#### **Senate Standing Committee on Community Affairs**

## Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

#### Submission provided by

# DrinkWise.

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#### Introduction

DrinkWise is an independent, evidenced-based organisation that has been promoting the National Health and Medical Research Council (NHMRC) alcohol pregnancy guideline as part of the DrinkWise Fetal Alcohol Spectrum Disorder (FASD) Awareness Program.

As an organisation with a focus on preventing FASD, DrinkWise is pleased to provide details of our extensive and sustained activities promoting the NHMRC's advice that *It's safest not to drink while pregnant*. These activities illustrate effective, integrated approaches to raise awareness across both broad and targeted populations.

The DrinkWise education initiatives have been recognised and utilised by governments, health media providers, organisations and individuals working to prevent FASD and support people impacted by FASD.

#### **DrinkWise FASD Awareness Program**

The DrinkWise FASD Awareness Program provides an innovative, integrated and wide-reaching approach to promoting the NHRMC's recommendation regarding alcohol and pregnancy. The program adopts an evidence-based approach that communication campaigns are most effective when consumers receive consistent and sustained messaging and information in a range of settings and across multiple mediums<sup>1</sup>.

A considerable number of bespoke communication channels have been employed to reach and engage the community, including:

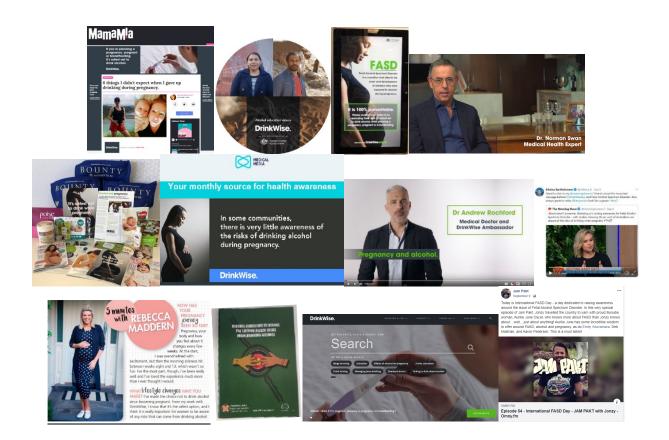
- medical practices
- aboriginal medical services
- hospitals
- online women's media networks
- pregnancy retail websites
- pregnancy magazines
- electronic direct mail messaging
- social media
- radio music and health promotion programs
- schools
- community groups
- broadcast sporting programs
- retail points of sale.

Details of the assets and activities are provided in this submission.

<sup>&</sup>lt;sup>1</sup> World Health Organisation 2013 – Health Literacy, the Solid Facts. http://www.euro.who.int/ data/assets/pdf file/0008/190655/e96854.pdf?ua=1

The integrated approach to implementation of the program achieves extensive reach. By way of example:

- 14 million exposures a month through alcohol and pregnancy messaging appearing in over 4,400 medical practices.
- 225,000 pregnant women reached via full page colour messaging in pregnancy magazines.
- 250,000 new mothers receiving information via double sided leaflets in Bounty bags distributed in hospitals.
- Over four million views each month through Australia's online (female-focused) media networks.
- Millions reached via the dedicated in-program messaging, editorials and audio rolls as part of an Indigenous health promotion and music radio program, played weekly across 265 community radio stations.
- Video materials made available to nearly 200,000 state secondary school students as part of alcohol and other drugs curriculum.



#### DrinkWise FASD Awareness Program – details of program elements

#### **General practice waiting rooms**

Medical centres are trusted environments where health and lifestyle decisions are made. Women aged 25-54 years represent over half of the visitors to general practices, where there is an average wait time of 35 minutes to see a doctor. This provides an ideal opportunity to deliver alcohol and pregnancy messaging and DrinkWise has been providing information to patients and health practitioners since 2012.

DrinkWise's early work in promoting the message and information about why it's safest not to drink alcohol while pregnant, was undertaken in partnership with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists. Consumer brochures were produced and disseminated nationally in general practices as was messaging for health practitioners, encouraging them to talk to their patients about alcohol during pregnancy. The Royal Australian College of General Practice assisted in the distribution of materials through its network of members. This early work complemented the point-of-sale alcohol and pregnancy national education activities that were undertaken with funding from the Gilliard/Rudd Government in 2012. (This activity is outlined on page 11).



