

FASD FETAL ALCOHOL SPECTRUM DISORDER

Co-ordinated by: Brent Cole – brent.cole@inl.co.za, Features360, Cape

September 9 – International Fetal Alcohol Spectrum Disorder (FASD) Day

As we observe International Fetal Alcohol Spectrum Disorder (FASD) Day on September 9 with the Foundation for Alcohol Related Research (FARR), this day reminds us of the harm caused when a foetus (unborn baby) is exposed to alcohol.

The teratogenic (toxic) effect of alcohol causes permanent, irreversible damage to the developing cells of the unborn baby. Since the baby's brain starts developing soon after conception, the brain of the foetus is especially vulnerable to the damaging effects of alcohol. For this reason, children with FASD are born with permanent brain damage. However, it is important to note that any other organ of the unborn baby can also be affected. Fetal Alcohol Syndrome (FAS) is the most severe form of FASD, but there are a variety of other conditions as well.

Further risks associated with alcohol exposure includes miscarriage, stillbirth, prematurity, low birth weight and even cot death.

Due to high prevalence rates in South Africa, FASD is a public health concern in many communities, but unfortunately very little, if any, education is given to students in the health, education and social work sectors. To successfully prevent this condition, it is essential to raise awareness in the general public. Professionals should receive the necessary training and skills to diagnose and manage FASD and to implement awareness and prevention strategies.

The first International FASD Day was held on September 9, 1999. Around the world, scores of people meet on September 9, at 9am, to share a FASD prevention message and wear the FASD

Awareness Knot.

Members of the public who are interested in raising awareness regarding FASD are requested to share the prevention message with small groups of friends/colleagues or other community members in doing the following:

- Meet on September 9, at 9am
- Hand out FASD knots, if available (order from FARR)
- Share a short FASD prevention message
- **9.08am:** Observe one minute of silence to think about individuals affected by FASD and their family/caregivers, as well as how one can go about sharing this message with friends and family;
- **9.09am:** Break the silence by ringing a bell (or bells, eg. church, school or hand bells), thereby calling people to take action in creating awareness about FASD, especially regarding the importance of alcohol-free pregnancies;
- Encourage participants to wear the FASD knot for the day and to share the message with at least nine other people.

The number nine is a reminder of the importance of nine alcohol-free pregnancy months. Research has shown that even small amounts of alcohol can cause prenatal damage and FASD. The message for International FASD Day is therefore: **"No amount of alcohol is safe during pregnancy."**

FASD Awareness Knot

The knot consists of a white rope tied in a specific way, known as the reef knot or the fisherman's knot. The knot is worn on your chest to raise awareness about FASD.



The knot symbolises the following:

- **The rope:** Symbolises the umbilical cord whereby the foetus (unborn baby) is supposed to receive nutritious food and not alcohol;
- **The worn ends of the rope:** A reminder of the damage that prenatal alcohol use can cause to the central nervous system (brain) and other organs of the foetus;
- **The knot:** This type of knot (fisherman/reef) is so strong that it will not break if traction is put on it, it will only pull tighter. This symbolises the strong support that we are supposed to give pregnant women to abstain from alcohol use;
- **The circle inside the knot:** Symbolises the womb (uterus) of the pregnant woman which should provide a safe environment for the foetus, free of alcohol.



What does FARR do?

FARR is celebrating its 23rd anniversary this year. Since the first FASD prevalence study in 1997, the foundation has done 14 community prevalence studies in Gauteng, Free State, Northern, Eastern and Western Cape Provinces, reporting rates ranging from 27/1000 (2,7%) to 282/1000 (28%). South Africa has the highest reported FASD rates in the world.

FARR runs evidence-based awareness, prevention, pregnancy support and training programmes all over South Africa. The foundation conducts continuous research into the size of the FASD problem in South Africa and the best ways of assisting prospective mothers, affected individuals and communities. Their

main focus is on the Healthy Mother Healthy Baby programme.

The aim of the programme is to provide pregnant women with information, and the necessary skills to make informed decisions regarding their own health and the health of their unborn babies. The ultimate goal is to support them to have healthier pregnancies and healthier babies.

