

# “None 4 Nine”



# Esperance Local Drug Action Group



- ▶ Our vision is to bring together members of the community who, on a voluntary basis, combine to undertake a range of activities to prevent and reduce drug related harm in their local communities.
- ▶ Esperance Local Drug Action Group meets on the First Thursday of every month at the Gumtree Church at 12 noon. BYO lunch

# NOFASARD



## GOAL

- ◆ To prevent fetal alcohol exposure during pregnancy, reduce the incidence of FASD and support those living with FASD

## AIMS

- ◆ To function as the peak body for FASD in Australia
- ◆ To raise awareness
- ◆ To provide advocacy and referral options
- ◆ To contribute a community perspective as required
- ◆ To provide information and support for all Australians living with FASDs and those who care for them
- ◆ To collaborate with service providers and other community organisations to raise awareness and build capacity
- ◆ To promote and participate in evidence based research

# Outline

- ④ FASD Facts and Figures
- ④ Asking & Advising All Women About Alcohol
- ④ Support for Families Impacted by FASD
- ④ Diagnostic Features of FAS

# FASD Facts & Figures



## Foetal Alcohol Spectrum Disorder

FASD is a term that describes a 'spectrum' or a range of physical, mental, behavioural and learning disabilities that are a direct result of alcohol use during pregnancy.

FASD is a name for a range of diagnosis that come under this umbrella term which are;

- @FAS = Foetal Alcohol Syndrome
- @pFAS = partial Foetal Alcohol Syndrome
- @ARND = Alcohol Related Neuro-developmental Defects
- @ARBD = Alcohol Related Birth Defects

# Guilt & Shame!

Women who drank alcohol during pregnancy may feel a sense of guilt & shame.

Women who drank alcohol during pregnancy were either;

- un-informed
- mis-informed
- ill & informed

(Activity: The Information Vacuum)



# THE FASD Story.....

- ④ 1750 – A letter was written to Parliament in England regarding the national consumption of Gin stating that it was the cause of “weak, feeble and distempered children”
- ④ 1865 – Dr E Lanceraux, a French Physician describes some of the characteristics of FAS.
- ④ Late 1800’s – Animal research begins and proved potential harm existed from prenatal alcohol use.
- ④ 1920’s research ceases as prohibition begins
- ④ 1940’s research begins again. Some scientist argued that parental alcohol use might contribute to behavioural issues but it was most likely postnatal home and social conditions.

# Doctors Begin to Swing in the Sixties!

- ▶ 1960's – large amount of medical literature supported moderate alcohol use during pregnancy, doubting any relationship with birth defects other than a hereditary basis.
- ▶ French researchers reported that children of alcoholic parents experienced high incidences of delayed growth & development & medical disorders, other world's researchers expressed no concern about alcohol ingestion & birth defects.
- ▶ 1968 – The association between alcohol exposure in pregnancy & physical abnormalities was first published in medical literature.



# FAS was First Diagnosed in 1973

- ④ 1973, Drs. Kenneth Jones & David Smith noted unusual physical features & a failure to thrive in infants of alcoholic mothers at the Harborview Hospital in Seattle, Washington, brought to their attention by a Paediatric resident, Dr. C. Ulleland.
- ④ They sought the assistance of a child psychologist who diagnosed various levels of mental anomalies.
- ④ Drs. Jones and Smith later published their findings in the medical journal, Lancet. In a subsequent Lancet publication that year, they formally used the term, Fetal Alcohol Syndrome.

# International FAS Day 9/9/1999

- ④ Bonnie Buxton – frustrated by the lack of public awareness of FASD by both the public and professionals, she had sought help on an online support group, Faslink, for two years or more.
- ④ Then on one winter morning in January 1999, Buxton began to wonder: “What if, on the 9th minute of the 9th hour of the 9th day of the 9th month of the year 1999, we asked the world to remember that during the 9 months of pregnancy, a woman should remain alcohol free?”
- ④ In 2011 the WA Health Department still has not marked this date in their Health Promotions Calendar & the Federal Government is just now listing FAS as a disability.

