

History of the Russell Family Fetal Alcohol Disorders Association

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Background to the rffada

Elizabeth [Anne] Russell, the founder of the rffada, is the birth mother of two children with Fetal Alcohol Spectrum Disorder; her youngest son has full FAS. She has lobbied extensively on both a state and national level to raise awareness about FASD issues since 2000. In addition to the key activities undertaken by volunteers of the rffada, Anne has also written three books on this condition and her family's journey, the first books on FASD in Australia. She has also delivered training and development workshops to parents, carers, drug and alcohol workers, disability workers, mental health workers, medical practitioners, midwives and other various community organisations throughout Australia.

Anne has been | is on a number of consultation groups:

- She was a Senior Consultant on the Australian FASD Collaboration which has developed a screening and diagnostic tool for FASD in Australia
- A member of the Collaboration for Alcohol Related Developmental Disorders [CARDD] [Formerly FASD Research Network], University of Queensland's Centre for Clinical Research
- Team member undertaking research on the Knowledge and Attitudes of Criminal Justice Personnel on FASD in Queensland
- Member of the National Parents Advisory Group [FASD]
- Member of the FASD Consortium

In the financial year 2014-2015, the rffada delivered 41 education and training workshops to 394 participants in remote Indigenous and mainstream communities across Australia. We prepared 7 submissions and facilitated 5 face to face support groups since they commenced five months ago. We have over 500 individuals and organisations in our main FaceBook group and almost 200 parents supported in our 'secret' parents and carers FaceBook group. Our FaceBook page for people with FASD where they are able to speak to each other, learn from each other, and support each other has been utilised by a great many more people than expected.

The flow on effect from the delivery of our presentations, the support of our parents and carers and the dissemination of information through our Facebook groups is estimated to have helped a great many more people.

We have distributed 10,000 brochures. We had printed 5,000 mainstream brochures and 5,000 brochures specifically for Indigenous people. rffada Fact Sheets have been printed and distributed to participants at each of the education or training sessions that has been delivered.

This year the rffada has travelled to many different locations to deliver training: Doomadgee, Mornington Island, Cairns, Brisbane, Karratha, Townsville, Thursday Island, Bamaga, Seisia, New Mapoon, Napranum, Nanum, Mapoon, Lockhart, Cooktown, Hopevale, Wujal, Beswick, Katherine and Alice Springs.

The rffada has been featured in several publications. The NOFAS Circle of Hope Newsletter, Iceberg, the Cairns Post and has been on the radio and television.

Association Achievements

- Attendance at the 2nd International Conference on FASD in Victoria BC in March 2007
- Invited attendance at the 3rd International Conference on FASD in Victoria BC in 2009
- 2003 Attendance at the 2003 conference on Fetal Alcohol Syndrome in Winnipeg
- 2002 Attendance at the Yukon 2002 Prairie Northern Conference on Fetal Alcohol Syndrome in the Yukon
- Visit to the David Livingstone School in Winnipeg to scope education and FASD
- Attendance at the NOFAS Conference in Seattle – Building Bridges to Success
- Attendance at Diane Malbin’s ‘Fetal Alcohol Spectrum Disorders : Into Action’ 2009 in Seattle
- Visit to Canberra three times to discuss FASD with various Ministers
- Development by the rffada of the first ¹nationally accredited available training modules on FASD in Australia
- Agreement of ²Dr Sharman Stone MP Co-chair ‘Parliamentarians for the Prevention of FASD’ to be the Patron
- Agreement of Diane Malbin MSW and International Consultant on FASD to be International Patron
- 2013 Developed the first Australian FASD Apple | Android App for smart phones
- 2011 Invited attendance at the 4th International Conference on FASD in Vancouver BC
- 2010 Invited to present on FASD and employment in Canada – this presentation was based on Elizabeth’s Russell’s book entitled “Strategies for Employment Services Specialists”
- 2013 Lodged modular training with ASQA for accreditation
- 2013 was approved for funding to train volunteers from the Department of Health and Ageing
- 2013 On the steering committee for the first Australasian Conference on FASD
- 2013 Participated in International Tele-Summit ‘Living with FASD’ A 12-Day Resource for Families Living With FASD
- 2013 Development of the first Android and Apple APP on FASD in Australia
- 2013 First training on FASD accredited with ASQA
- 2014 supported the establishment of a face to face support group in Cairns
- 2014 with the support of My Pathway delivered training to remote Indigenous communities around Australia
- 2015 supported the establishment of face to face support groups in Perth, Alice Springs, the Gold Coast and Cairns

