Symbolic painting created for NOFASD by an Australian Aboriginal woman.

The pregnant woman is resting below the tree and is part of the landscape. Her face is reaching up to the stars (ancestors).

The original painting was presented to NOFASD Founder Sue Miers in honour of NOFASD’s 20th anniversary.

The artist’s identity is confidential.
Our Mission
To be a strong and effective voice for individuals and families living with FASD, while supporting initiatives across Australia to promote prevention, diagnosis, intervention and management.

Our Vision
The prevention of alcohol exposed pregnancies in Australia and an improved quality of life for those affected by FASD including those living with FASD and their parents and carers.
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 people including pregnant women, parents and carers, adults who believe they have FASD, partners of individuals with a FASD diagnosis, and health professionals with questions about how to best support their clients.

NOFASD received and responded to 1072 contacts this year via email, phone, and website enquiries. This is an average of 3 contacts per day, for 365 days. A majority of contacts involve follow up support, meaning that each individual received multiple calls and/or emails.

Helpline services included:
- Referral for FASD diagnosis
- Assistance with NDIS applications
- Provision of FASD training
- Mailing printed resources
- Providing electronic resources
- Advertising FASD research, to increase participation
- Answering questions from individuals living with FASD
- Helping students with assignments on FASD
- Responding to carers and individuals who needed someone to talk to about their experience. In addition to listening and providing support, the Helpline Manager connected some of these callers to others with lived experience, for peer support.

NOFASD maintains 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.

An evaluation of NOFASD’s helpline was conducted throughout the year. Participants included parents, partners, grandparents and foster carers of individuals with FASD. Callers reported feeling more confident about responding to FASD and less upset after speaking to a NOFASD staff member. Service providers also participated in the helpline evaluation, with a majority of callers describing the information received as “very beneficial”.

Feedback from parents and carers who contacted the NOFASD helpline:

I have contacted you before and it is so good to have someone who understands.

A really good efficient service.

Happy with feedback I am getting.

Needs to be more awareness of the dangers of alcohol when pregnant.

Received gratefully.

I could so hug you right now!
The NOFASD Australia website received 152,873 page views this year, which is an average of 419 views per day. The most popular page, with 43k views, was “What is FASD”, with the next most accessed page being NOFASD’s collection of FASD Fact Sheets. Resources for families and online courses (including webinars) were also in high demand. Demographic information shows that 78% of website visitors were female, with 41% aged between 18 and 34 years. 86% of NOFASD’s visitors were new users.

NOFASD Australia also maintains active social media pages with daily posts. Online activity prioritises Facebook and Twitter, with a less frequent presence on Instagram and LinkedIn. Posts include FASD resources, new research, words of inspiration, prevention messages, upcoming events and much more.
NOFASD publishes regular blogs on our website, providing up-to-date FASD information and creating a blog library which can be accessed at any time. Blog topics include knowledge translation, prevention ideas, resource summaries, support strategies, and lived experiences of FASD.

NOFASD published 63 blogs this year, 52 written by NOFASD Australia and 9 provided by guest bloggers. Blogs were viewed over 17,000 times by 6715 unique readers. NOFASD has been privileged to publish guest blogs from the mother of an adolescent with FASD and from an adult living with FASD (read about them below). Guest blogs were also provided by a psychologist, who shared a case study on Play Therapy for FASD, and a counsellor who provided a detailed explanation of Equine Assisted Therapy for FASD.

**Top blog posts**

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<thead>
<tr>
<th>Title</th>
<th>Views</th>
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<tbody>
<tr>
<td>New Resources for Educators</td>
<td>1162</td>
</tr>
<tr>
<td>Coroner’s Inquest</td>
<td>1158</td>
</tr>
<tr>
<td>Online FASD Course</td>
<td>1111</td>
</tr>
<tr>
<td>FASD Strategic Action Plan 18-28</td>
<td>1103</td>
</tr>
<tr>
<td>FASD Prevalence Research</td>
<td>1024</td>
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**Guest bloggers**

**Mama Maremma** is a full-time carer for her child who is living with FASD. She likens herself to the Maremma breed of dog who are renowned as guardians and protectors. Her blogs include reflections on the challenges and importance of self-care, moments of joy and support, and lived experience of raising a teenager with FASD.

