



Alcohol and Pregnancy & FASD Research Team







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Alcohol and Pregnancy & FASD Research

At **Telethon Kids Institute** we are committed to improving the health of children and young people through research that makes a real difference.

The **Alcohol and Pregnancy & FASD Research Team** is conducting research in collaboration with partners across Western Australia.

We have built, and will continue to develop a **state**, **national and international reputation as a high-quality research team** that delivers improvements in outcomes and is highly responsive to community and stakeholder needs.

Our goals are to:



Our Team

Team members include academic and community researchers, clinicians, and project/program managers

We added 11 new team members in 2016







Our partners & collaborators

Consumer and community representatives 20 Community organisations Aboriginal communities Commonwealth & State Government departments Philanthropic & corporate sponsors 16 Universities and research institutes Other funders (grants)

Alcohol in Australia



We celebrate many events in our lives with alcohol

Women of all ages drink alcohol











Fewer
Aboriginal
women drink
alcohol than
non-Aboriginal
women

Women from all sectors of Australian society drink alcohol

20% of Australian women continue to drink alcohol after finding out they are pregnant



That's 2 in every 10 women

What are the risks of drinking alcohol during pregnancy?

Prenatal alcohol exposure can result in Fetal Alcohol Spectrum Disorder (FASD) which is characterised by severe impairment in many aspects of a child or young person's life. This can include their ability to learn and remember things; how to interact with others that may result in poor social skills and behaviour problems; poor impulse control and understanding the consequences of their actions. Without diagnosis and early support for the young person with FASD and their family the lifelong disability can result in poor educational outcomes and employment opportunities, mental health and substance use problems and engagement with the justice system.

ALL WOMEN WANT TO
HAVE A HEALTHY AND
CONTENTED BABY
WHO DEVELOPS INTO A
HAPPY AND SUCCESSUL
CHILD AND YOUNG
PERSON





What are we doing to help?

The Alcohol and Pregnancy & FASD Research Team is working to:



Raise community awareness of the risks of drinking alcohol during pregnancy



Reduce the number of pregnant women drinking alcohol during pregnancy and while breastfeeding



Increase knowledge of health professionals of guidelines in relation to alcohol consumption during pregnancy and while breastfeeding



Increase awareness and use of the Australian Guide to the diagnosis of FASD



Improve clinical practice and diagnosis of FASD



Increase awareness of a young person's cognitive strengths and difficulties as early as possible in their interactions with the justice system



Increase sustainable workforce development programs for health, justice, child protection, education, disability and other service providers



Change policies and practices relating to alcohol guidelines, labelling and other licensing

Highlights for 2016

Launch of the
Hedland FASD
Project
'Warajanga Marnti
Warrarnja –
Together We Walk
On Country'

Completion of the Australian Guide to the diagnosis of FASD & e-Learning modules

Australian
Guide to the
diagnosis of
FASD

TELETHON KIDS INSTITUTE

Creating a collaborative circle of care



cilitator Training Program

Carolyn
Hartness
Healthway
Visiting Fellow
in Perth, Pilbara
& Kimberley

Wellness Centre Hedland May, 2016 FASD Research
Australia Centre
for Research
Excellence
established

Rates of drinking alcohol during pregnancy in the Fitzroy Valley (Kimberley) have been reduced from 70% to 20%

International collaboration on FASD Prevention that will impact 500,000 people across 3 countries commenced

Highlights for 2016



Raising awareness of not drinking alcohol during pregnancy with Telethon Kids Institute staff



- Section 1

Telethon
weekend and
Discover Day –
fun taking 3D
facial images

Science Week,



Visit from Dr James Reynolds, Kids Brain Health Network in Canada – seminars with all Telethon Kids Institute staff and meetings with our Team

Our projects

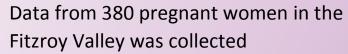
Our research projects encompass the following four key areas related to FASD. Some projects may fall within several areas, for example the 'Management of youth with FASD in the justice system' falls within 3 areas – diagnosis, management and FASD and justice.