Funding Received

- From ³AER Foundation for a joint research project between the rffada and the University of Queensland – Dr Jan Hammill and Professor Heather Douglas to gauge the knowledge and attitudes of criminal justice personnel with regard to FASD
- AER Foundation attendance at several overseas conferences
- Obtained funding from the Australian Government through the Department of Health and Ageing for NOFASARD
- Sponsorship of my second book by my employer ITEC Employment
- Sponsorship of my attendance at the 2nd International Conference in Victoria BC in 2007 by my employer ITEC Employment
- Sponsorship of the accreditation of the first publicly available training on FASD in Australia
- Funding from Centacare Cairns to purchase promotional items around the message ‘for a healthy baby, no alcohol while pregnant is safest’
- Funding received from DOHA for training on FASD for rffada volunteers
- Donation received from Peggy Oba Family
- Funding donated by Liz Hornibrook and Family
- Funding from FARE and My Pathway to attend AMA Alcohol Summit in Canberra October 2014
- Funding received from My Pathway to present at AOD Wintersun Conference in Brisbane

¹ Late in 2012

² Dr Stone is the Federal Member for Murray since 1996. Sharman has previously been the Shadow Minister for the Status of Women, Early Childhood Education and Childcare, Shadow Minister for Immigration and Citizenship and before that the Shadow Minister for Environment, Heritage, the Arts and Indigenous Affairs. Sharman was the Minister for Workforce Participation in the former Howard Government and was previously the Parliamentary Secretary to the Minister for Finance and Administration. Her first ministerial appointment was as Parliamentary Secretary to the Minister for the Environment and Heritage from 1998 to 2004.

³ Now the Foundation for Alcohol Research and Education [FARE]