# Alcohol and Pregnancy in Australia

## **1995 – 1997 (4 839 non-indigenous WA women)**

- ④ 80% reported drinking 3 months prior to pregnancy
- ④ 59% drank alcohol in at least one trimester
- ④ 15% in the first trimester drank alcohol
- ④ 10% in the second and third trimester

## **2005 (532 indigenous and non-indigenous in Cairns)**

- ④ 25% consumed alcohol during pregnancy

## **2006 (1 103 Australian women of childbearing age)**

- ④ 24% would continue to drink if pregnant
- ④ 34% continued to drink during their previous pregnancy

## **In a Random sample of non-indigenous women in WA**

- ④ 47% indicated their pregnancy was unplanned

Alcohol and Pregnancy Project. Alcohol and Fetal Alcohol Spectrum Disorder; a Resource for Health Professionals (1<sup>st</sup> revision). Perth: Telethon Institute for Child Health Research: 2009

# The biggest reason not to drink; is a little one!

- ④ The one & only cause for FASD is a mother drinks alcohol during pregnancy.
- ④ Alcohol is a teratogenic. (Poisonous to the fetus)
- ④ Alcohol passes unfiltered through the placenta.
- ④ The babies liver is not fully developed & cannot break alcohol down easily or efficiently.
- ④ Unborn babies go to the toilet more & therefore absorbs alcohol through amniotic fluids.
- ④ The BAC of the fetus becomes equal to or greater than the BAC of the mother.
- ④ The unborn baby takes longer to process the alcohol.

(Activity: What mother drinks baby drinks!)



When you drink alcohol, your unborn child drinks it, too

# Asking & Advising All Women About Alcohol

- ④ 97% of WA Health Professionals thought women should be informed about the consequences of alcohol during pregnancy.
- ④ 55% of Health Professionals caring for pregnant women did not routinely ask about alcohol use in pregnancy
- ④ 75% did not routinely provide information on the consequences of alcohol use pregnancy
- ④ 33% of Child bearing women were unaware of the consequences of parental alcohol use on the fetus.
- ④ 91% of Australian women think that health professionals should advise pregnant women to give up drinking alcohol

*“Women may not ask about alcohol consumption during pregnancy because as they expected important issues to be raised by Health Professionals”*

Alcohol and Pregnancy Project. Alcohol and Fetal Alcohol Spectrum Disorder; a Resource for Health Professionals (1<sup>st</sup> revision). Perth: Telethon Institute for Child Health Research: 2009

# Barriers to addressing alcohol use in pregnancy for Health Workers

- ④ Lack of Knowledge about FASD; only 12% knew the essential features in WA
- ④ Information on Alcohol difficult to elicit; 32% found it difficult to ask
- ④ Concerns about 'labelling' & stigmatising; 53% thought diagnosis could stigmatise
- ④ NHMRC Guidelines not well known! The National Health and Medical Research Council guidelines is as follows;

“Maternal alcohol consumption can harm the developing fetus or breastfeeding baby.

- ④ For women who are pregnant or planning a pregnancy, not drinking is the safest option.
- ④ For women who are breastfeeding, not drinking is the safest option”



# Supporting Affected Families

Raising children with conditions that make up FASD can be challenging.

- Stable living environments.
- Early diagnosis and appropriate services.
- Specialised parenting & education programs.

Can improve outcomes for these children & reduce the severity of the behavioural & social problems exhibited by an affected child.



# Giving Mum LEGS to move forward.

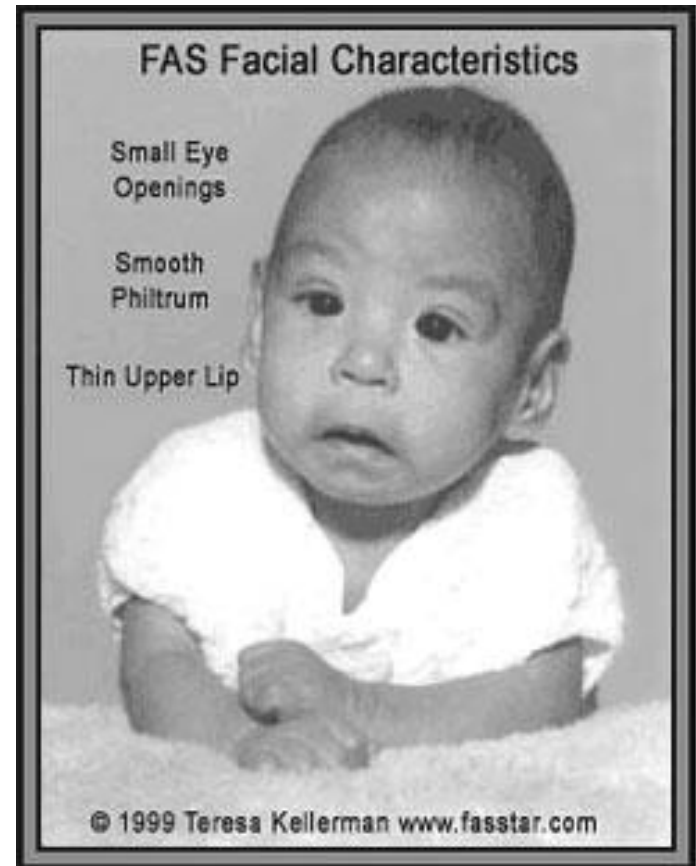
Mothers who drank alcohol need LEGS to move forward.

