ALCOHOL & PREGNANCY & FASD
RESEARCH PROGRAM
Our goal is to improve the health and wellbeing of children through excellence in research

Our research aims to:

* prevent alcohol use in pregnancy and its effects on child health
* decrease the incidence of Fetal Alcohol Spectrum Disorders (FASD)
* improve FASD diagnostic capacity
* improve management of children and young people with a FASD through effective interventions

To achieve this we will work with children, their families & communities and build on partnerships with government & non-government organisations, policy makers, service providers, politicians, educators, researchers, and international organisations

For information on alcohol and pregnancy and FASD, our research, publications and resources visit our website http://alcoholpregnancy.telethonkids.org.au/

You can contact us on email fasd@telethonkids.org.au or by phone +61 8 9489 7724
ALCOHOL & PREGNANCY

5 out of 10 pregnancies are unplanned

47% of Australian women consumed alcohol while pregnant, before knowing they were pregnant

There is a strong association between binge drinking and unplanned pregnancy

Alcohol can cross the placenta so the baby is exposed to the same level of alcohol as the mother and the effects can last longer

Alcohol can alter the normal development of the growing baby, including the brain and other organs

There is no safe amount or safe time to drink alcohol during pregnancy which is why we recommend ....

FOR WOMEN WHO ARE PREGNANT OR PLANNING A PREGNANCY OR BREASTFEEDING .......... NOT DRINKING IS THE SAFEST OPTION
FETAL ALCOHOL SPECTRUM DISORDERS

Australian FASD Diagnostic Instrument – diagnostic subcategories:
* FASD with three sentinel facial features (similar to the previous diagnostic category of Fetal Alcohol Syndrome)
* FASD with less than three sentinel facial features (encompasses the previous diagnostic categories of Partial Fetal Alcohol Syndrome and Neurodevelopmental Disorder – Alcohol Exposed)

The effects are lifelong and may not be seen at birth

- Brain damage
- Birth defects
- Delayed development
- Learning problems
- Poor growth
- Social & behavioural problems

This can lead to:
* difficulty planning, setting goals, being on time and managing money
* problems at school
* multiple foster care placements
* depression and reduced self-esteem
* inappropriate sexual behaviour (victim & perpetrator)
* problems with alcohol and other drugs
* inability to live independently
* unemployment
* poverty
* trouble with the law
OUR JOURNEY
<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002 - 2004</td>
<td>Survey of WA health professionals’ knowledge, attitudes &amp; practice in relation to alcohol use in pregnancy and FASD</td>
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<tr>
<td>2006 - 2008</td>
<td>Resources health professionals developed and evaluated: Booklet, Fact Sheet, Wallet card to be given to pregnant women</td>
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<td>2009 - 2016</td>
<td>Studies looking at outcomes of children of mothers with alcohol related diagnoses - health, education, birth defects, disabilities, mental health, justice</td>
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<td>2010 - 2012</td>
<td>Collaboration with the WA Department of Health on the development of the WA FASD Model of Care</td>
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<td>2010 - 2016</td>
<td>FASD Diagnostic Instrument: Development and implementation of FASD diagnostic instrument for Australia, Development of on-line training for health professionals</td>
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<tr>
<td>2011 - 2013</td>
<td>Evaluation of FASD information &amp; services for parents and carers</td>
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<tr>
<td>1995 - 1997</td>
<td>Survey of WA women about alcohol use in pregnancy</td>
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<td>2002 - 2004</td>
<td>Collaboration with WA Drug &amp; Alcohol Office on prevention messages for Aboriginal &amp; non-Aboriginal populations</td>
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<td>2006 - 2008</td>
<td>Liliwan Project Fitzroy Valley</td>
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<tr>
<td>2009 - 2015</td>
<td>Alcohol &amp; pregnancy &amp; FASD: Midwives’ knowledge, attitudes &amp; practice</td>
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<tr>
<td>2013 - 2015</td>
<td>Development of resources &amp; training for midwives</td>
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<tr>
<td>2011 - 2015</td>
<td>FASD Prevention Strategies Kimberley &amp; Pilbara: Prevention strategies, Diagnostic clinics and training, Evaluation of multi-disciplinary team assessments, Therapy and management – Alert Program*</td>
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<tr>
<td>2015 - 2016</td>
<td>Knowledge of breastfeeding &amp; alcohol guidelines by health professionals &amp; mothers</td>
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**Prevention**
- APSU: Australian Paediatric Surveillance Unit
- FAS: Fetal Alcohol Syndrome
- FASD: Fetal Alcohol Spectrum Disorders
- NDIS: National Disability Insurance Scheme
- WARDA: Western Australian Register of Developmental Anomalies

**Diagnosis**
- FASD in the NDIS – development of best practice guidelines
- FASD and Justice: FASD knowledge, attitudes & practice in the WA justice system, Development of FASD resources for justice professionals, FASD in juvenile justice – diagnosis & workforce development

**Management/Therapy**
- 2014 - 2016: FASD in the NDIS – development of best practice guidelines
- 2015 - 2016: Knowledge of breastfeeding & alcohol guidelines by health professionals & mothers
IMPACT
Identified emerging data on the prevalence of Fetal Alcohol Syndrome (FAS) and have continued to monitor the prevalence of Fetal Alcohol Spectrum Disorders (FASD) through the WA Register of Developmental Anomalies; diagnostic clinics in the Kimberley and Perth; and Banksia Juvenile Detention Centre.

Developed and currently implementing a diagnostic instrument for FASD in Australia.

Identified the FASD knowledge, attitudes and practice of WA health professionals and developed three resources based on their needs.

Collaborated with other researchers and organisations to develop prevention messages for alcohol use in pregnancy.

Identified the FASD information and services available for parents and carers and based on the priorities identified by carers organised face to face workshops on managing children and young people with FASD.

Increased community awareness and knowledge about FASD and its impacts.
8. Measured and reported on the prevalence of neurodevelopmental impairment and FASD in remote WA communities.

9. Developing and implementing strategies to increase the proportion of women abstaining from alcohol while pregnant in the Fitzroy Valley.

10. Learned from Aboriginal communities on collaborative approaches to research.

11. Identified the Alcohol & Pregnancy & FASD knowledge, attitudes and practice of midwives and are currently developing resources for midwives to ask, assess and provide brief interventions for pregnant women.

12. Building health practitioners’ awareness of guidelines and resources about drinking alcohol for breastfeeding mums.

13. Through the use of record linkage identified new evidence about the outcomes for children of mothers with alcohol related diagnosis.
Identified the FASD knowledge, attitudes and practice of WA justice professionals and translated the outcomes into the first FASD educational resources for justice professionals in Australia.

Established a FASD Clinical Network to build a statewide approach and ensure broad consultation and linkages with clinical sites/teams across WA, with government departments and legal organisations.

Built positive working relationships with advocacy groups; parents & carers; consumers and community organisations; State and Commonwealth government departments such as health, drug & alcohol, justice, corrective services, child protection & family support, Aboriginal Affairs, education, disability services; and individual professionals across these many sectors.

Working with communities and schools to implement a program to improve self-regulation and executive functioning skills of primary school aged children in the Fitzroy Valley.

Established multi-disciplinary diagnostic clinics and helped change service delivery in the Kimberley.

Bringing together families, health workers and schools to support children with FASD and provide them with a solid start to life.