Presentations, Conferences, Fora and Sponsorship undertaken by the rffada

- Training TAFE students who are undertaking Community Services, Youth and Drug and Alcohol services
- Presenting at a FASD forum on the North Coast of New South Wales
- Working with the Salvation Army in their position on alcohol and pregnancy
- Launching my first book on alcohol and pregnancy [the first book in Australia on the condition]
- Presenting at the National Midwives Conference in Sydney [received standing ovation]
- Featuring in a DVD for students on FASD
- Featuring in the panel discussion on FASD by the Rural Health and Education Foundation
- Presenting to the Indigenous National Aboriginal Islander Child Care Association in Cairns [SNAICC]
- Presenting at the Sisters Inside Conference in Brisbane in 2006
- Presenting at the Westmead Hospital in their workshop on FASD in 2006
- Presenting in Dunedin at the Cutting Edge Conference
- Presenting in Auckland at the NZ FASDAY forum by the Auckland Region Fetal Alcohol Network
- Discussion with Minister Sharman Stone Minister for Workforce Participation
- Preparation of a tender to provide youth services in four remote Indigenous communities in the Northern Territory with a heavy focus on FASD 2006
- Guest Speaker 1st National FASD Conference, Launceston 2007
- Presentation in Mount Isa for the Royal Flying Doctor Service
- Presentations in New Zealand in 2010 for Alcohol Health watch 2007 and 2010
- Presentation in Brisbane at Pregnancy Support Conference
- Invited participant and guest presenter to the National FAS Workshop conducted by the National Expert Advisory Committee on Alcohol and the Australian National Council on *Drugs* Sydney 2000.
- 2nd International Conference on Fetal Alcohol Spectrum Disorder Vancouver 2009
- 4th Biennial Conference on Adolescents and Adults with FASD Vancouver 2010
- Presentation for RFDS Mount Isa
- 2008 IGCD FASD Workshop Adelaide
- 2005 National Midwife Conference Sydney
- 2005 presentation at Auckland NZ
- 2005 Dunedin NZ Cutting Edge Conference
- 2005 University of Auckland Presentation
- 2005 Westmead Hospital forum on FASD Sydney
- 2005 Salvation Army joint launch of first book and Salvation Army's stance on alcohol and pregnancy
- 2004 presented to students and medical personnel at The Townsville Hospital Townsville
- 2004 presented to ATODS Mackay and Moranbah
- 2004 National Foster Care Conference Brisbane
- 2006 Sisters Inside Conference Brisbane
- 2007 Conference on FASD in Australia Tasmania
- Filming with Video producer – educational video on FASD to be released 2007
- 2007 VADA Conference Melbourne
- 2006 Women's Referral and Access Presentation
- 2006, 07, 08, 09, 10, 11 International Conferences on FASD on Vancouver and Vancouver Island
- 2011 Rural and Remote: The Heart of a Healthy Nation Perth
- 2011 Drug Week panel and presentation Devonport and Launceston Tasmania invited by Drug Education Network
- 2011 Keynote Speaker Working in the West and FASD
- 2011 Poster presentation APSAD Conference Hobart Tasmania
- 2012 Invited as first speaker to the House Standing Committee on Social Policy and Legal Affairs on the Inquiry on Foetal Alcohol Spectrum Disorder at their first stop around Australia in Cairns
- 2012 Presentation to the Training and Support Unit of Aboriginal Mothers and Babies Children State Wide Forum
- 2012 Presentation to Freeman House Rehabilitation Project in Armidale NSW
- 2012 Attendance requested at the Western Australian FASD Model of Care
- 2012 Discussion with Alison Xamon, Greens Senator regarding the impact of alcohol and pregnancy in WA
- 2012 Presentation to the Queensland Premiers Department regarding FASD and criminal justice issues
- 2012 Presentation at the National Indigenous Drug and Alcohol Committee Conference on Leading the Way by Understanding FASD from a Birth Mother's Perspective Freemantle
- 2012 Presentation at the NADA Forum in Sydney on FASD
- 2012 presentation at the NIDAC Conference in Freemantle

- 2012 presentation for the Training and Support Unit of the Aboriginal Mothers and Babies
- 2012 presentation at the Queensland Foster Carers Conference in Ipswich
- 2012 presentation at the ATCA Conference in Launceston
- 2012 participation in the University of Queensland FASDAY panel of activities
- 2012 presentation in Canberra to parliamentarians on FASD for FARE
- 2011-2012 financial year delivered training to 348 individuals
- 2012 participated in developing NADA's Complex Needs Clients Workshop
- 2013 Invited to present at the 2nd International Congress of Gynecology and Obstetrics to present on "Involving consumers and the community in the development of a diagnostic instrument for fetal alcohol"... at session St 5-2: Adverse Pregnancy and Child Health Outcomes and Maternal Health Following Complicated Pregnancies under track STREAM 5: Maternal-Fetal Medicine
- 2013 Helped plan and organise the first Australasian FASD Conference in Brisbane
- 2013 Presented at the first Australasian FASD Conference in Brisbane
- 2014 Information Sessions in Cairns for public
- 2014 Abstract accepted for FASD Conference Vancouver
- 2015 Delivered 2 information sessions in Cairns over 2 days – total of 30 professional participants
- 2015 Delivery of training to Cooktown, Hopevale, Wujal and Laura communities
- 2015 Attended AMA Alcohol Summit in Canberra
- 2015 delivered presentation at 2015 AOD Wintersun Conference in Brisbane
- 2015 verbal and written dialogue with the Queensland Commissioner for Mental Health