More recently, DrinkWise has been fortunate to work with Dr Norman Swan, producer and presenter of the ABC's *Health Report*, in the production of video messaging about the risks of consuming alcohol during pregnancy and FASD. Dr Swan offers advice about abstaining from alcohol when planning a pregnancy, while pregnant and breastfeeding and encourages patients to talk to their doctor for further information. https://drinkwise.org.au/#q=pregnant&r=true



In partnership with Tonic Health Media, Dr Swan's video has played across 1,700 general practices nationally and is supplemented with DrinkWise consumer brochures and posters, encouraging abstinence when planning a pregnancy and while pregnant, to avoid the risks of FASD. The brochures and posters have been promoted in many more thousands of waiting rooms, representing 70% of all general practices nationally. (The supplementary resources are resonating with visitors in general practice waiting rooms and performance information is provided on pages 15-16 of this submission).



#### **Accessible resources**

The DrinkWise pregnancy and FASD resources are frequently requested by hospitals, medical practices, youth and community services, pregnancy and IVF clinics and student/education services. The resources are available to download from our website, where additional information is provided about the risks of consuming alcohol as it relates to fertility, planning a pregnancy, while pregnant, breastfeeding and FASD.



#### Rural and remote general practices and aboriginal medical services

In 2011, DrinkWise partnered with the Aboriginal Drug and Alcohol Council (ADAC) of South Australia to produce an Indigenous adaptation of the NHMRC alcohol guidelines for use by health workers and drug and alcohol counsellors. The guidelines encourage abstinence from alcohol if pregnant and breastfeeding, and explain how alcohol can affect the baby, including FASD. The resource remains available through ADAC and has been circulated extensively.



The Australian Government partnered with DrinkWise in 2018 to produce FASD video materials and practitioner messaging for use in medical settings to increase the Australian community's awareness and understanding of FASD.

The Australian Government Minister for Health, the Hon Greg Hunt MP, launched the videos and messaging on 10 September 2018 and DrinkWise was fortunate to have the support of June Oscar AO, Aboriginal and Torres Strait Islander Social Justice Commissioner as part of this work. June Oscar lead the first ever Australian FASD prevalence study and has continued to advocate for early diagnosis and appropriate responses and treatment to support individuals and families impacted by FASD. Link here to the launch: <a href="https://drinkwise.org.au/our-work/drinkwise-fasd-awareness-program-partners-with-federal-government-for-new-education-materials-featuring-deborah-mailman-and-aaron-pedersen/#">https://drinkwise.org.au/our-work/drinkwise-fasd-awareness-program-partners-with-federal-government-for-new-education-materials-featuring-deborah-mailman-and-aaron-pedersen/#</a>





The videos feature Deborah Mailman and Aaron Pedersen. As part of their personal messaging, Deborah reflects on her own experience as a pregnant woman and explains why it's safest not to drink when planning a pregnancy, while pregnant or while breastfeeding, in order to prevent FASD. Aaron reflects on the importance of ensuring partners, family members and friends support women to avoid FASD by abstaining from alcohol, to have a healthy pregnancy and a healthy baby.

The videos, which are shown in general practice waiting rooms, are complemented with messaging for practice staff (via direct electronic direct messaging and digital poster display), encouraging them to remind their patients that it's safest not to drink alcohol while planning a pregnancy, pregnant or breastfeeding.

The videos and practice staff messaging have been displayed in rural and regional medical practices since September 2018 and continue to be displayed today. The Australian Government has provided further in-kind support through extending promotion of the FASD videos across the Aboriginal Health Television Network this year. The videos are currently seen in 160 Aboriginal Medical Services (AMS), which will increase to 260 AMS locations over the coming months, as the network continues to grow.





Link to website here: https://drinkwise.org.au/our-work/drinkwise-videos-for-education-programs/#

#### School and community programs

DrinkWise, with the funding support provided by the Australian Government in 2018, has also produced extended versions of the FASD videos to educate students about FASD, peer pressure and the importance of not drinking until they are at least 18 years of age.

