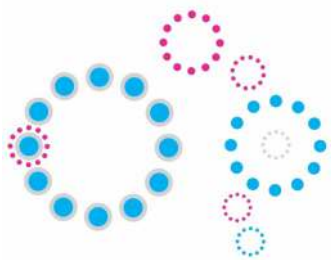


# 2017 - 2018 Annual Report



Photo by DJ, aged 13, who has FASD



## Who We Are



### Some of our staff and volunteers

Back row: Ana Clarke, Jess Hannan, Nicole Hewlett, Christine Brooks, Cheryl Dedman, Rachel Boyd, Leonard Tay  
Front row: Janet Woollard, Louise Gray, Sue Miers, Tony Miers, Robyn Smith

Our vibrant team includes our patron Dame Quentin Bryce; dedicated board members; a passionate team of health professionals with a wide range of skills including education, child development, occupational therapy and psychology; skilled volunteers who generously donate their time and energy; and ambassadors within Australia and overseas who specialise in FASD and support our cause worldwide.



### NOFASD's patron

Dame Quentin Bryce's contribution to advancing human rights and equality, the rights of women and children, and the welfare of the family was recognised in her appointment as an Officer of the Order of Australia in 1988.

Quentin Bryce has enjoyed a rich and distinguished career as an academic, lawyer, community and human rights advocate, senior public officer and university college principal.

In her civic role as Governor of Queensland, Ms Bryce continued her work with women, families and young people while extending her influence across the State's broad and diverse spectrum including the rural, regional, aged, indigenous, migrant, and disability sectors.

In 2008 Ms Bryce was sworn in as Australia's twenty-fifth Governor-General. As the first woman to take up the office, she was a pioneer in contemporary Australian society, and yet one who brought more than 40 years of experience in reform, community building and leadership to the role.

# Volunteers

NOFASD's wonderful team of volunteers has contributed over 2090 hours to our cause this financial year. This equates to more than a full time work week every week of the year. Our skilled volunteers contribute in numerous ways including foster carer presentations, social media campaigns, graphic design, reading and distributing news and research, FASD information and awareness building at events and conferences, phone support to parents and carers, FASD support groups and representing the voices of parents and carers on committees.

NOFASD Australia was founded on the 23rd March 1999 by a group of volunteers led by Sue Miers, who was motivated by her personal experience of struggling to find information and support in caring for a child with FASD. Sue founded the organisation, which was initially called the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD), in collaboration with a small group of committed volunteers. NOFASD was run on a volunteer basis for many years and volunteers continue to be very important contributors. Thanks to the efforts of early volunteers, significant steps have been made to advance the awareness of FASD in Australia and to provide information and support to individuals and families at a grassroots level. NOFASD has now become the leading provider in Australia of information, services, linkages and referrals regarding FASD.

Sue Miers continues to volunteer with NOFASD Australia. She was awarded the Member of the Order of Australia in 2006 for her services to the community through the establishment of NOFASD, community education and reconciliation.

2090

Volunteer hours  
this year

20

Years of  
volunteer support



NOFASD volunteer Ana Clarke

## Awards

Two of NOFASD's volunteers were shortlisted for the Australian Not-for-Profit Technology Awards in May 2018. The Awards acknowledge the accomplishments of organisations and individuals and the improved product and/or service offerings brought to the charitable sector through technology. Sue Miers, the Founder of NOFASD Australia, was selected as a finalist for the Lifetime Service Award and volunteer Ana Clarke was selected for developing and running NOFASD's Nine for November social media campaign. Sue and Ana were selected as 2 of only 15 finalists shortlisted from many nominations.

## Conferences

NOFASD staff attended 25 conferences this year, delivering 9 presentations and displaying numerous stalls with information, handouts, and promotional items. Total delegate attendance at these conferences was approximately 10108, with occupations including GPs, allied health professionals, psychologists, counsellors, OTs, nurses, psychiatrists, teachers, professors, support workers, program managers and coordinators, justice system judges, lawyers and commissioners, research scientists and parents of children with FASD. NOFASD staff were present to answer questions, build networks, and hand out promotional items (including information sheets, posters, lip balm, coasters, pens and lanyards).