**CJ Lutke** is a member of the Adult Leadership Committee of FASD Change Makers. She is a well-known speaker on FASD, and also provides mentoring, role modelling and friendship to young adults with FASD. CJ writes blogs for adults and adolescents with FASD, and for the people who care for and support them. She shares her personal experiences of living with FASD, including a description of the sensory challenges of buying a coffee and the impact of the language used in FASD diagnosis.
Training Workshops

NOFASD delivers a range of workshops across Australia, in remote communities as well as capital cities. These are attended by parents, carers, health professionals, foster agencies, teachers, counsellors, corrective service staff, and other professionals.

NOFASD’s Train it Forward Masterclass provides participants with the knowledge and confidence to share information, resources and ideas with their colleagues and communities. Upon completing this workshop participants have a good understanding of FASD, including strategies for supporting individuals. This year’s 191 newly trained FASD advocates can now share their knowledge with others.

NOFASD’s FASD Information Workshop provides an overview of FASD and its challenges. The workshop is tailored for each audience, with 242 participants attending this year.

Workshop participants were asked to rate their knowledge of FASD before and after training, with a significant improvement evident (see graph). Workshop evaluations were overwhelmingly positive.

Workshop evaluation feedback:

- Excellent speaker – clear, natural, and well versed in the subject. Great resources too.
- Well presented. I felt engaged and interested all the way through.
- Fantastic, great to be able to pass this learning on to Foster Carers.
NOFASD staff and volunteers attended 10 conferences this year, delivering 14 presentations and displaying numerous stalls with information, handouts, and prevention flyers. Conference presentations included:

- 2nd Australasian FASD Conference
- 8th International Conference on FASD
- EU FASD Conference
- Aboriginal Health Conference
- Occupational Therapy Paediatric Symposium

NOFASD staff, board members, and volunteers presented on a range of topics including the parent experience of FASD, supporting families, social media prevention campaigns, health professional education, and the implications of FASD in an education setting.

NOFASD hosted a parent/carer dinner at the 2nd Australasian FASD Conference, providing an opportunity for shared stories and the creation of peer support networks between families with similar lived experiences. NOFASD staff facilitated the evening, pictured on the right.

**Conference Highlight**

At the 2nd Australasian FASD Conference in Perth, an historic Memorandum of Understanding (MOU) was signed between the FASD Research Australia Centre of Research Excellence and the Canada FASD Research Network (CanFASD). This is a 3-year commitment of collaboration to enhance research into the prevention, diagnosis and intervention of FASD.

*Celebrating the MOU: NOFASD Executive Officer Louise Gray, CanFASD Executive Director Audrey McFarlane, and Professor Carol Bower, Professor Elizabeth Elliott, and Program Manager Narelle Mullan from the Centre of Research Excellence.*
NOFASD continued to develop and update the printable resources available on our website, with the most frequently accessed being:

- FASD fact sheets and strategies for parents and carers
- Toolkit 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 distributed thousands of resources, including:

- 1320 Community Advice Cards, for parents and carers to hand to members of the public when their child experiences a sensory overload in public
- 1140 Police Advice Cards, for individuals with FASD to hand to officers to explain their brain injury
- 141 Parent Support Packs: comprehensive folders of information and strategies which are given to families when they receive a FASD diagnosis
- 885 Preventable Disability brochures
- 2090 prevention flyers
- 730 prevention posters
- numerous FASD information sheets

**Advice card feedback:**

From a police officer:
*The card looks great, very clear and concise, good job.*

From parents:
*I didn’t feel any need to stay and explain, because it was all on the card, which was such a relief.*

*I hand these out in an attempt to gain understanding, not judgement, from others.*
Community Prevention Campaigns

NOFASD Australia ran multiple prevention campaigns this year. These included extensive social media activity, regular newsletters, press releases and media interviews. NOFASD’s social media following increased significantly over this period, and posts regularly featured prevention messages and awareness raising information.

Christmas Campaign
NOFASD Australia ran a prevention campaign from the end of November through to Christmas Eve. As well as promoting the fact that no alcohol is safe at any point in a pregnancy, this Christmas campaign encouraged community members to support women who are pregnant, or who could be pregnant, to stay alcohol free at Christmas.