FARR also implements a variety of awareness programmes and offers training to educators, social workers, health professionals and students.

For more information, contact FARR on 021 686 2646 or on 083 275 0202, or visit: www.farsa.org.za



Aware.org

The Association for Alcohol Responsibility and Education (Aware.org) urges women who are planning to fall pregnant and those who are pregnant to avoid alcohol at all costs. "There is no sufficient education and awareness regarding FASD, but it is the responsibility of our communities to ensure that we create a FASD free South Africa," said Ingrid Louw, CEO of Aware.org.

Aware.org is mandated to address the concerning rise of FASD in the country, which is one of its six key pillars in the fight against

alcohol harm, as well as educating and creating awareness, in regards to promoting a culture of responsible alcohol consumption in South Africa.

"In recognition of International FASD Awareness Day, Aware.org together with FARR are asking South Africans to make an effort in learning and creating awareness about FASD across the continent.

With the advent of COVID-19, now more than ever, we need to look after each other and it is our collective responsibility to listen, learn and support," said Louw.

What can the community do?

The most important role the community can play in preventing FASD, is in spreading awareness about the risks of alcohol exposure during pregnancy. Speak to friends and family about FASD and create an informed and supportive environment for pregnant mothers in your immediate circle. It has been shown countless times that anger and judgement do not help to change behaviour. Trying to scare someone into doing the right thing is also not effective. We can fight against FASD by creating loving and caring environments for expectant mothers.

What about those people already affected?

For many people, it is too late for prevention and there are children and adults who are already affected by FASD and will have to live with the consequences of alcohol exposure their whole lives. International FASD Day is also about recognising these individuals and their challenges.

What can we do for them? The most important thing is to forget all the scary stories and myths we have heard. Individuals with FASD are not criminals, they are not dangerous and they do have potential. All that they need is to be given the right support and a chance to flourish. If we treat individuals with FASD with care, empathy and support we can make their futures brighter.

How do I have a conversation about drinking during pregnancy?

Talking to someone about substance use, especially during pregnancy, can be a daunting task. Remember that a conversation like this is not an argument. Here are some tips about how to approach the conversation:

- **Empathy** – Substance use and health behaviours do not happen in a vacuum. Acknowledge the challenges faced by the person you are talking to. Do not judge them, rather try and understand where they are in their journey.
- **Responsibility** – Understand that people are responsible for their own decisions, and they need to grow at their own pace. Your role is to guide them and show them the possibilities held by a substance free pregnancy and a healthier baby.

- **Positivity** – Highlight all the good things the person is already doing. Just having a conversation is a big step. Show that you believe in them.

- **Confidence** – The most important thing is that the person must believe in themselves and their ability to make positive decisions. Let them know that even if there are setbacks you know that they can do it.

What can help an individual with FASD?

Not all persons with FASD are alike. There are many different challenges associated with alcohol exposure during pregnancy. There are however some general concepts that can assist children and adults with FASD.

- **Empathy** – Not all the damage caused by alcohol exposure in pregnancy is visible. Remember that the behaviour and problems that you see are most likely caused by brain damage, not disobedience. Understand that the person is doing their best while faced with a multitude of challenges. Give them time, give them patience and give them love.

- **Structure and routine** – The nature of the brain damage caused by alcohol makes it difficult for affected persons to deal with change and new situations. Making important aspects of daily life routine will help them become more independent. If every day's activities are done in the same order, they will know what to expect.

- **Keep it simple** – When giving instructions or tasks, keep it short and simple. An individual with FASD cannot juggle many pieces of information at once. Determine what they can reliably manage and don't exceed it.

- **Repetition** – People with FASD can learn and grow, but it will take time and repetition. When they forget, it is because they have problems forming new memories, not because they did not listen or do not want to co-operate. Be prepared to say the same thing over and over again. If you couple this with routine, eventually learning will happen.

Remember to give yourself credit for what you are doing. It is not easy to assist someone with FASD. You are making a difference, you are taking on a challenge and you do not need to be perfect.