NOFASD prevention flyers were included in many conference satchels, with a total of 3880 distributed in this way. Prevention flyers and information brochures were also distributed to GPs across Australia. In addition, NOFASD developed targeted 6-page booklets for the Australian and New Zealand Society of Criminology conference, which contained information on FASD, case management, and useful links to FASD justice information. 300 booklets were distributed at this conference.

25

Conferences  
Attended

9

Presentations  
Delivered

10,108

Delegates in Attendance

7,109

Promotional Items Distributed

4,850

Prevention Flyers Distributed



### Feedback regarding NOFASD's conference attendance:

*Teachers don't think that FASD concerns them, but after talking to NOFASD staff at the conference they have changed their minds and often come up with a number of students that this information may relate to.*

*Many studying to be an OT knew very little about FASD before speaking to NOFASD staff.*



# Community Prevention Campaigns

NOFASD Australia ran multiple prevention campaigns this year. This included extensive social media activity, regular newsletters, press releases and media interviews, face to face initiatives, extensive reach-out to allied health professionals, and targeted community awareness campaigns through the year. NOFASD's social media following increased significantly over this period, with a 48% growth on Facebook, 62% growth on Instagram, and 26% growth on Twitter.

150k

Community Members  
Reached in September

38,530

Health Professionals Reached

16,344

Newsletters Sent

## International FASD Awareness Day

NOFASD obtained a reach of 150,000 across media platforms, promoting the importance of alcohol free pregnancies.

## Allied Health Professionals

NOFASD increased awareness of FASD by writing articles for physiotherapy and occupational therapy publications, creating professional development webinars for nurses and occupational therapists, distributing information in GP clinics, and supporting multidisciplinary health professional events.

## Father's Day Campaign

Father's Day was used to launch the Pregnant Together campaign, promoting alcohol free pregnancy as a whole of community concern. The Pregnant Together microsite was developed to highlight the role which fathers and other community members play in supporting healthy pregnancy.

## Nine for November Campaign

This campaign highlighted fun, healthy, inexpensive group activities for the beginning of summer. It encouraged a whole of community approach to preventing alcohol consumption during pregnancy by encouraging young people to organise alcohol free activities with their friends.

## Christmas Campaign

A short film was developed, looking at Christmas through children's eyes and reminding viewers that the festive season is not all about alcohol. This reached 31,000 viewers.

## Newsletters

16,344 electronic newsletters were distributed containing news, strategies, and events for parents, carers and health professionals.

## GP advertising campaign

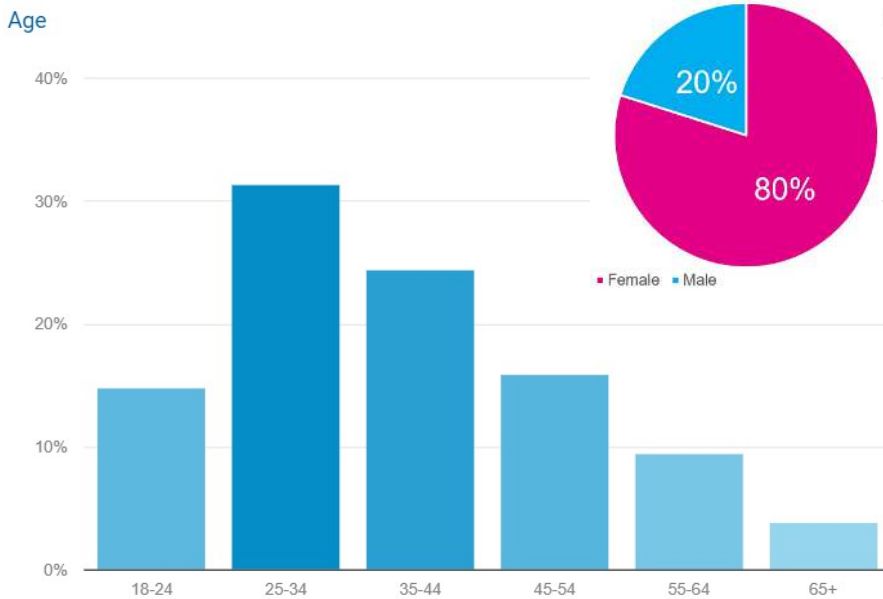
NOFASD placed advertisements in the Waiting Room magazine and on Tonic Media infomercials in GP clinics across Australia. These clearly conveyed the message that when pregnant, planning or could be, no alcohol is the safest choice.