Read about each project on pages 10 – 18



3M FASD Prevention Strategy: Marulu, Mass Media and Midwives





Rates of drinking alcohol during pregnancy have been reduced from 70% to 20%



403 surveys completed by people from 20 communities in the Fitzroy Valley



Knowledge that drinking alcohol during pregnancy can harm the baby has increased to 97%



8 community researchers worked with the research team



Community members participated in activities on FASD Awareness Day



Read more about this project and watch our videos or contact Kaashifah Bruce



Midwives and Women Audit C Intervention (part of 3M project)



Group discussions and individual interviews with women with current or recent experience of maternity care

Group discussions and individual interviews with midwives working in a variety of roles in a public hospital



Developed a learning package for midwives that includes:

- 4 self-directed learning modules about FASD, understanding & using AUDIT-C, brief interventions and breastfeeding and alcohol
- printable handy prompt guide for using the Women-held pregnancy record AUDIT-C screening tool and brief intervention in maternity care
- links to additional resources and online education

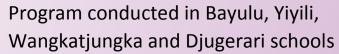


Re

Read more about this project or contact <u>Tracy Reibel</u>



Alert Program®





Alert Program® has been adapted to honour the cultural and contextual uniqueness of Fitzroy Valley



Parents and school staff completed questionnaires about the children in the program



All members of the project team completed 4 wheel drive and first aid training



Project Coordinator Bree Wagner recipient of Telethon Kids Institute Kudos Award

Read more about this project or contact Bree Wagner



Hedland FASD Project

Warajanga Marnti Warrarnja – Together we walk on country



Conducted 297 surveys with people in Hedland, Warralang and Yandeyarra about their knowledge of alcohol use during pregnancy and FASD

Conducted 405 surveys after the prevention strategies were introduced into the community



Launch of the project in October 2016
Community Reference Group formed with 12 representatives



Pilot of the Alert Program® conducted with 57 children across three classrooms



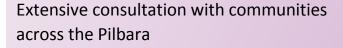
Sissy Ramirez recipient of Telethon Kids Institute Kudos Award

Read more about this project, check out the resources and watch our videos or contact Kaashifah Bruce



P

Pilbara FASD Project



Focus groups with community people in Newman, Jigalong and Parnngurr

Carolyn Hartness, Healthway Visiting Fellow, presented at workshops in Newman and Roebourne

Research Team shared information about the project and identified people who were interested in being part of the project

3 Community Reference Groups formed to work with the research team

Met with key stakeholders to identify activities and strategies

Presented to the Pilbara Aboriginal Health Planning Forum

Commenced surveying people in the Pilbara to find out what they know about alcohol and pregnancy and FASD

Held a planning day for all researchers based in Perth and the Pilbara

Read more about this project or contact Kaashifah Bruce















More than 100 sentenced young people participated in a multidisciplinary asessment



Preliminary data shows between 30%-40% of young people assessed in the study have FASD



Read the media release and watch the video



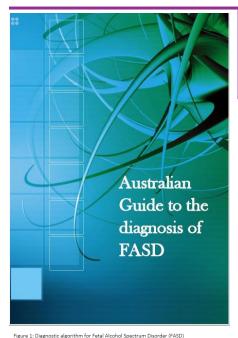
Knowing more about the neurodevelopmental impairments of these young people and their strengths and difficulties can facilitate change



Working with custodial staff developing training resources with the aim of better supporting young people in detention with FASD and other neurodevelopmental impairments



Read more about this project or contact Noni Walker



Prenatal alcohol exposure (PAE) Confirmed absent Neurodevelopmental criteria Met* (c) domains severely impaired) Confirmed absent Neurodevelopmental criteria Met* (c) domains severely impaired) Confirmed absent Neurodevelopmental criteria Met* (c) domains severely impaired) Confirmed absent Confirmed absent

FETAL ALCOHOL SPECTRUM DISORDER					
	Diagnostic categories				
Diagnostic criteria	FASD with 3 Sentinel Facial Features	FASD with < 3 Sentinel Facial Features			
Prenatal alcohol exposure	Confirmed or unknown	Confirmed			
Neurodevelopmental domains Brain structure/Neurology Motor skills Cognition Language Academic Achievement Memory Attention Executive Function, including impulse control and hyperactivity Affect Regulation Adaptive Behaviour, Social Skills or Social Communication	Severe impairment in at least 3 neurodevelopmental domains	Severe impairment in at least 3 neurodevelopmental domains			
Sentinel facial features - Short palpebral fissure - Smooth philtrum - Thin upper lip	Presence of 3 sentinel facial features	Presence of 0, 1 or 2 sentinel facial features			

