


Marulu: the continuing story

1st International Conference, FASD Prevention

Edmonton, Canada, 2013



June Oscar
Jadnah Davies
Elizabeth Elliott



Uluru, Northern Territory (79%)



Initiatives

- 2007:
 - Alcohol restrictions
- 2008:
 - Marulu strategy
- 2009-13:
 - Lililwan project
 - FASD prevalence

A community in crisis

2006: Alcohol-induced

- Domestic Violence
- Injuries
- Car accidents
- Illness
- Over 50 deaths including 13 suicides
 - “Enough is enough”
 - WA liquor licensing board

“Yajilarra” – to dream (2008)



YAJILARRA

To Dream: Aboriginal women leading change in remote Australia

Marrthawarrtkura Women's
Resource Centre presents a
Reverb film by Melanie Hogan

Music
David Page
Sound Design
Sam Petty
Cinematography
Carolyn Constantine

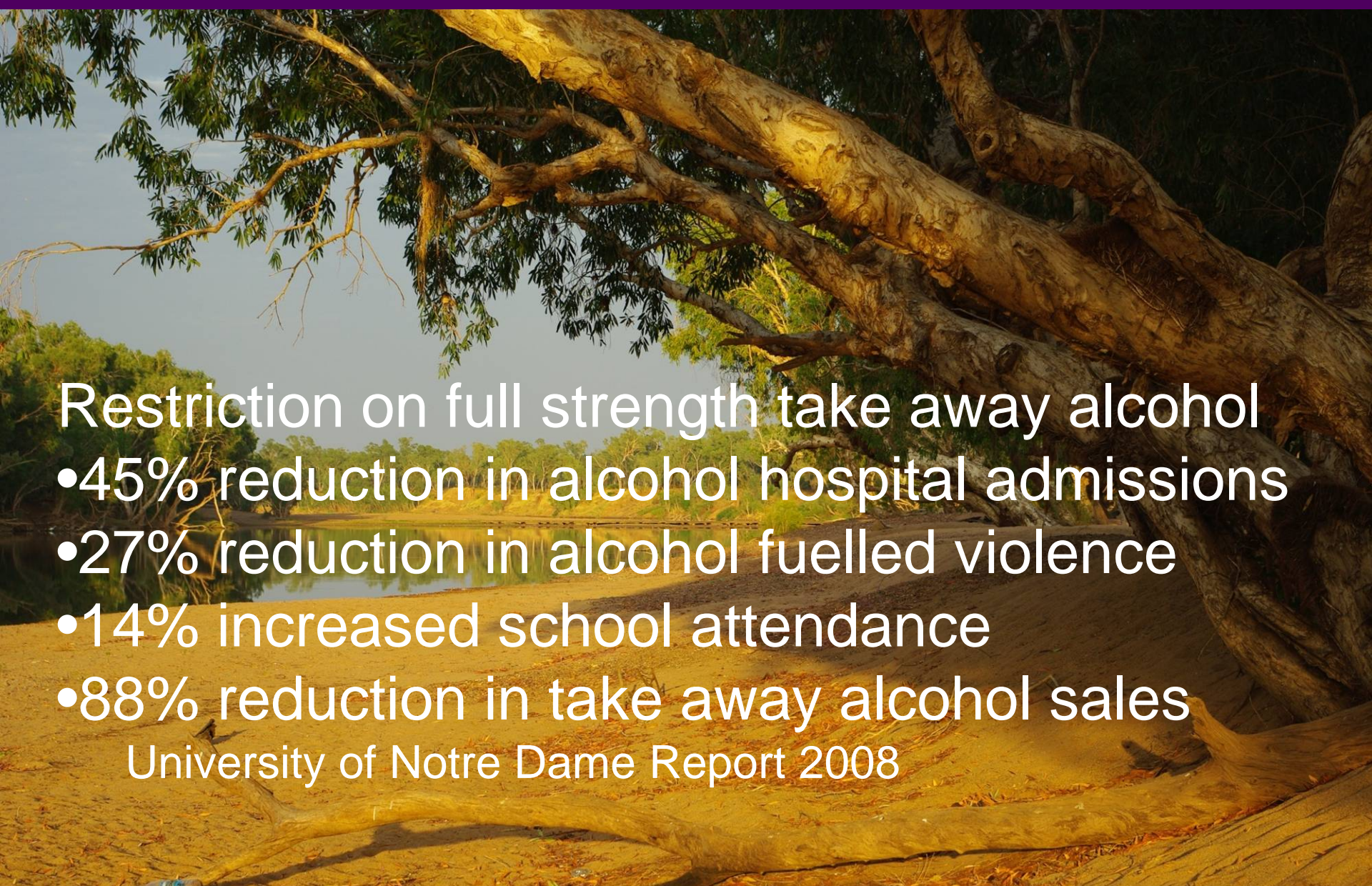
A film sponsored by a generous
Australian Family, the Rita Hogan
Foundation and Oasi Dawson