Stay in the Loop and receive our monthly  
e-newsletter direct to your email.

# NOFASD Website

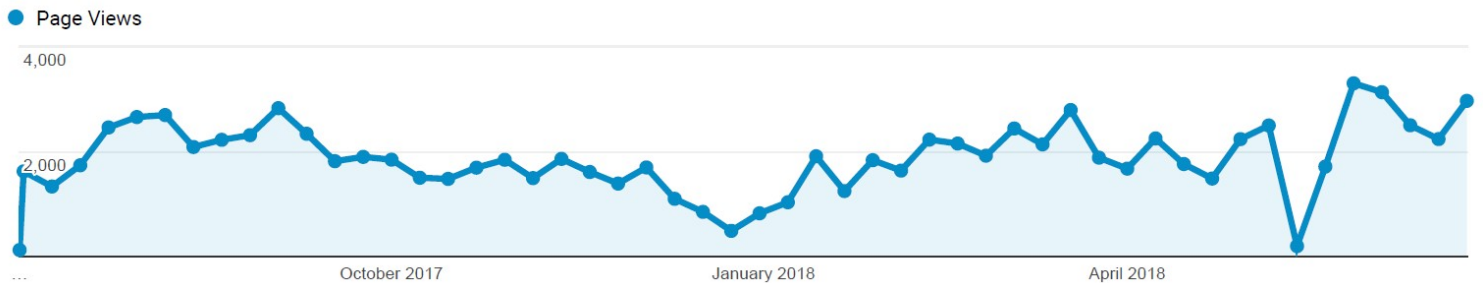
A new website was developed and launched in May 2018, which improved the accessibility of the NOFASD website and included new resources. Over the last 12 months the NOFASD website has been accessed regularly, with 36,449 new users.



Demographic information shows that the website is reaching our target audience. Of the 36,964 individuals who visited the NOFASD website last year, 80% are female and 46% are aged between 18 and 34 years.

There were 98,743 page views, which equates to an average of 1899 per week. Visits increased to over 3000 page views in busy periods.

The NOFASD website provides a wealth of resources including information on FASD and diagnosis, available support, current news and events, research, prevention messages, fact sheets, strategies, webinars, reading lists and lots more



Most popular pages	Views
What is FASD	30,936
NOFASD homepage (information on FASD and helpline)	11,319
Useful links	3,198
Diagnostic information	2,036
International FASD Awareness Day (includes an information pack)	1,154
FASD and education (for teachers)	1,106
Resources (reading list, videos, links)	974

**36,964**  
Total Users

**98,743**  
Page Views

# FASD Resources

NOFASD continued to develop and update the printable resources available on our website, with the most frequently accessed being:

- Toolkit for parents and carers
- FASD fact sheets and strategies for parents and carers
- Frequently asked questions
- Alcohol-free pregnancy poster and flyers
- Fact sheet for health professionals

These resources were also posted to individuals and health professionals who requested them.



NOFASD Australia developed and distributed Parent Support Packs for families who receive a FASD diagnosis. 400 of these Parent Support Packs were distributed to clinics across Australia, containing:

- A strategies book which many parents describe as helpful
- A collection of useful information including FASD fact sheets and website links
- Information sheets for public distribution, containing information to help people understand how individuals with FASD (over 13 and under 13) process information
- Referral information to NOFASD Australia for support
- The Foster Parents Guide to supporting a child with FASD, by Dr Sara McClean.