Deborah Mailman's video reflects on her experiences growing up, including her decisions to wait until she was older to drink alcohol and not to drink during her pregnancies, advising kids to talk to a trusted adult or doctor if they have any questions about alcohol.

Aaron Pedersen's video discusses the impact FASD can have on people's lives, the importance of supporting loved ones not to drink when planning a pregnancy, pregnant or breastfeeding and reminds kids that it's ok to say no if people are pressuring them to have a drink. Link to videos here: https://drinkwise.org.au/our-work/drinkwise-videos-for-education-programs/#

#### **School programs**

The videos were endorsed by the former Shadow Minister for Indigenous Affairs and Aboriginal and Torres Strait Islanders who assisted in seeking broader dissemination of the video materials across schools nationally.

The video materials have been integrated into:

- state secondary schools' alcohol and other drugs curriculum, available to thousands of school students and their teachers
- the Red Dust Strong Young Women's Program, delivered in secondary school settings in Alice Springs,
   Northern Territory
- follow-up resources provided through an interactive and educational mobile pop-up laboratory experience, delivered to secondary students across the Northern Territory
- a tertiary program supporting aboriginal community-controlled health services.

#### **Community programs**

#### **Northern Territory**

The video materials have also been integrated into alcohol education programs delivery by an aboriginal community-controlled health organisation operating in and around Alice Springs and several remote communities of central Australia.

Ongoing positive feedback about the video materials has been received from education providers:

"We have been showing those ads prior to going in and doing our FASD Focus Groups and they have helped our participants to gain an understanding of what causes FASD".

"The feedback has been really well received, people understand the concept, it's explained clearly largely thanks to the way Deb and Aaron talk".

"Can use the Clinical ads for Workforce Development in AMS's".

"The fact that Aaron is a local aboriginal man has allowed a deeper conversation to happen because of those ties so we are making some dents in the education of FASD".

Specific feedback received from participants of the programs also reveals the value of the video materials:

"We know of Aaron and trust what he's talking about."

"The ads are easy to understand, plain English."

"Even though they are actors, they are normal people."

"Deb and Aaron sound very honest and sincere in speaking."

"The ads weren't too long, good length."

Incorporation of the video materials into the DrinkWise funded *Red Dust Strong Young Men and Strong Young Women's Programs,* delivered as community education programs in remote communities in Central Australia, has reached 415 young men and women in 2018-19 in schools, supported accommodation and community settings in Alice Springs and in two remote communities.

#### **New South Wales**

In New South Wales, video materials have been integrated into the sporting, scholarship, out-of-home and transitioning from out-of-home care programs, delivered by a large foster care agency.

#### **South Australia**

In South Australia, the video materials have been integrated into alcohol education programs operated by an aboriginal corporation delivering a range of alcohol and other drug services.

#### Retail – labelling on alcohol products and packaging

In July 2011, DrinkWise and its industry partners voluntarily introduced the *Get the Facts* labelling initiative, applying consumer information messages to alcohol product labelling and packaging in Australia. The labels included specific alcohol and health warnings, including *It's safest not to drink while pregnant* as well as encouraging consumers to *Get the Facts* by visiting the DrinkWise website, which provides evidence-based information about a range of alcohol and health issues.

Late in 2011, the Council of Australian Governments Legislative and Governance Forum on Food Regulation recognised DrinkWise and the industry's early work on this initiative in their response to the *Labelling Logic* report, supporting the prioritisation of the pregnancy and alcohol messaging. This voluntary system resulted in the significant majority of alcohol products sold in Australia featuring either the pregnancy pictogram or NHMRC guideline statement that *It's safest not to drink while pregnant*.

This voluntary initiative was also recognised by the Australian Government, who subsequently supported DrinkWise to produce and promote a range of complementary messaging for use in retail points of sale (detailed below).

DrinkWise supports the decision by the Food Minister's Forum to introduce a mandatory labelling standard for pregnancy warning labels on packaged alcoholic beverages. DrinkWise also supports the leading Australian authority, the NHMRC, to provide the best advice regarding alcohol guidelines based on the available evidence.



#### **Retail - point of sale**

DrinkWise, in collaboration with its industry partners, has also been promoting the pregnancy message in retail settings, such as liquor stores, licensed venues, shopping centres and cellar doors, to increase the reach of this important message.