Hangman
June Oscar
Producers
Jane Lattimer, Melanie Hogan
Directed and Edited
by Melanie Hogan

Image by Oasi Dawson



Fitzroy Valley Alcohol Restrictions (2007)

- 
- Restriction on full strength take away alcohol
 - 45% reduction in alcohol hospital admissions
 - 27% reduction in alcohol fuelled violence
 - 14% increased school attendance
 - 88% reduction in take away alcohol sales

University of Notre Dame Report 2008



“FASD is a tragedy that somehow transcends other aspects of grief and trauma. Here is innocent young life; the future of our people and all that goes with it – our culture, our language, knowledge about the magic creation and laws of our country – being born into this world with brains and nervous systems that are so impaired that life for that person from birth to death is cruelly diminished.”

June Oscar, Address to Parliament

Marulu: Strategy to address FASD



Three themes: DIAGNOSE, SUPPORT, PREVENT (2008)

A partnership: Marulu and The Lililwan Project



- Nindilingarri Cultural Health-Fitzroy Crossing.
- Marninwarntikura Fitzroy Women's Resource Centre- Fitzroy Crossing.
- The University of Sydney
- The George Institute for Global Health.





TRISTAN

Tristan tells the story of a 12-year old boy born with one of the Fetal Alcohol Spectrum Disorders – the result of exposure to alcohol during pregnancy. The film is both confronting and courageous in its ability to transport the viewer to north-west Australia to experience the hopes, dreams and challenges facing Tristan. It has been produced as part of the Liliwan Project, a research collaboration between Marninwarntikura Women's Resource Centre and Nindilingarri Cultural Health Services in Fitzroy Crossing; The George Institute for Global Health and Sydney Medical School at The University of Sydney. The collaboration recognises the courage of Tristan and his family in sharing their story.

Marninwarntikura Women's Resource Centre and Nindilingarri Cultural Health Services present a film by Melanie Hogan

Directed and Edited by [Melanie Hogan](#)
Producers [Jane Latimer](#), [Melanie Hogan](#)
Narration [Tristan McCarthy](#)
Cinematography [Carolyn Constantine](#)
Sound Design [Sam Petty](#)
Music David Page, Ranahl Skeen, Troy Laurel, Leah Flanigan, Stephen Pigram, Patrick Davies

Funding for Tristan was provided by the Yajilarra Trust; the Foundation for Alcohol Research and Education; and Ashurst Australia (formerly known as Blake Dawson Lawyers) with advice from The Australian Human Rights Commission.

TRISTAN

HOPES, DREAMS AND CHALLENGES
OF A YOUNG BOY LIVING WITH FASD



TRISTAN

HOPES, DREAMS AND CHALLENGES OF A YOUNG BOY LIVING WITH FASD



Images by E Elliott and C Constantine

Yajilarra

The Lililwan Project

‘Lililwan’ is a Kimberley Kriol word
meaning ‘all the little ones’

The Lililwan Project (2009)

- First population-based study of FASD prevalence
- Fitzroy Valley
- 4,500 mainly Aboriginal
- 45 discrete communities
- 5 language groups
- Community consultation

Lililwan is a Kimberley Kriol word meaning 'all the little ones'