## Feedback from clinic staff who distribute Parent Support Packs:

*They have been fantastic.*

*They are really helpful for us because the clients get all the information on FASD.*

*Helpful for clients to receive those contact details.*

*Feedback from clients has been good.*

*“Strategies not Solutions” is the one thing families really like. We reinforce this.*



## TOOLKIT

*‘Hope from the Darkness’*

FASD Support for Parents and Carers in Australia



175

Toolkits Downloaded

7315

Viewed Fact Sheets

400

Parent Support Packs

# Helpline Support

NOFASD Australia provides a telephone and email helpline which is available 9 hours a day seven days a week. This service provides information and support to a range of individuals including pregnant women, parents who are concerned about their biological or foster children, adults who believe they have FASD, and health professionals with enquiries on how to best support their clients.

NOFASD received and responded to 599 contacts this year via email, phone, and website enquiries. In addition to supplying information and referring callers to NOFASD's online resources, NOFASD compiled and updated a referral list of health professionals across Australia who specialise in FASD diagnosis and treatment. This list was shared with helpline callers, providing them with a list of specialists in their local area.

Helpline callers included adults who believe they have FASD. One caller expressed great relief to hear that all his years of not understanding, having different thought patterns, memory problems, learning difficulties, and not quite fitting in could be attributed to FASD. He said he grew up believing that these difficulties were his own fault.

An evaluation of NOFASD's helpline was conducted in June 2018. This involved phone calls to clients and service providers who had accessed NOFASD services within the past year. Participants included parents, grandparents and other carers of children with FASD. Clients reported feeling more confident and less upset after speaking to a NOFASD staff member, and every person interviewed said they received beneficial information. The service providers interviewed also reported being very satisfied with the NOFASD helpline, saying they received information which was valuable to them and to the foster carers and other clients who they support. One service provider said "this is such a core issue for the children in care here".



**599**  
Helpline Contacts



## Feedback from parents and carers who contacted the NOFASD helpline:

*I was put in touch with local providers. A whole network of support is in place now through NOFASD's information and connections. NOFASD is an ideal first point of call.*

*I always find NOFASD a really good wealth of knowledge. The key thing is I can be so open without being judged.*

*It was great to speak to someone that understands.*

*I found the NOFASD website pretty easily with a lot of useful information. By calling the helpline I was able to find out who to call and I struck bingo. My experience was very, very helpful. The work that you guys are doing is fantastic. It's so crucial.*

# Advice Cards for Community



In early 2018 NOFASD became aware of a need in the Australian community, and developed these cards to meet that need. These wallet-sized cards are for parents and carers to hand to members of the public when their child experiences a sensory overload in public. 1885 cards were requested and distributed in the first month.

Parents and caregivers know which strategies are most effective in managing and de-escalating meltdowns in those with FASD, however well-meaning community members sometimes jump to the conclusion that simple solutions like firm parenting and the use of consequences might solve behaviour problems. These Advice Cards enable parents and care-givers to enlist the support of observers by wordlessly explaining what is going on and asking for their cooperation, including not staring or becoming involved unless assistance is requested. Through networking, NOFASD discovered the organisation Parenting Complex Children had developed these cards. They gave NOFASD permission to adapt and produce them for the Australian population.

1885

Cards Distributed

## Feedback from families requesting advice cards:

*Thank you so much for producing these, they are exactly what I have been needing!*

*Yes please I would love a set of cards. What a brilliant idea.*

*Please send me a set of cards for community for me to use with my son and promote in my workplace.*

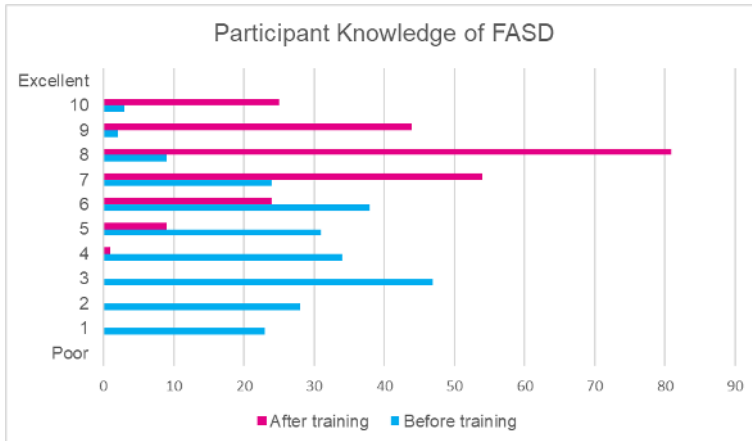
*As a foster carer who has many FAS children placed with me, I would love a set of these cards. Thank you.*