FASD Diagnostic Instrument Pilot and Implementation

Australian Guide to the diagnosis of FASD published

Read the Guide

FASD diagnostic categories

- FASD with 3 sentinel facial features
- FASD with less than 3 sentinel facial features

Online e-Learning modules to accompany the Guide available

Log onto the modules

The availability of the Guide and online training modules will provide:

- foundation to improve rates of diagnoses of FASD in Australia
- promote timeliness and consistency in diagnosis
- help estimate the prevalence of FASD in Australia

Read more about this project or contact Carol Bower











NHMRC alcohol and breastfeeding guidelines, clinician & maternal uptake

Data collected from 240 maternal health professionals about their knowledge of the National Health and Medical Research Council Guideline

'For women who are breastfeeding, not drinking is the safest option'

Read about the evidence and the Guideline

Child Health Nurses, Midwives and GPs used this new knowledge 'sometimes' in their daily practice

Paediatricians and Obstetricians remain to be 'persuaded' of its usefulness and inclusion in their practice

<u>Feedsafe app</u> - Get the right information, so you can make the best choice

Read more about this project or contact Roslyn Giglia























FASD Research Australia Centre for Research Excellence

Two Research Hubs

- Perth
- SydneySupported by 8 organisations

The Centre's Governance Structure was established and three Post-Doctoral Research Fellows appointed

Community Conversations were held in Darwin and Brisbane. Ideas were gathered on how to:

- improve information sharing
- establish an effective National Community Reference Group

Inaugural FASD Research Symposium involving stakeholders from Justice, Education, Disability, Health, Child Protection sectors and NOFASD

Research leaders from across Australia shared their latest research. Future research ideas and advocacy opportunities were shared with the Commonwealth Department of Health

Read more about the CRE or contact Narelle Mullan

Success in 2016

Publications (Alcohol and Pregnancy & FASD Research Team members)

- Lucas BR, Doney R, Latimer J, Watkins RE, Tsang TW, Hawkes G, Fitzpatrick JP, Oscar J, Carter M, Elliott EJ. Impairment of motor skills in children with fetal alcohol spectrum disorders in remote Australia: The Lililwan Project. <u>Drug and Alcohol</u> Review 2016
- Lucas BR, Latimer J, Fitzpatrick JP, Doney R, Watkins RE, Tsang TW, Jirikowic TL, Carmichael Olson H, Oscar J, Carter M, Elliott EJ. Soft neurological signs and prenatal alcohol exposure: A population-based study in remote Australia. <u>Developmental</u> <u>Medicine & Child Neurology March 2016</u>
- 3. **Mutch RC, Jones HM, Bower C, Watkins RE**. Fetal Alcohol Spectrum Disorders: Using knowledge, attitudes and practice of justice professionals to support their educational needs. J Popul Ther Clinical Pharmacol Vol 23 (1) March 2016
- 4. White B, White J, **Giglia R**, Tawia S. Feed Safe: a multidisciplinary partnership approach results in a successful mobile application for breastfeeding mothers. Health Promotion Journal of Australia. 2016; 27(2):111-117.
- 5. **Giglia R**. Alcohol and Breastfeeding, and the Australian Breastfeeding Association. <u>Breastfeeding Review 2016;24:7-11</u>.
- 6. Passmore HM, Giglia R, Watkins RE, Mutch RC, Marriott R, Pestell C, Zubrick SR, Rainsford C, Walker N, Fitzpatrick JP, Freeman J, Kippin N, Safe B, Bower C. Study protocols for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. BMJ Open 2016,6:e012184
- 7. White BK, Martin A, White JA, Burns SK, Maycock BR, **Giglia RC**, Scott JA. Theorybased design and development of a socially connected, gamified mobile app for men about breastfeeding (Milk Man) <u>JMIR Mhealth Uhealth 2016 (Jun 27)</u>; 4(2):381
- 8. Lucas BR, Latimer J, Doney R, **Watkins RE**, Tsang TW, Hawkes G, **Fitzpatrick JP**, Oscar J, Carter M, Elliott EJ. Gross motor performance in children prenatally exposed to alcohol and living in remote Australia. <u>Journal of Paediatrics and Child Health. July 2016 doi:10.111/jpc.132540</u>
- 9. White B, Burns S, **Giglia R,** Scott J. Designing evaluation plans for health promotion mHealth interventions: a case study of the Milk Man mobile app. <u>Health Promotion</u> Journal of Australia. 2016;27(3):198-203.
- 10. Wagner B, Fitzpatrick JP, Symons M, Jirikowic T, Cross D, Latimer J. 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. Australian Occupational Therapy Journal. November 2016
- 11. Doney R, Lucas BR, Jirikowic T, Tsang TW, **Watkins RE**, Sauer K, Howat P, Latimer J, **Fitzpatrick JP**, Oscar J, Carter M, Elliott EJ. Graphomotor skills in children with prenatal alcohol exposure and fetal alcohol spectrum disorder: A population based study in remote Australia. <u>Aust Occup Ther J 2016 Sep 19. Epub 2016 Dec 19</u>
- 12. **Fitzpatrick JP**, Pestell C. Neuropsychological aspects of prevention and intervention for FASD in Australia. <u>Journal of Pediatric Neuropsychology</u>. 2016.