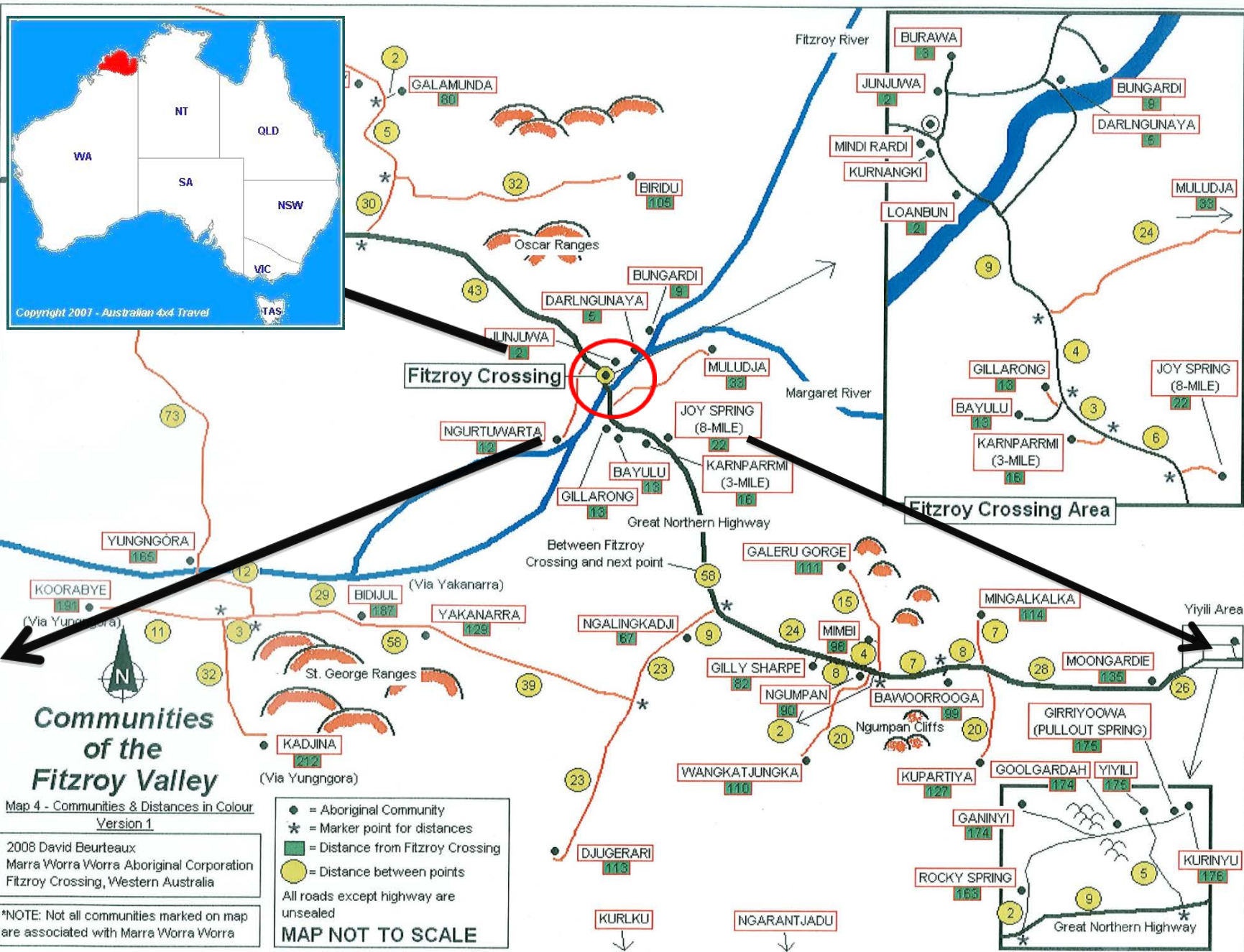
The Investigators



James Fitzpatrick



Elizabeth, Maureen, June, Jane







The Lililwan Project

The first population-based study of FASD prevalence in Australia

Stage 1 (2010)