*I would love a set of these cards. I have three adopted kids with FASD.*

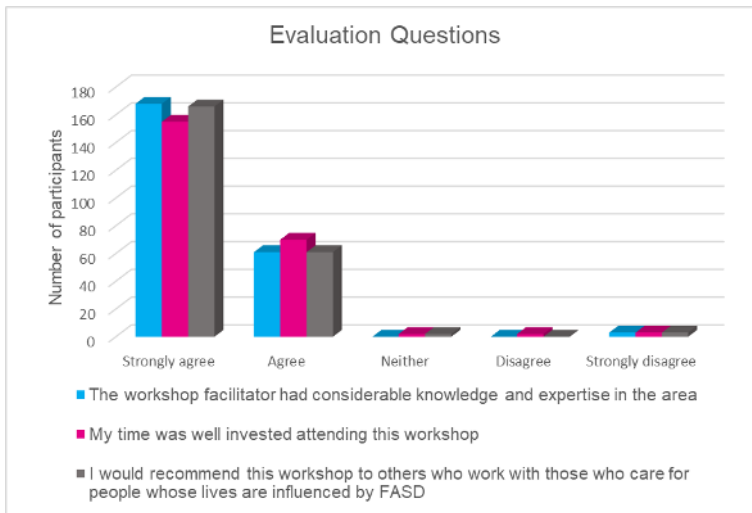
*We raise our granddaughters 5 & 7. Miss 5 has a diagnosis of FAS and we are currently waiting on a diagnosis for the Miss 7. We would love to have some of these cards.*

# Community Workshops

NOFASD's Community Workshops are delivered in locations across Australia and are available to remote communities as well as capital cities. They are attended by parents, carers and health professionals and give an overview of FASD.



NOFASD delivered 20 community workshops across Australia, providing FASD training to 383 parents, carers, teachers and service providers. Workshop participants were asked to rate their knowledge of FASD before and after training on a scale from 1 to 10, with a significant improvement evident (see graph on left). Evaluation questions also provided positive feedback.



NOFASD has advisory groups in different states, which include members living with FASD and carers of those with FASD. Some of these members attend presentations and workshops to share their lived experience of FASD. This has proven to be very valuable for participants, who get inside knowledge of what FASD is like, and for the carers who attend, who are passionate about sharing information on FASD.



20

Community Workshops

383

Participants

## Workshop evaluation feedback:

*Amazing insight to my own child. I will be following up to have a diagnosis. Thank you.*

*The workshop was excellent, it will help with the people (students) we work with on a daily basis.*

*It was really informative and has provided me with valuable resources to support carers who care for children with FASD.*

*I think the presentation was great. Significant information – clear and precise info.*

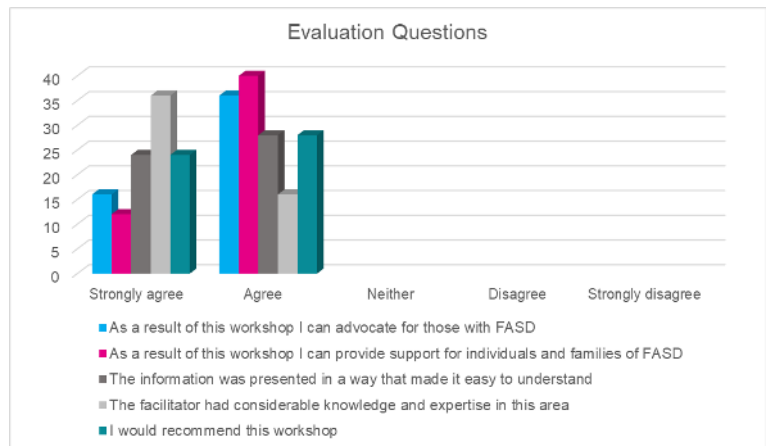
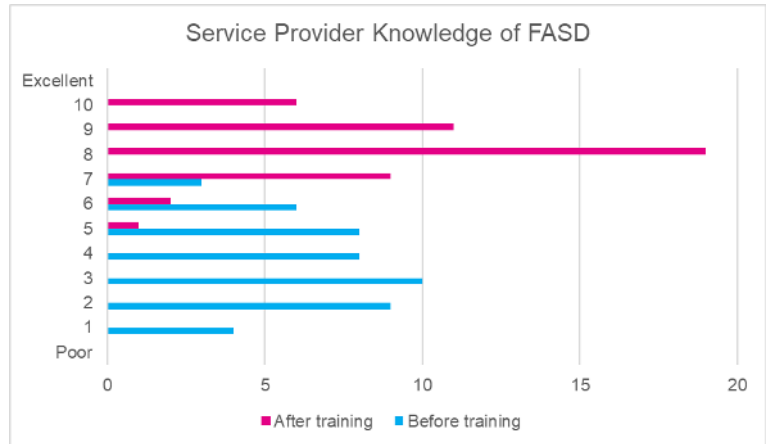
# Train it Forward Workshops