Collaborations

- The Development of Screening-Diagnostic Instrument for FASD in Australia [FASD Project] Australian FASD Collaboration – *Senior Consultant*
- Journal of Judicial Administration – Judicial views of foetal alcohol spectrum disorder in Queensland's criminal justice system *Heather Douglas, Janet Hammill, Elizabeth Anne Russell, Wayne Hall*
- The Importance of Foetal Alcohol Spectrum Disorder for criminal law in practice: Views of Queensland lawyers *Heather Douglas, Janet Hammill, Elizabeth Anne Russell, Wayne Hall*
- 'Health professionals' perceptions about the adoption of existing guidelines for the diagnosis of fetal alcohol spectrum disorders in Australia', [BMC Pediatrics 2012, 12:69 Rochelle E Watkins, Elizabeth J Elliott, Raewyn C Mutch, Jane Latimer, Amanda Wilkins, Janet M Payne, Heather M Jones, Sue Miers, Elizabeth Peadon, Anne McKenzie, Heather A D'Antoine, Elizabeth Russell, James Fitzpatrick, Colleen M O'Leary, Jane Halliday, Lorian Hayes, Lucinda Burns, Maureen Carter and Carol Bower]
- Participation in the FASD Research Network, University of Queensland's Centre for Clinical Research activities for FASD DAY 2011
- Screening for fetal alcohol spectrum disorders in Australia: A modified Delphi study Rochelle E Watkins, Elizabeth J Elliott, Raewyn C Mutch, Jane Latimer, Amanda Wilkins, Janet M Payne, Heather M Jones, Sue Miers, Elizabeth Peadon, Anne McKenzie, Heather A D'Antoine, Elizabeth Russell, James Fitzpatrick, Colleen M O'Leary, Jane Halliday, Lorian Hayes, Lucinda Burns, Maureen Carter and Carol Bower
- Participation in the development of the FARE Australian FASD Action Plan
- Participating in the briefings of 55 politicians in Parliament House Canberra on FASD and the Australian FASD Action Plan
- Participation in the Collaboration for Alcohol Related Developmental Disorders [CARDD] [Formerly FASD Research Network], University of Queensland's Centre for Clinical Research activities for FASD DAY 2012
- On the Steering Committee for the Australasian FASD Conference to be held in November 2013
- The rffada collaborated with CARDD, NOFASD and FARE to organise a petition to have FASD recognised as a disability [petition was tabled by Senator Sue Boyce in December 2013
- Petition commenced on Change.org for additional names to be put forth to the Senate
- 2014 - with Dr Doug Shelton Manager of the Gold Coast Hospital diagnostic clinic, Patrick McGee Coordinator of the Aboriginal Disability Justice Campaign, Professor Heather Douglas from the TC Bernie School of Law, University of Queensland, Jerrod Brown, Kaashifah Bruce, Marulu FASD Prevention Strategy Coordinator, Telethon Kids Institute, Diane Malbin Founder of FASCETS, Dr Kerryn Bagley, Dr James Fitzpatrick, Telethon Kids Institute and other individuals for the development of a DVD for parents and carers
- Collaboration with My Pathway to deliver training to remote Indigenous Communities
- Collaboration with Mooroolbool Hub to deliver training to at risk 'Booya' Girls
- 2014 delivery of FASD training to all My Pathway communities
- Member of the FASD Consortium
- Member of the National Parents Advisory Group

Submissions Lodged

2012 Submission to the House Standing Committee on Social Policy and Legal Affairs
2012 Submission to the Western Australian Legislative Assembly on Education and Health Inquiry
2012 Submission to the Draft Ten-Year Road Map for Mental Health Reform
2012 Submission to the National Disability Insurance Scheme
2012 Submission to the ANCD on FASD
2012 Submission on Motherhood and the Economy
2012 Feedback on Queensland Mental Health
2012 Submission for the Suicide Prevention Strategy
2013 Submission for the Suicide Prevention Strategy
2013 Submission re the Sale and Consumption of Alcohol in SA
2014 Submission to the Child Protection Agency
2013 Submission to the ANCD
2013 Submission to the NDIS
2013 Submission to NCETA
2013 Submission for the Western Australia Criminal Law [mentally impaired accused]
2013 Submission to the Social Development Committee in South Australia
2013 Submission to the Suicide Prevention Strategy for Indigenous Australians
2014 Submission to ANCD and PHA
2014 Submission to the National Mental Health Commission
2014 Submission to the Productivity Commission
2014 Submission to ANPHA
2014 Submission for Safe Night Out Strategy
2014 Submission to the Northern Territory Inquiry on FASD
2014 Submission for the Harmful use of alcohol in Aboriginal and Torres Strait Islander communities
2015 Submission to National Alcohol Strategy
2015 Submission to the Queensland Mental Health Commission
2015 Submission re Nanny State
2015 Submission for Inquiry into Out of Home Care
2015 Submission to Aurizon