**Identified all children born in
2002 or 2003 living in the Fitzroy
Valley**

**Conducted interviews with
parents/carers**



95% participation rate

Stage 2 (2011)

**Interdisciplinary assessment and
development of individual
management plans**



97% participation rate



Train, equip 'Community Navigators'

Methods

- Developed and administered questionnaire
 - 114 items, 40 mins
 - Demographics
 - antenatal exposures
 - alcohol
 - living conditions
 - early life trauma
 - Neonatal, health outcomes



Dr James Fitzpatrick; a carer; community navigator Emily Carter

Assessing Alcohol intake

- Type
- Volume
- Timing
- Frequency
- Number of drinks on 'typical' occasion
- Estimated standard drink (10g alcohol) per occasion
- Occasions of >6 drinks
- **Audit-C to score 'risk'**

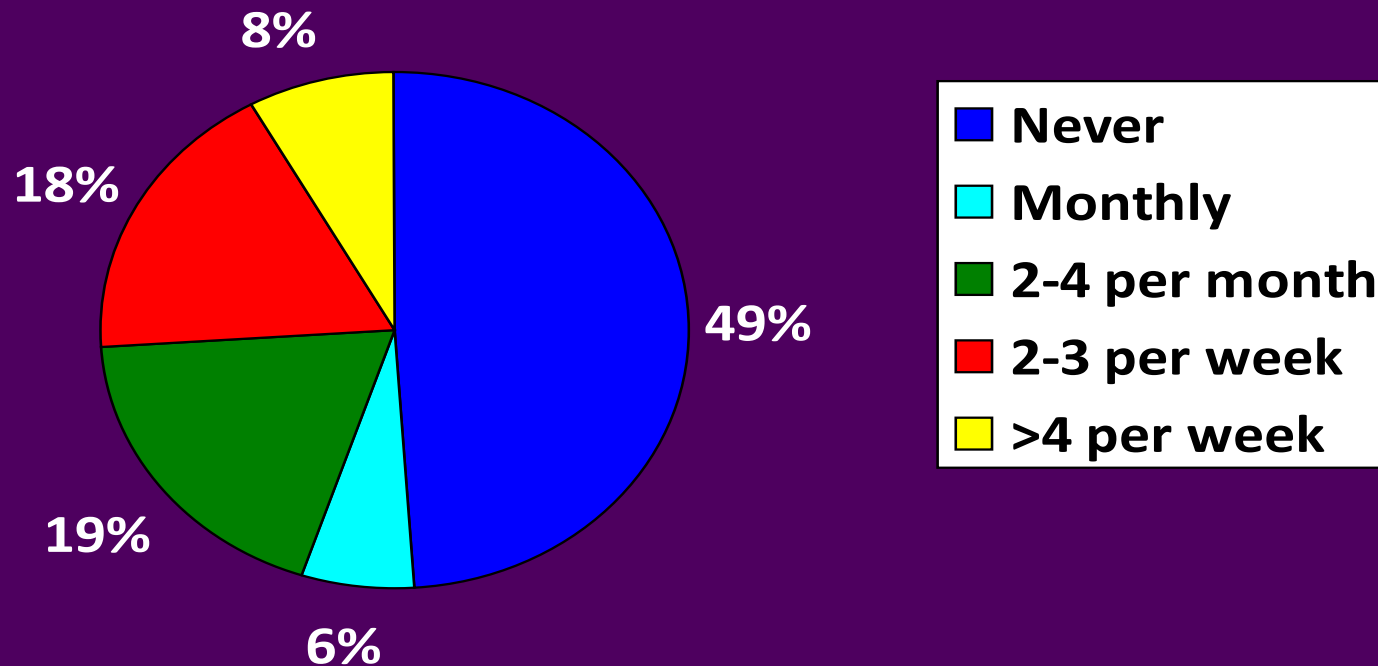
Type of grog



Size of grog



Frequency of alcohol use in pregnancy

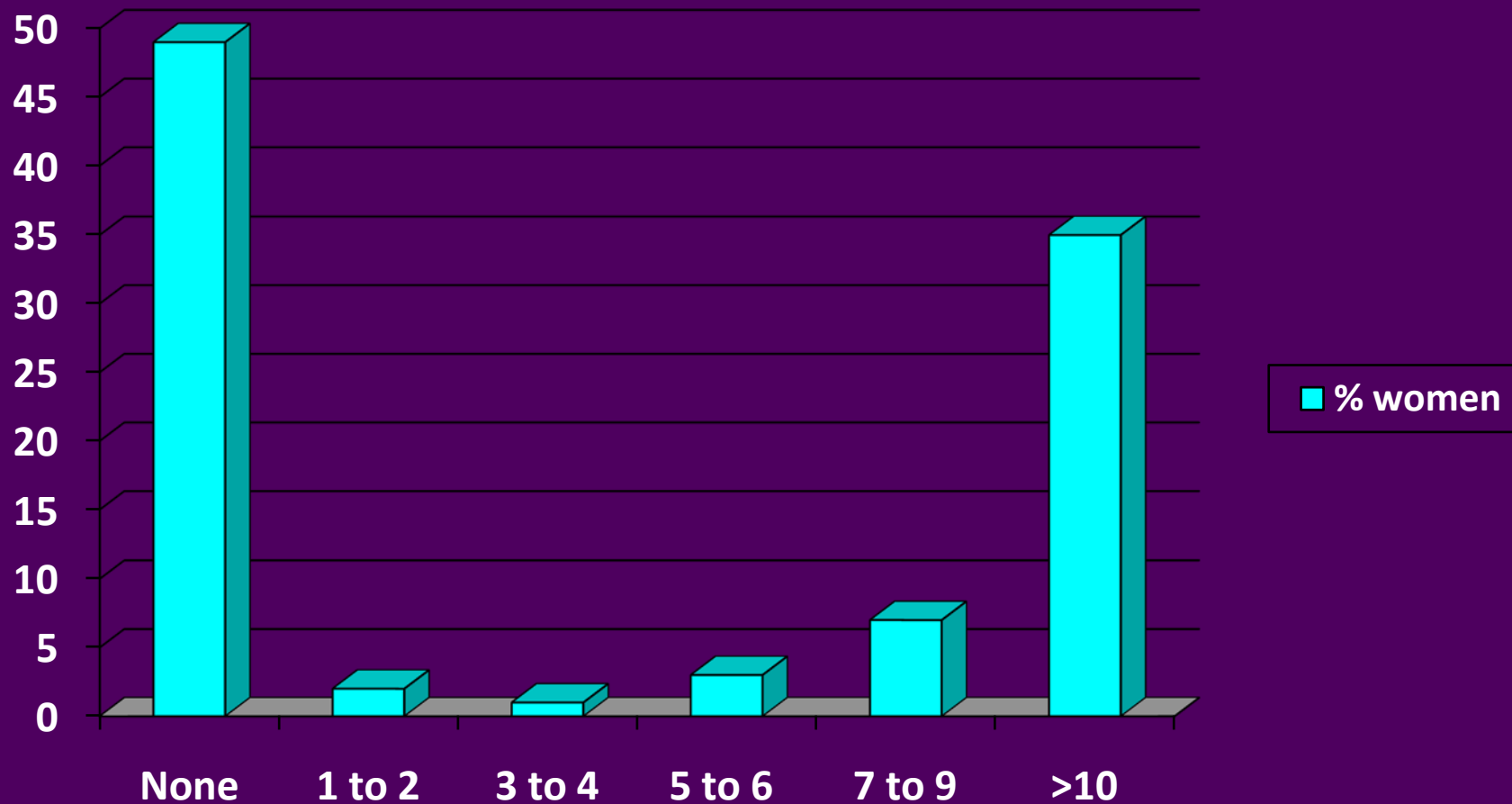


68% drank in 3 months prior to pregnancy

51% mothers drank alcohol during pregnancy

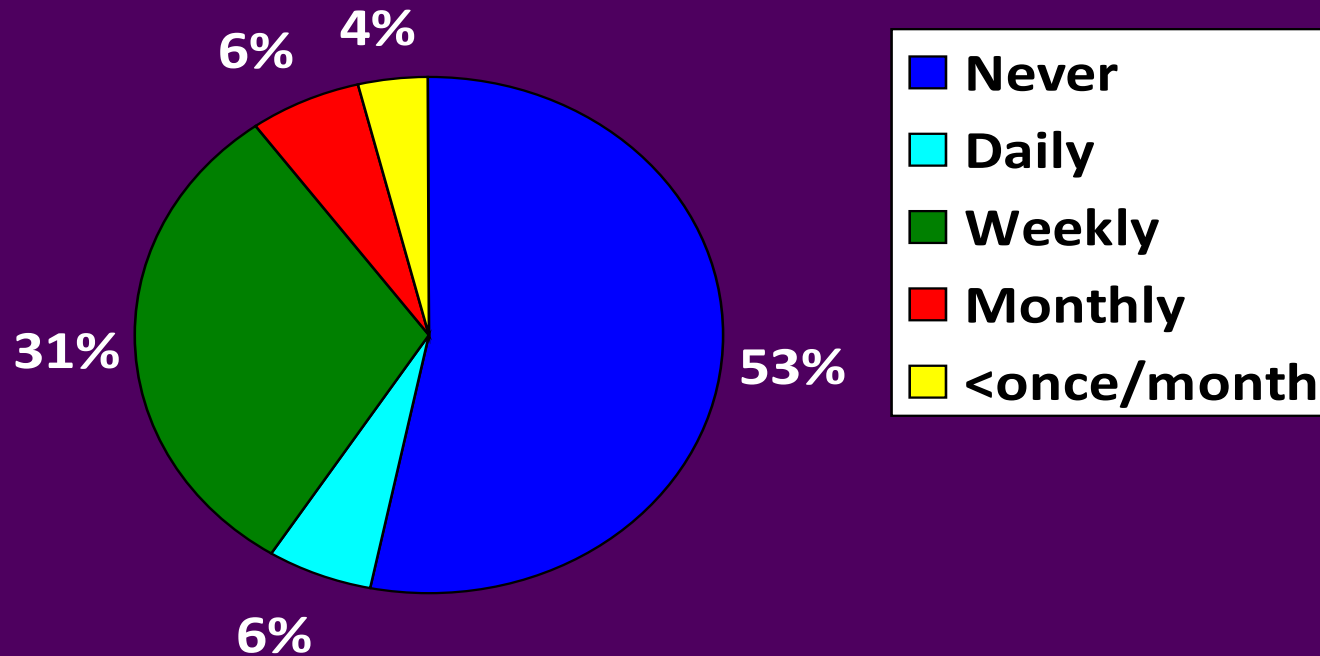
24% of mothers drank in all three trimesters