NOFASD's Train it Forward workshops were developed to provide health professionals with the knowledge, confidence and tools to become workplace advocates for FASD, enabling them to share their learning with others in their organisations and communities.

NOFASD facilitated 4 Train it Forward workshops, training workplace advocates across Australia. Workshops were delivered in South Australia, Western Australia, Queensland and the Northern Territory. Positive feedback was provided by a number of organisations, who said they were impressed by the high standard of the training.

Evaluation data show significant improvement in participant knowledge of FASD, and the responses to evaluation questions were overwhelmingly positive, as shown in the graphs to the right.

Train it Forward participants also made positive written comments, some of which are displayed in the feedback section below.



**52**  
New Workplace  
Advocates

**4**  
Train it Forward  
Workshops

## Feedback from clients who completed Train it Forward:

*We are lucky to have amazing people like you teaching about FASD.*

*Very good training, definitely worthwhile – thank you.*

*Value the opportunity to have access to training of this standard and skill development to be able to present this information to others.*

*Thank you both for your great presentation and resource material.*

# NOFASD Webinars

NOFASD is committed to supporting all Australians, wherever they live and whatever their situation. To cater to those in remote areas who are unable to attend training, and for those who have busy schedules and find it difficult to attend day events, NOFASD has produced a series of webinars which can be accessed anywhere and at any time.



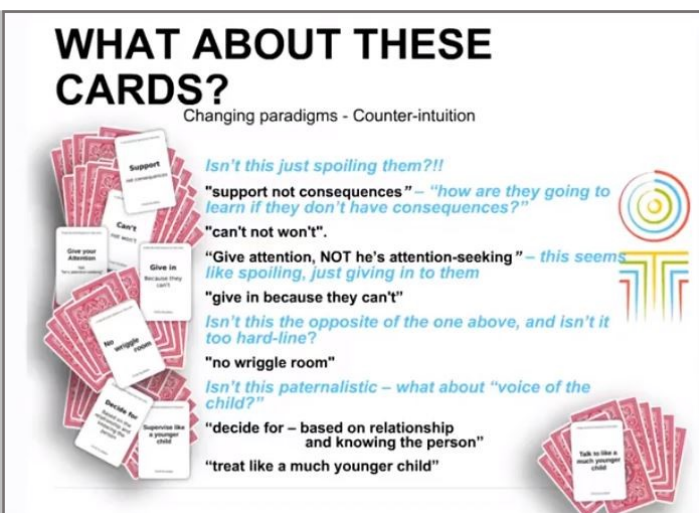
NOFASD currently has 5 webinars available on our website, with two of these recorded and posted in the last six months. In total these webinars have been viewed 1058 times, with a breakdown below:

Webinar	Views
For Parents and Carers	200
For Teachers and Educators	523
FASD Myths Exposed	241
Occupational Therapy and FASD (recording of the live webinar for OTs)	41
FASD Eyebites Cards	53