Facebook Groups

2012 Facebook group commenced – Russell Family Fetal Alcohol Disorders Association
2013 rffada group has over 500 members – increasing at the rate of 1 request per day
2013 rffada – living with FASD for people with FASD – currently has 15 members
2013 rffada – Circle of Hope for birth parents – currently has 2 members
2014 rffada – parents and carers group current has over 200 parents and carers

Memberships

Collaboration for Alcohol Related Developmental Disabilities
National Organisation for Fetal Alcohol Syndrome [NOFAS]
National Organisation for FASD
Queensland Network for Alcohol and Drug Association
National Organisation for Fetal Alcohol Spectrum Disorder [Australia]

Affiliations

Fetal Alcohol Syndrome Information Network
Telethon Institute for Child Health Research
Foundation for Alcohol Research and Education
Training Connections Australia
My Pathway
Synapse
National Parent Advocacy Group
FASD Consortium
Ambassador for NOFASD

Media

Print – Newspapers

- Sydney Morning Herald
- Townsville Daily Bulletin
- Courier Mail
- The Australian 2005
- The Age
- Cairns Post
- The Australian 2013
- 2015 Cairns Post

Print - Magazines

- That's Life
- Pregnancy and Birth
- The Bulletin Magazine
- The Australian 2009
- The Australian 2012
- 2013 About the House [Parliamentary Magazine]

Radio

- Various Radio Stations
- ABC local and national
- ABC 2013
- 2014 ABC
- 2015 ABC

Other

- Interview for FARE's Pregnant Pause
- Prepared several videos for YouTube on specific aspects of FASD

Television

- Sunrise Australia and Sunrise New Zealand
- Kerry Anne in the Morning
- 7.30 Report
- Channel 7 Central Queensland
- Channel 7 Queensland 2001; 2003; 2005; 2007; 2009; 2014
- Channel 9 State
- Channel 7 Cairns 2001; 2003; 2005; 2007; 2009; 2010; 2011; 2012, 2013, 2015
- Channel 9 Cairns
- Statewide
- Interview for the ABC at the FASD Conference in Brisbane
- Featured on The Project in an expose of FASD
- 2015 Four Corners
- 2015 ABC Morning Show

Special Achievements

- Peak Downs Shire Council Australian of the Year 1988
- 2005 published Alcohol and Pregnancy – A Mother's Responsible Disturbance
- 2007 published Alcohol and Pregnancy – No Blame No Shame
- 2009 published Strategies for Employment Services Specialists [emphasis on FASD]
- Strategies for Employment Services Specialists endorsed by NESA
- Co-development of a tool which was incorporated into the above book which identifies the barriers, needs and accommodations for people with a disability or disadvantage
- Presented at local, national and international conferences and workshops on Fetal Alcohol Spectrum Disorder
- 2011 Queensland finalist for Australian of the Year
- 2012 Finalist for the Community award provided by the Queensland Country Credit Union

- 2011 rffada developed FASD training in collaboration with Registered Training Organisation, Training Connections Australia
- 2011-2013 Training on FASD delivered around Australia
- 2013 FASD Training now nationally accredited
- 2015 FASD training shortly on the scope of Training Connections Australia
- 2015 rffada brochure translated into Spanish and delivered overseas to Spanish speaking countries