In 2012, in partnership with the Australian Government, DrinkWise was supported to produce and disseminate over one million information brochures across 3,500 retail stores nationally. This was supplemented with in-store messaging via digital displays, static displays and check-out screens.

Convenience promotion, with gender specific tailoring of the pregnancy message, was displayed in bathrooms of 476 licensed venues. Over 50 shopping centres also amplified the message in bathrooms.





In 2018, DrinkWise re-designed its pregnancy retail assets and has continued to promote the message in licensed venues and nationally through cellar doors.



#### Retail – pregnancy magazines and shopping sites

Promotion of the alcohol and pregnancy message in pregnancy magazines, such as Shopping for Baby, aimed at pregnant and new mothers, in addition to retail sites, such as Tinitrader, has enabled this important message to be seen by thousands of women at a time when they are engaged in making decisions around their pregnancy and baby.

This activity is supplemented with a double-sided leaflet about alcohol and pregnancy and avoiding the risks of FASD, which is included in Bounty bags issued to new mothers through hospitals nationally.

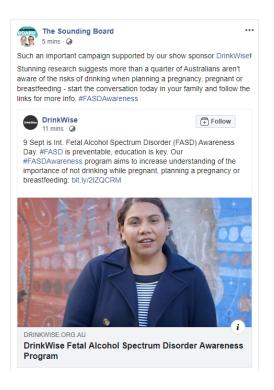


#### **Media partners**

DrinkWise in partnership with MamaMia, Australia's largest women's media brand with a monthly audience of over four million, has promoted FASD messaging across its website, including homepage takeovers, through editorials and via its social media channels.



In partnership with Sports radio broadcaster SEN, DrinkWise has promoted the FASD message during AFL and NRL broadcasts, via their news reports and social channels, again broadening exposure to this important message, this time to a largely male audience.



#### Indigenous music and health promotion radio program

Since September 2018, DrinkWise has sponsored the weekly Indigenous music and health promotion radio program, Jam Pakt. The program is broadcast across 265 community radio networks, providing inprogram editorial focusing on FASD messages.

Jam Pakt has featured interviews with June Oscar AO (Aboriginal and Torres Strait Islander Social Justice Commissioner), Deborah Mailman (actor and mother), Emily Wurramara (musician and new mother) and Aaron Pedersen (actor). Each interviewee has discussed FASD as it relates to their experiences, furthering awareness of the condition and providing advice about abstaining from alcohol to avoid the associated risks.



#### **DrinkWise spokespeople**

DrinkWise has been fortunate to have the support of high-profile women who have had a personal interest and commitment to raising awareness of the risks of drinking when planning a pregnancy and while pregnant to avoid the risks of FASD. Promotion of their stories through print, television, radio and social media accounts, has enabled extensive additional exposure to this information. In the lead up to and during the most recent International FASD Day, this DrinkWise activity resulted in over a million Australians being made aware of the disorder.





Dr Andrew Rochford has also been assisting DrinkWise to raise awareness of the risks of drinking alcohol when planning a pregnancy and while pregnant, to avoid FASD, for several years. In addition to the resources produced with Government funding for use in retail and convenience settings, his advice has been regularly broadcast through metro and regional radio and via videos on the MamaMia and DrinkWise websites. Below is an illustration of recent promotion undertaken as part of International FASD Awareness Day.





According to new research, one in three Australians are un aware

10 Sep 2019 04:07 PM • 2BS, Bathurst (16:00 Local News)

According to new research, one in three Australians are un aware of the risks of drinking while pregnant or breastfeeding. Dr Andrew Rochford, Drinkwise, says it could lead to foetal alcohol spectrum disorder.

Brief: Personal 1 - DrinkWise • ASR: AUD 60 • Duration: 0 mins 36 secs • Region: NSW • Market: Australia • Item ID: X00080358593 • Sentiment: Negative



Interviewees: Dr Andrew Rochford, DrinkWise

https://drinkwise.org.au/parents/how-alcohol-consumption-can-affect-your-baby/#

#### Community awareness of risks of alcohol consumption during pregnancy

DrinkWise's latest research, conducted in August 2019, reveals that 72% of the population are aware of the risks of consuming alcohol during pregnancy, with this result higher (79%) for females aged 18-44 years.