**5**  
Unique Webinars

**1058**  
Webinar Views



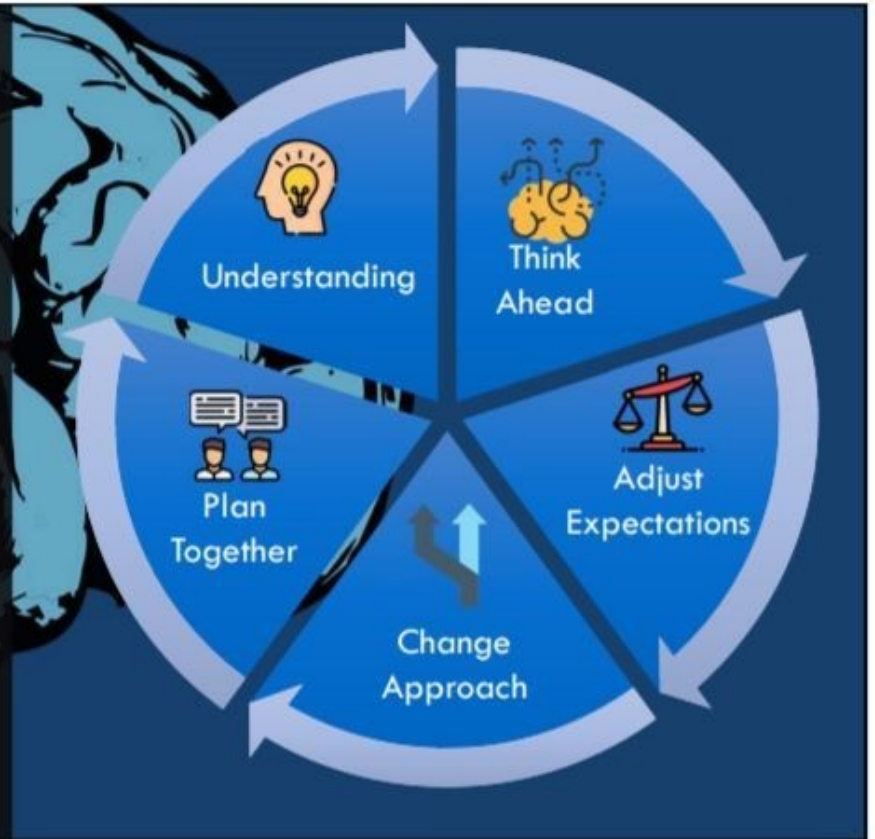
NOFASD Australia partnered with Oranga Tamariki, the Ministry of Vulnerable Children in New Zealand, to produce a webinar explaining how to use FASD Eyebites Cards. The webinar showcases these cards which are a fantastic resource for practitioners, parents and carers of individuals with FASD. These unique cards can assist families and service providers to explore key FASD-informed principles, and are useful as an everyday support. Following the live launch of the cards the recorded webinar was viewed a further 53 times and NOFASD Australia distributed 32 packs of Eyebites Cards.

# It's a Brain Thing! Webinar Series

## COGNITIVE SUPPORT

[kog-ni-tiv suh-pohrt]

1. Providing a support or intervention with a specific cognitive skill in mind.



NOFASD contracted international FASD specialist Nate Sheets to provide a free webinar series for parents and carers called “It’s a Brain Thing”. The series focused on the various cognitive skill challenges people with FASD experience and strategies to practically support them in their everyday lives. Cognitive support strategies included supporting executive functioning skills, communication, memory, and processing skills. The series was delivered in three 90-minute webinars, presented across three consecutive months, with opportunities for caregivers to practice strategies and ask questions. Participants were able to download the webinars to watch and re-watch when convenient. The webinars were strengths-based, with a focus on understanding why people with FASD behave the way they do. Nate encouraged caregivers to rethink their children’s behaviours, suggested practical strategies to provide cognitive support, and encouraged trying differently rather than harder.