Awards and Prizes

- 1. Hayley Passmore. Best 3 minute presentation. The 10th Annual student Circle Symposium. 12 September 2016
- 2. Bree Wagner. Public Health Association WA Aboriginal Health Award. 24 November 2016
- 3. Roz Walker. Public Health Association WA Lifetime Achievement Award. 24 November 2016
- 4. Banksia Hill study team. Telethon Kids Institute Kudos Award 2016 Collaboration Award
- 5. Jacinta Freeman. Telethon Kids Institute Kudos Award 2016 Engage and Inspire Award
- 6. Bree Wagner. Telethon Kids Institute Kudos Award 2016 EMCR Engage and Inspire Award

External Committees

National

- 1. Bower C, Mutch R. National FASD Network 2014-2017
- 2. Bower C. National Perinatal Epidemiology Statistics Unit Steering Committee for Congenital Anomalies. 2012 2017
- 3. Bower C. Australian Paediatric Surveillance Unit Scientific Review Panel. 2012 2017
- 4. Fitzpatrick J. Australian National Advisory Council on Alcohol and Drugs (expert member) 2014-2017
- 5. Bower C. Reference Group, Australian Indigenous Alcohol and Other Drugs Knowledge Centre 2014 2017

Telethon Kids Institute Committees and Working Groups

- 1. Wagner B. Kimberley/Pilbara Working Group 2016-2017
- 2. Wagner B. Scientific Retreat Planning Committee
- 3. Jones H. Brain and Behaviour Research Focus Area Steering Group
- 4. Jones H. Occupational Health & Safety Committee
- 5. Jones H. Chair Project Managers Forum
- 6. Fitzpatrick J. Research Excellence Council
- 7. Giglia R. Research Excellence Council + Research Culture and Environment Sub-Committee
- 8. Passmore H. Student Leadership Group
- 9. Passmore H. Student Leader
- 10. Passmore H. Student representative on the Research Excellence Council + Culture and Environment Sub-Committee
- 11. Reibel T. Research Excellence Council + Research Culture and Environment Sub-Committee
- 12. Walker R. Research Excellence Council

- 13. Walker R. Student Leadership Group
- 14. Symons M. Research Excellence Council

Active involvement with the external decision making and advisory groups

- 1. Bower C, Mutch R. National FASD Technical Network. 2015-2017
- 2. Jones H. Telethon Kids Institute representative WA Department of Health Child & Youth Health Network Expert Advisory Group 2015-2017
- 3. Giglia R. WA Breastfeeding Stakeholders Group, Department of Health, WA. Child and Adolescent Community Health 2015-2017
- 4. Jones H. WA Department of Health Child & Youth Health Network Youth Policy Working Group 2017
- 5. Fitzpatrick J. WA Primary Health Alliance. Child Mental Health FASD Working Group 2016
- 6. Bower, C. Fitzpatrick J. Department of Health Round Table on FASD Dec 2016.