- ④ Listened to not lectured to
- ④ Encouragement not Judgement
- ④ Guidance not dictated to
- ④ Supported not patronised

# Infants

Strategies in infancy should focus on efforts to:

- Calm the baby.
- Address failure to thrive.
- Special methods can be used to swaddle, hold, soothe, feed and stimulate the infant.



# Childhood

- Children may have Alcohol Related Birth Defects such as vision, hearing and speech problems impediments that should be assessed as early as possible.
- Recommendations for a positive learning environment include: calm and quiet, structure and routine, repetition and reducing distractions.

# Adolescence and Adulthood

- ④ When children with conditions that make up FASD reach adolescence, behaviour may become challenging at school and home. Difficulties may include mental health problems, substance abuse and trouble with the law.
- ④ In some cases, problems progress to include incarceration, early parenthood and difficulties with employment and independent living.
- ④ People with conditions that make up FASD fail to consider the consequences of actions and this can lead to many adverse situations.
- ④ Adaptive function and cognitive ability become worse as the child gets older, contributing to social problems. Adolescents continue to need secure and structured environments. Advocacy and case management are important services at this stage.

# Diagnostic Features of FAS

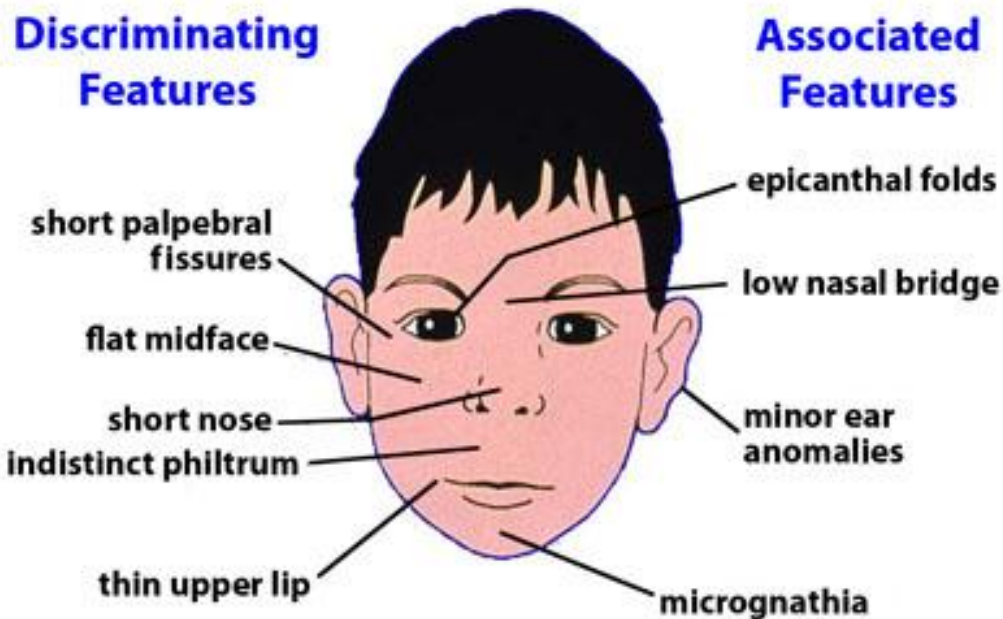
“A survey of Western Australian Health Professionals showed that only 12% could identify all four of the essential diagnostic features of FAS.”

- ④ Facial Features
- ④ Prenatal Alcohol Exposure
- ④ Growth Restriction
- ④ Central Nervous System Abnormalities

Alcohol and Pregnancy Project. Alcohol and Fetal Alcohol Spectrum Disorder; a Resource for Health Professionals (1<sup>st</sup> revision). Perth: Telethon Institute for Child Health Research: 2009

# FASD; Physical Aspects

## Faces in Fetal Alcohol Syndrome



### In The Young Child

Streissguth, 1994

*Note: Facial characteristics may more easily be recognized between the ages of one and eight, and may not be as apparent immediately after birth or during adolescence or adulthood.*

# Prenatal Exposure to Alcohol

This can be difficult to obtain due to feelings of guilt and shame.

Reassure mothers concerned that this is not about placing blame on what happened in the past; but about getting the very best support for their child now and into the future.

It is much easier to diagnose ADD and ADHD or even miss diagnose FAS!