With effective advertising, these prevention messages reached those who may not have been aware of the risks of alcohol exposure during pregnancy. Half of the people reached on social media were not followers of NOFASD.

This campaign had a focus on mocktails – promoting delicious and attractive alternatives to alcoholic drinks, to encourage alcohol-free parties and celebrations.

FASD Awareness Day Views

Newsletters
13,255 electronic newsletters were distributed to NOFASD’s 1516 subscribers. Newsletters contain special interest pieces, dedicated sections for families and professionals, new research publications and FASD news, and a range of resources, information and strategies for parents, carers and professionals.

International FASD Awareness Day
NOFASD continued to promote Red Shoes Rock this year, a campaign which was started by RJ Formanek, an adult living with FASD. He wears attention-grabbing red shoes in order to start conversations about this hidden disability. NOFASD encouraged the community to wear red shoes to start conversations, and created cute photographs of pets to encourage the sharing of prevention messages on social media. 25 thousand people were reached on the 9th of September, with prevention messages reaching many times this number throughout the 99 day campaign.
Awards

NOFASD’s FASD information workshop was recognised with a nomination to the 2019 National Alcohol and Other Drugs Excellence Awards. We were shortlisted by the Alcohol and Drug Foundation for their Primary Prevention Award.

NOFASD founder Sue Miers and Board Member Elizabeth Elliott were honoured with a number of prestigious awards this year.

**Professor Elizabeth Elliott AM** was the 2018 recipient of the Australian Medical Association (AMA) **Excellence in Healthcare Award**. Described as a “pioneer in FASD research, patient care, and advocacy”, Professor Elliott received this award in recognition of her significant contributions to improving health in Australia. Professor Elliott used her position within the AMA to move the following motion: *That the AMA support NHMRC guidelines that clinicians should advise women who are pregnant or planning a pregnancy that the safest option is to avoid alcohol entirely.* This motion was passed by the AMA, a significant step towards preventing FASD, given that a majority of GPs don’t feel confident raising this with patients.

Professor Elliott also received the prestigious **Starfish Award** at the 8th International Conference on FASD in Vancouver, March 2019. This was awarded by the Adult Leadership Committee of FASD Change Makers (five community leaders living with FASD). This year the Starfish Award went to two leading researchers for their immense contribution to the field: Professors Elizabeth Elliott and Claire Coles.

**Sue Miers AM** was the recipient of the **Unsung Hero Award** in the 2018 HESTA Community Sector Awards. Sue was recognised for her voluntary work supporting families struggling to manage and understand FASD, and for her tireless efforts to increase awareness and prevention of the disability.

Soon afterwards, Sue was named **Citizen of the Year** by the District Council of Yankalilla at their Australia Day ceremony.

Sue Miers AM also received the inaugural **Lifetime Achievement Award** at the 2nd Australasian FASD Conference. She received a standing ovation as the conference chairs announced that, from this day forward, the Lifetime Achievement Award will be known as the “Sue Miers Award”. Co-chairs of the conference described Sue’s persistence, persuasiveness and patience as the keys to her success in raising awareness and support around this lifelong disability.
This year we celebrated our 20th anniversary of providing advocacy and support for families living with FASD. NOFASD was founded in 1999 by a small group of volunteers, led by Sue and Tony Miers, to address “the apparent lack of information and acknowledgement of FAS in Australia”.

NOFASD was founded on the 23rd March 1999 by Sue Miers, who was motivated by her personal experience of struggling to find information and support in caring for a child with FASD. NOFASD was run on a volunteer basis for many years, and volunteers continue to be important contributors. Thanks to these early efforts, 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 and support.

Our founder Sue Miers said:

This is a celebration of the achievements of many. We would not have made it through the challenges and curve balls of the last 20 years without the dedication and commitment of those staff, board members, colleagues and friends who have continued to support us in so many ways. Thank you all! Special thanks must also go to the families who work so hard to support their loved ones who have FASD and especially to all who have FASD and are doing their best to make their way in a world that does not always provide the understanding and accommodations they deserve to enable them to reach their full potential and live fulfilling lives! Together WE WILL make a difference!
Image and message created by a family living with FASD.
This card is shared with families across Australia.
Photo taken by DJ, a young person with FASD.

NOFASD Australia is funded by the Australian Government Department of Health