Invited Presentations

International

- Fitzpatrick JP. Making Fetal Alcohol Spectrum Disorder History in Australia: The art and science of the possible. Department of Paediatrics & Child Health and Department of Public Health seminar, co-hosted by the Society of Youth Health Professionals Aotearoa New Zealand. 29 July 2016
- 2. Bower C, Pestell C. FASD and juvenile justice in Australia. European FASD Conference. London September 2016
- 3. Bower C. Development of FASD resources for justice professionals. European FASD Conference. London September 2016
- 4. Fitzpatrick J. Making FASD History in Australia. European FASD Conference. London September 2016
- Fitzpatrick J. Lililwan Project Neurodevelopmental outcomes in a population-based cohort of children living in remote Australia: The Lililwan Project European FASD Conference. London September 2016

National

- 1. Bower C. AAP&FASD research and implementation of the diagnostic instrument for FASD. RACP Conference Evolve, Educate, Engage, Adelaide Australia, May 2016
- Bower C. Justice Research at Telethon Kids Institute. Reintegration Puzzle
 Conference Disability and Incarceration: Multiple disadvantage and the need for
 individualised support. Geelong, Australia, June 2016
- 3. Jones H. Alcohol, Pregnancy & FASD Research at Telethon Kids Institute. IASSD Conference. Melbourne, Australia, 14-19 August 2016
- 4. Giglia R. Fetal Alcohol Spectrum Disorder. Diseases caused by alcohol conference. Perth. 25-26 August 2016.

- 5. Mutch R. FASD and Justice. IASSD Conference. Melbourne, Australia, 14-19 August 2016
- 6. Fitzpatrick J. Making FASD History in Australia. Neurodevelopment & Behavioural Paediatricians Society of Australia Conference. Perth, Australia. 25-27 August 2016
- 7. Mutch R. What is FASD and how is it diagnosed. Faculty of Forensic Psychiatry. The Royal Australian & New Zealand College of Psychiatrists 2016 Conference. Fremantle. 9 September 2016.
- 8. Mutch R, Freeman J, Kippin N, Safe B, Pestell C. Shields H. FASD & the criminal justice system: A case study presentation. Faculty of Forensic Psychiatry. The Royal Australian & New Zealand College of Psychiatrists 2016 Conference. Fremantle. 9 September 2016.
- 9. Jones H, Passmore H. Building capacity in the justice system. Faculty of Forensic Psychiatry. The Royal Australian & New Zealand College of Psychiatrists 2016 Conference. Fremantle. 9 September 2016.
- 10. Walker N. Banksia Hill FASD & neurodevelopmental impairments project. Australasian Youth Justice Conference. Brisbane. 12-14 September 2016.
- 11. Reibel T. Fetal Alcohol Spectrum Disorder. Australian Institute of Medical Scientists /Australian Academy of Clinical Biochemistry. Perth. 15 October 2016.
- 12. Wagner, B. The Alert Program study. Presented at the Advancing FASD Research Together Research Symposium (FASD Research Australia CRE), 27 October 2016

Workshops/Symposiums where sessions were conducted by members of the AAP&FASD Research Team

- 1. Walker N, Bothma H, Safe B, Hamilton S, Passmore H, Kippin N. Banksia Hill Juvenile Detention Centre Senior Officers Forum. Perth, Western Australia. 28 January 2016 (2 presentations to different audiences)
- 2. Freeman J, Passmore H, Walker N. Early Intervention and Family Support Forum. Perth, Western Australia. 2 March 2016
- 3. Bower C, Mutch R. Youth Justice Reference Group Department of Corrective Servicers. Perth, Western Australia. 8 March 2016
- 4. Wagner B. Alert Program® study school staff training (2 days) Yiyili 1 April + 14 May, Wangkatjungka 26 April + 15 May, Bayulu 1 July + 15 August, Djugerari 25 July + 15 August 2016
- 5. Freeman J, Walker N. Youth Justice Forum. Perth, Western Australia. 4 April 2016
- 6. Jones H. Peel Health Campus. Social Workers Professional Development session. Mandurah, Western Australia. 21 April 2016
- 7. Walker N, Freeman J, Kippin N, Safe B, Taylor J, Passmore H, Hamilton S. Banksia Hill Senior Officers Forum. Banksia Detention Centre. Perth Western Australia. 28 April 2016
- 8. Bower C, Mutch R, Hamilton S. Perspectives on FASD: The Invisible Disability. Women's Health & Family Services. Perth, Western Australia. 10 May 2016
- 9. Jones H, Passmore H. Crime Prevention Officers Workshop, Perth Western Australia, 7 June 2016

