



ST JOHN OF GOD

Raphael Services

Driving Change: pregnancy, parenting, alcohol and other drugs conference

Welcome



ST JOHN OF GOD

Raphael Services

Developing a FASD Hub for Australia

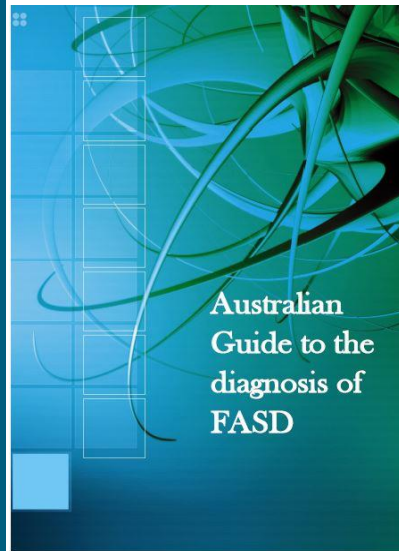
Narelle Mullan

Manager, FASD Research Australia Centre of Research Excellence

Telethon Kids Institute



FASD
Information
for
everyone



FASD Hub Australia



- Identified as a priority by the National FASD Technical Network
 - Funded by the Australian Government Department of Health
 - Developed by an alliance of organisations in 2017
 - Ongoing development in 2018
 - Advisory Group of individuals with significant experience and expertise has been established to provide leadership and strategic direction – health professionals, representatives from justice and education sectors, parents and carers, government
-

FASD Hub Australia - development



- Face to face meetings with parents and carers
 - Telephone interviews with parents & carers, health professionals, researchers, government and policy makers
 - Informed development of key user journeys, functional design and content
 - Content developed by the Project Team with advice from a Working Group and key stakeholders
-

FASD Hub Australia - evaluation

Online survey

- Most responders to the online survey were health professionals (54%) and parents/carers (33%)
 - site was easy or very easy to use
 - met their needs very well or extremely well
 - was trustworthy and evidence-based
 - Participants provided positive feedback and suggestions for additional content
-

Information for?

- Health professionals
 - Educators
 - Justice professionals
 - Researchers
 - Service providers
 - Parents & carers
 - Policy makers
-

What can I find on the website?

FASD Hub Australia

Find information on Fetal Alcohol Spectrum Disorder (FASD) for Australian health professionals, teachers, justice professionals, service providers, researchers or parents and carers.

Watch video: FASD in Australia ▶



<https://www.fasdhub.org.au/>

Understanding FASD

- What is FASD?
- Living with FASD
- Brain impairment
- Common tips and difficulties
- Common myths
- Videos



<https://www.fasdhub.org.au/fasd-information/understanding-fasd/>

Challenges and Hopes

- Watch here: <https://www.youtube.com/watch?v=-4SENPA-qQo>



Assessment & Diagnosis

- Australian Guide to the diagnosis of FASD
- Diagnostic categories and criteria
- Assessing maternal alcohol use
- Assessing neurodevelopmental impairment
- Assessing facial features & growth
- Formulating the diagnosis
- Developing a management plan
- Reporting a diagnosis
- Benefits of a diagnosis



<https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/>

FASD – diagnostic definition in Australia



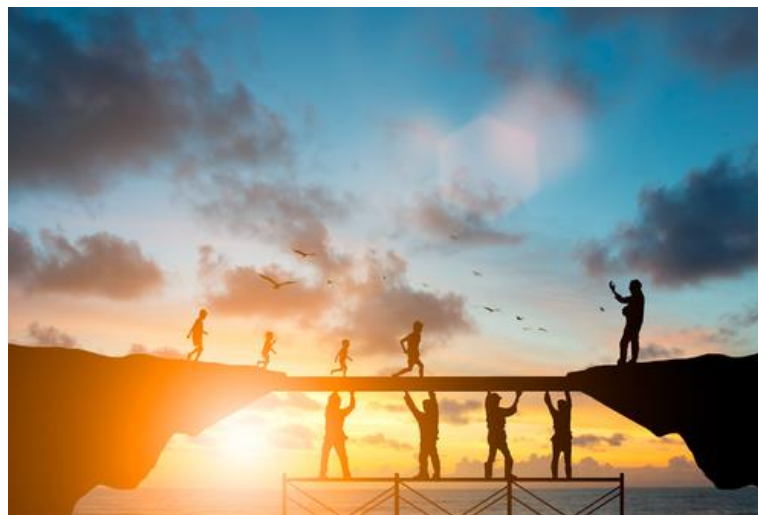
Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term for severe neurodevelopmental impairments that result from brain damage caused by alcohol exposure before birth

The Australian Guide to the diagnosis of FASD refers to FASD as a diagnostic term with two diagnostic sub-categories:

- FASD with three sentinel facial features
 - FASD with less than three sentinel facial features
-

Managing FASD

- Principles of management and successful interventions
- What health professionals can do
- What parents & carers can do
- What teachers can do
- What justice professionals can do
- What service providers can do



<https://www.fasdhub.org.au/fasd-information/managing-fasd/>

Preventing FASD

- Australian Guidelines to reduce health risks from drinking alcohol
- Prevention overview
- Prevention strategies



<https://www.fasdhub.org.au/fasd-information/preventing-fasd/>

Services Directory

- Find health professionals and services with FASD experience and expertise



<https://www.fasdhub.org.au/services/>

Training & Support

- Web based education and training
- Face to face education and training
- Links to Australian FASD Support Groups



Research, Resources & Publications

- Australian research projects
- Resources
- Australian publications



<https://www.fasdhub.org.au/>

FASD Hub – ongoing development



Suggestions for new content has come from the evaluation

To assist the project team review & update current content and develop new content a Subject Matter Expert Panel (SMEP) has been established

The SMEP members will bring a range of experience and expertise including:

- lived experience of having FASD or caring for a person with FASD
 - health and other professionals, researchers in the field of alcohol and pregnancy and FASD and policy makers
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FASD Hub contact details

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Coming soon:



FASD Research Australia

Centre of Research Excellence

Supported by:



Funded by:



FASD Research Australia aims to contribute to the sustainable empowerment of communities, organisations and professionals to address FASD, and reduce its compounding impact on children, their families and the wider community.

Information on:

- Who is part of the team
- Committees
- Community involvement
- Research activities

For more information about FASD Research Australia contact the Program Manager Narelle Mullan

fasdaustralia@telethonkids.org.au

<https://www.fasdhub.org.au/research-and-publications/fasd-research-australia/>



For information on registrations and speakers visit the website <http://fasdconference.com>

Registration (early bird registrations close 31 August)

- Standard
- Person living with FASD/Parent/Carer
- Student
- Daily registrations will also be available

Keynote Speakers

- Professor Svetlana Popova – research focuses on epidemiology, economic costs, prevention & intervention strategies
- Professor Michael Kobor – Department of Medical Genetics at the University of British Columbia
- Ms Claire Gyde – Chairperson of New Zealand's national FASD support group
- Professor Elizabeth Elliott – Consultant Paediatrician and Professor of Paediatrics at the University of Sydney

A workshop focussing on assessment & diagnosis of FASD will be held prior to the conference – register your interest in attending this workshop by emailing fasdaustralia@telethonkids.org.au