218

Participants

### Feedback from participants:

*Thank you so much for this opportunity. We are a small school with two students with FASD. So happy to be learning more.*

*Thank you so much ... I have enjoyed and appreciated all of this. I'll look forward to watching it again.*

*Thanks so much have great tools to work with my daughter.*

*This has been invaluable thank you.*

*Thanks Nate. Great presentation and well explained.*

*The slides are easy to read/understand and not overwhelming. He is also thought provoking, which I really like, because it really feels interactive.*

*Thank you for the practical ideas for managing my little men.*

## Australian Ambassadors

We are grateful for the continued support of our Ambassadors, who are committed across Australia to raising awareness of FASD and improving support services available to those affected. NOFASD welcomed Dr Heidi Webster and Dr Jeff McMullen this year to our growing list of supporters. These are our amazing ambassadors:



**Carmela Pestell**



**John Boulton**



**June Oscar**



**Michael Thorn**



**Marcel Zimmet**



**Sharman Stone**



**James Fitzpatrick**



**Carol Bower**



**Heidi Webster**



**Jeff McMullen**



**Kerryn Bagley**



**Doug Shelton**



**Heather Douglas**



**Steve Allsop**



**Nick Rushworth**



**Sue Miers**



**Elizabeth Elliott**

Congratulations to Professor Elizabeth Elliott, AM, who was awarded the Australian Medical Association's 2018 Excellence in Healthcare Award. Professor Elliott is a true pioneer in the FASD field and has contributed to research, prevention, diagnosis, and intervention for over 20 years. She played a significant role in developing much-needed guidelines for FASD diagnosis and in opening the first Australian FASD assessment clinic.

## International Ambassadors

NOFASD Australia continues to build strong networks within Australia and globally. International relationships enable the sharing of new research, resources, and best practice in the prevention and support of families with FASD. NOFASD welcomes our six new international ambassadors.



**Dr Christina Chambers** is a perinatal epidemiologist whose research is focused on environmental exposures and pregnancy and child health outcomes, including birth defects. She co-directs the Centre for the Promotion of Maternal Health and Infant Development in the Department of Paediatrics at UCSD and is the Program Director of Mother To Baby California – a telephone-based service providing individualised risk assessments for pregnant women and their providers.



**Dr Kenneth Lyons Jones** is a world-renowned pediatrician, dysmorphologist, teratologist and researcher in the field of birth defects. Since first describing fetal alcohol syndrome in 1973 with David W. Smith, Dr Jones has made extensive contributions to the prevention, improved diagnosis, and treatment of fetal alcohol spectrum disorder through his research efforts and clinical care. He has trained international physicians in the diagnosis of FASD and has organized FASD evaluation programs worldwide.



**Professor Philip May** is an American Demographer/Epidemiologist who has studied fetal alcohol spectrum disorder (FASD) and overseen the implementation and evaluation of FASD prevention and intervention programs. In 1980 he directed and carried out the first population-based epidemiology study of fetal alcohol syndrome in the United States, and he has contributed extensively to FASD research since this time.



**Dr Nancy Poole** is the Prevention Lead for the CanFASD Research Network guiding a network of researchers, service providers, policy analysts and community-based advocates working on FASD prevention. Dr Poole participates in Canadian and international research teams studying Indigenous approaches to FASD prevention and healing from substance use concerns, and strives to be a solid ally in research, practice and policy initiatives undertaken with Indigenous partners.



**Professor Jeffrey Wozniak** is a clinical paediatric neuropsychologist at the University of Minnesota whose research is focused on FASD. He directs the University's FASD Research Program which conducts neuroimaging, neurocognitive and intervention studies. Dr Wozniak and his team work closely with their colleagues in the Minnesota Organization on Fetal Alcohol Syndrome to inform the local community about the dangers of prenatal alcohol exposure and to train physicians and other professionals in diagnosing and assisting individuals.



**Professor Albert (Ab) Chudley M.D.** has specialty certifications in Paediatrics, Clinical Genetics and Medical Genetics. His clinical and research interests are in the areas of recognition, delineation and prevention of birth defects, fetal alcohol spectrum disorder, developmental disabilities including autism spectrum disorder, syndrome and gene discovery. Currently his interests are in genetic and epigenetic factors in FASD. He has taught and supervised students at the undergraduate, graduate and postgraduate levels on the topics of genetics, FASD, neonatology, paediatrics and ethics.



*Sometimes FASD is a lonely journey*

Photo taken by DJ, a young man with FASD