- 10. Bower C, Fitzpatrick J, Jones H. Creating a collaborative circle of care. 2 day workshop. Perth Western Australia. 14-15 June 2016
- 11. Giglia R. Women and Newborn Health Service, KEMH. Department of Nursing and Midwifery Education and Research Advances in Antenatal Care Study Day 15 June 2016
- 12. Jones H, Dudley A, Passmore H, Hamilton S. Peel Health Campus. Health Professionals Understanding FASD session. Mandurah, Western Australia. 19 July 2016
- 13. Jones H, Reynolds N. CPFS Foster Carers Workshop. What is FASD and how can you manage children with FASD. 21 July 2016
- 14. Fitzpatrick J. & Pestell C. Fetal Alcohol Spectrum Disorder: New Developments. Neurosciences Unit, Mt Claremont, 24 August 2016.
- 15. Jones H. Drug and Alcohol Youth Services (Mental Health Commission). Understanding FASD. 29 November 2016.
- 16. Jones H, Reynolds N. South West Foster Families Workshop. Understanding children with FASD and cognitive impairment. Boyanup. 2 December 2016

Reports provided for government/industry

- 1. Bower C. Walker N. Hamilton S. Pearson G. Part of the First Peoples Disability Network Australia submission to the Senate Inquiry into the indefinite detention of people with cognitive and psychiatric impairment in Australia. April 2016.
- Wagner B. Consumer & Community Participation in Fetal Alcohol Spectrum Disorder (FASD) Intervention Research. WA Council of Social Services – Early Years Network website
- 3. Mutch R. Walker N. Evidence to the Community Affairs Reference Committee hearing in Perth (Senate Inquiry into the indefinite detention of people with cognitive and psychiatric impairment in Australia). 19 September 2016.
- 4. Fitzpatrick J. Pestell C. NT Royal Commission into Youth in Detention. 7 December 2016.

Team members currently undertaking post graduate research and students on placement from Western Australian universities

PhD candidate

Hayley Passmore (The University of Western Australia)

Masters student

- Bree Wagner (Master of Child Health Research, The University of Western Australia)
- Bernadette Safe (Master of Child Health Research, The University of Western Australia)

Masters student placements with the Alcohol and Pregnancy & FASD Research Team

- Tracy McRae (Master of Public Health, Curtin University)
- Renee Gardner (Master of Dietetics, Curtin University)

Health Promotion student placements with the Alcohol and Pregnancy & FASD Research Team

- Amariah Payet (Curtin University)
- Nikkita Daguio (Curtin University)
- Paula Buffery (Curtin University)

Medical student placement with the Alcohol and Pregnancy & FASD Research Team

- Sophia Connor (The University of Western Australia)
- Sophie Wiegele (The University of Western Australia)
- Ally Hawthorne (The University of Western Australia)
- Vinka Barunga (The University of Western Australia)

Work experience student

• Jesika Sarson (Carine High School Year 10)

Acknowledgements

Thanks to all staff at Telethon Kids Institute who supported and worked with our team in 2016. Special thanks to Claire Fowler who provided outstanding assistance with travel and accommodation arrangements, grant applications and building databases.



The team would also like to thank the many volunteers who worked with our team in 2016. Their contributions greatly enhanced our capacity to undertake our research.



Alert Program®



Improving the management of young people with FASD in the justice system

- Tracy McRae
- Siobhan McNabb
- Kaitlan Collison
- Bruno Saragiotto
- Tie Yamato
- Natrisha Barnett
- Grace McKie
- Angela Ussivane
- Barbara Lucas
- Jane Latimer

- Sienna Samuels
- Lorren Stanton
- Melissa Tanteckchi
- Nina Lindroos

Contact us

If you have any questions in relation to this report or the projects being undertaken by the Alcohol and Pregnancy & FASD Research Team please contact us:

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Read more about our work on our website

https://alcoholpregnancy.telethonkids.org.au/