Standard drinks (10g) on 'typical' day

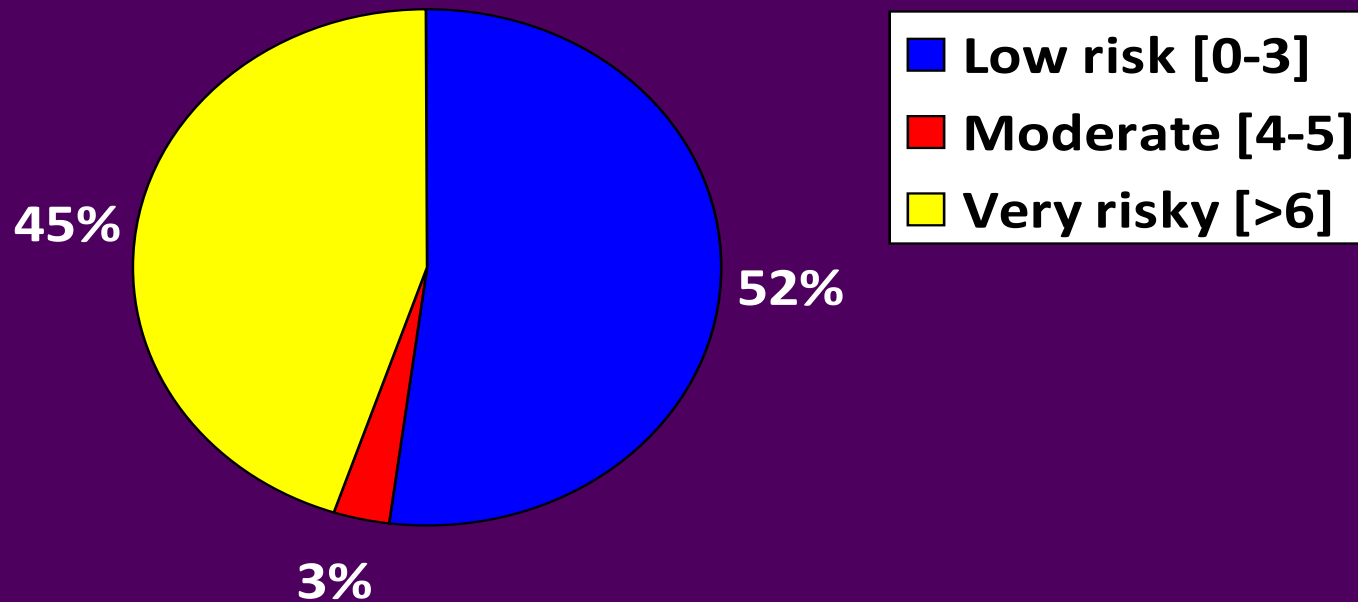


35% >10 SD on a typical day

Frequency of intake >6 drinks per day



Audit-C score



93% women who drink do so at 'very risky' levels

The Lililwan Project

The first population-based study of FASD prevalence in Australia

Stage 1 (2010)

**Identified all children born in
2002 or 2003 living in the Fitzroy
Valley
Conducted interviews with
parents/carers**



95% participation rate

Stage 2 (2011)

**Interdisciplinary assessment and
development of individual
management plans**



97% participation rate

Stage 2. Interdisciplinary assessment (3 days)



Results

- Behaviour
- Learning
- Health
- Mental health
- 401 health referrals in 108 children
- CAMS
- ENT/Audiology
- Remedial Education
- Urgent service need





This research is "a genuine partnership - one where research is done with the community and not just about the community," that it is "guided by a relationship underpinned by meaningful, respectful engagement and collaboration."



***Mr Mick Gooda, ATSI Social Justice Commissioner
Australian Human Rights Commission***

Why I became involved ..

My interest into Fetal Alcohol Spectrum Disorders began when I started to learn about the disturbing consequences of drinking alcohol while pregnant.

The lack of support for the families and those affected saddened me. I felt we wanted to be a part in the prevention of more children being born with FASD.

I see it in my peers and families.

I also felt that my community did not know enough about the effects of drinking when pregnant and its consequences to the unborn child.

Building my knowledge about FASD as Youth..

Building my knowledge through:

- Research
- Talking to local networks
- Preparing and testing presentations
- Attending meetings and forums on FASD
- Identifying specific issues regarding FASD i.e. teen pregnancy, over coming shame, addressing myths & truths
- Developing resources on FASD to suit local context to engage our target audiences.

Our target groups & making connections..

- **Youth between the ages of 10-24**
 - **Ante Natal groups**
 - **School groups**
 - **Language groups**
 - **Girls groups**
 - **Sporting groups**
 - **Early Childhood Learning groups**

My goals..

- Ensure more youth are aware of FASD in our community.
- Establishing a Youth focussed FASD network across the Fitzroy Valley.
- Highlight needs of young individuals and families living with FASD.
- Babies being born without FASD.
- Community members encouraging & promoting our messages.
- More people aware & accepting the current reality about FASD in our community.

Thank You and I look forward to your feedback..

Contact Details:

Ph: 08 9191 5284


Fax: 08 9191 5611

**PO Box 43 Fitzroy Crossing WA
6765**

E: jadnah.davies@hotmail.com

**I welcome any
suggestions and
resources
available to help
me with my Youth
Focussed
Prevention
Strategy.**





**June Oscar
Jadnah Davies
Elizabeth Elliott**

Photograph
Courtesy of the
Bunuba people