The same research revealed that 90% of women reported that they would stop drinking completely if they thought there was a chance that they were pregnant and 92% would stop if pregnancy was confirmed.

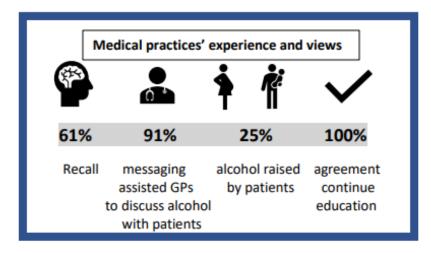
The research reflects responses from a nationally representative sample of 656 Australians aged 18+ years, including 509 females aged 18-44 years.

While these results are sound, there is still work to do to continue to increase awareness of the risks of consuming alcohol when planning a pregnancy and while pregnant, across the population.

### Adequacy of health advice provided to women about the risks of alcohol consumption

General practices were surveyed by Swift Media in December 2018 to assess performance of the two FASD videos (featuring Aaron Pedersen and Deborah Mailman), produced by DrinkWise in partnership with the Australian Government and the messaging produced for general practitioners and their staff.

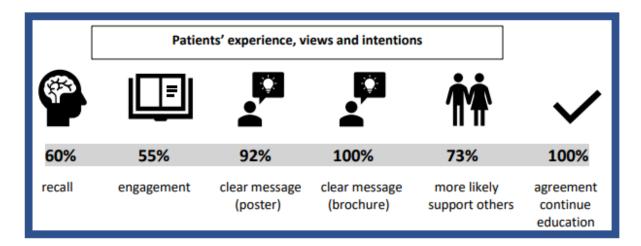
Results from the 73 responding practices to Swift Media's survey revealed a very solid foundation had been established, with high rates of awareness of the messaging and support of its importance. Importantly, one quarter of general practices reported that as a result of the video messaging, alcohol consumption during pregnancy had been raised by their patients.



Patients have also been surveyed by Tonic Health Media to assess performance of the DrinkWise pregnancy brochures and posters. A survey of 92 patients (aged 18-54 years), revealed that the DrinkWise pregnancy poster and brochure in waiting rooms is having the desired impact, with 60% of patients specifically noticing alcohol and pregnancy messaging and 55% engaging with either the poster or brochure while waiting for their consultation.

100% of patients agreed that it was clear that the advice presented in the brochure was to abstain from alcohol if planning a pregnancy, while pregnant and/or breastfeeding, with 92% agreement in relation to the poster.

All agreed that it was important to continue to educate the community about alcohol and family planning/pregnancy/breastfeeding. Importantly, 73% reported that as a result of seeing the alcohol and pregnancy messaging, they would be more likely to encourage and support others to abstain from alcohol if planning a pregnancy and/or pregnant.



## Barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information and advice on alcohol and pregnancy

DrinkWise's approach to its FASD prevention activities are undertaken without judgement and aimed at the whole population (including partners, family members, friends who can support their loved ones), as well as women.

#### International best practice in preventing, diagnosing and managing FASD

The DrinkWise FASD Awareness Program adopts the World Health Organisation's evidence-based approach to building health literacy, that communication campaigns are most effective when consumers receive consistent and sustained messaging and information in a range of settings and across multiple mediums<sup>2</sup>.

## Awareness of FASD in schools and the effectiveness of systems to identify and support affected students

Red Dust is an organisation working in remote communities of the Northern Territory and has conducted an evaluation of the performance within schools of the DrinkWise FASD video resources (produced in partnership with the Australian Government). Prior to the videos being integrated into its *Strong Young Women's and Strong Young Men's Programs*, results revealed very low to no awareness of FASD, with the overwhelming majority of girls having little-to-no awareness of the specifics of FASD or how it affected women and the community.

Following delivery of the DrinkWise video-based education in women's programs at two remote communities, participants indicated they had a good understanding of causes and issues surrounding FASD. Overall, there was an 85% increase in awareness amongst participants in both community programs.

Strong Young Women's Program	remote	remote	Total
	community 1	community 2	
Number of girls attending the program	22	46	68
Number of girls who knew about gender specific	0	1	1
health issues including FASD <b>prior</b> to program			
Number of girls who knew about gender-specific	22	36	58
health issues including FASD after program			
% change in awareness	100%	78%	85%

The young women's feedback on why they thought it was important to know about the effects of FASD also indicated that they now not only had an idea of what the issue was, but how it affected themselves, children and the community:

World Health Organisation 2013 – Health Literacy, the Solid Facts. http://www.euro.who.int/ data/assets/pdf file/0008/190655/e96854.pdf?ua=1

Red Dust reported that students participating in the program at a secondary school had a very limited understanding of the health risks of alcohol and its impact on women and the community prior to the sessions.

It was found that those who attended the program and education sessions had a substantially improved understanding of the health impacts of alcohol both on themselves and others in the community. The Secondary School Girl's Academy Coordinator provided her perspective of the impact of the program on the young women: "There's a name for it now (FASD). When you put a name to it, they know, 'oh that's what that is.""

Red Dust distributed surveys to male participants prior to and after attending a remote community program to gain an understanding of the extent to which their awareness of gender-specific health issues, including FASD, had improved as a result of the content covered.

Prior to the program, only one out of 38 boys had any awareness of the specifics of FASD or how it affected women and the community. After the program, 34 of the 38 participants (close to 90%) indicated they now had a good understanding of causes and issues surrounding FASD.

Strong Young Men's Program	38
Number of boys who knew about gender-specific health issues including FASD	1
prior to program	
Number of boys who knew about gender-specific health issues including FASD	34
after program	
% change in awareness	89%

The boys' feedback on why they thought it was important to know about the effects of FASD also indicated that they now not only had an idea of what the issue was but how it affected women, children and the community:

<sup>&</sup>quot;When mum Drinks, baby drinks."

<sup>&</sup>quot;Grog hurts babies' brains."

<sup>&</sup>quot;We need to look after our kids when pregnant."

<sup>&</sup>quot;If I drink when pregnant, my kid can get sick."

<sup>&</sup>quot;I should only drink water."

<sup>&</sup>quot;Because it hurts baby.".

<sup>&</sup>quot;Shouldn't drink when having baby."

<sup>&</sup>quot;Mum should stay healthy."

<sup>&</sup>quot;No good to drink."

<sup>&</sup>quot;We should help our wife."

<sup>&</sup>quot;Grog hurt baby inside."

<sup>&</sup>quot;Grog no good for strong baby."

## Prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and Indigenous communities

DrinkWise continues to monitor the prevalence of FASD in communities and the important work of other stakeholders in building capacity to screen, diagnose, treat and appropriately respond and support those living with the condition.

As mentioned previously, the video materials have been integrated into programs provided as part of a broad foster care program delivered in New South Wales.

### The social and economic costs of FASD in Australia, including health, education, welfare and criminal justice

FASD is a key priority for DrinkWise, in recognition of the impacts of FASD and the need to continue to generate awareness of the condition and how it can be prevented across the whole community.

The DrinkWise FASD Awareness Program not only represents the hundreds of thousands of dollars spent by DrinkWise itself, but the significant additional investment by our industry partners and the Australian Government (plus additional in-kind support). Financial and in-kind contributions to this program have included:

- \$600,000 Australian Government contribution (2012)
- \$970,000 in additional industry contributions (2018-2019)
- \$233,000 Australian Government contribution (2018)
- in-kind Australian Government contribution to place 2 x 30 second FASD videos across the Aboriginal Health TV Network (2019).

## The need for improved perinatal data collection and statistical reporting on FASD and maternal drinking

The Murdoch Children's Research Institute (MCRI) *Asking Questions about Alcohol (AQUA)* Study has collected information from over 1,500 pregnant women as part of its longitudinal study about the effects of low/moderate alcohol exposure in pregnancy. MCRI has identified characteristics of pregnant women who either abstain, drink until pregnancy awareness or drink throughout pregnancy and has published its findings in 2016. <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4969642/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4969642/</a>.

Research that identifies why women may continue to drink during pregnancy (particularly at low levels) is critical for enabling targeted approaches that will effectively build the capacity of women to abstain from alcohol.