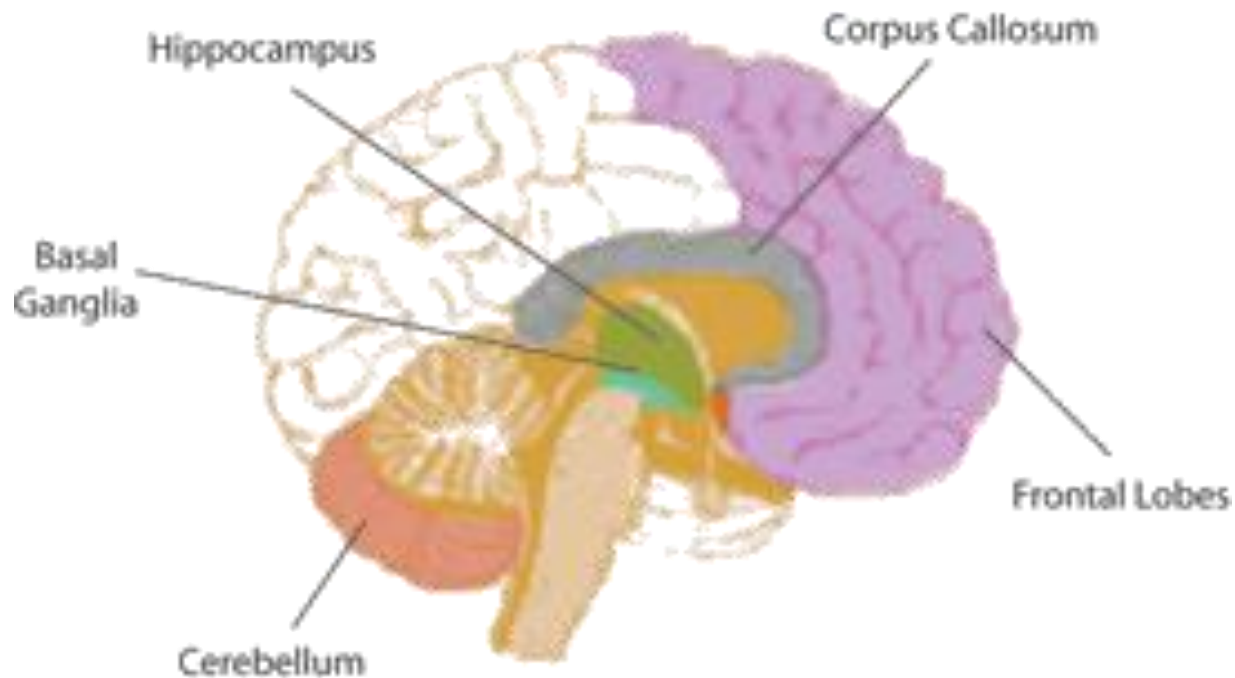
# Growth Restriction

At least one of the following:

- ⊙ Low birth weight for gestational age
- ⊙ Failure to thrive post-natally not related to nutrition
- ⊙ Disproportional low weight to height ratio

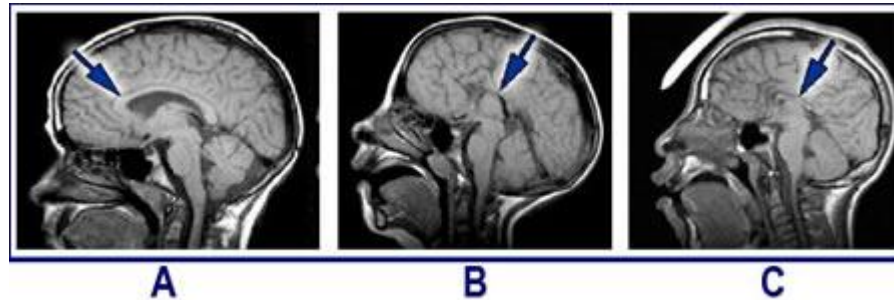


# Central Nervous System Abnormalities



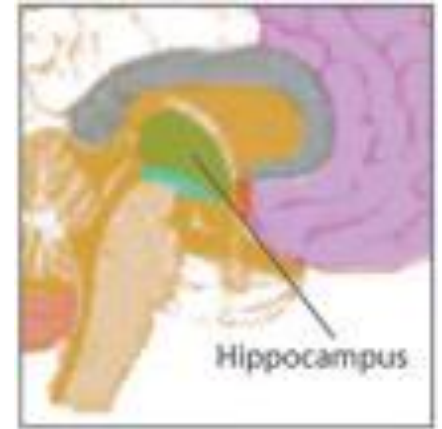
# The Corpus Callosum

- The Corpus Callosum connects the two hemispheres of the brain, allowing the left and right sides to communicate. These abnormalities have been linked to deficits in attention, intellectual function, reading, learning, verbal memory, executive function, and psychosocial functioning.



**Source:** Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49-52.

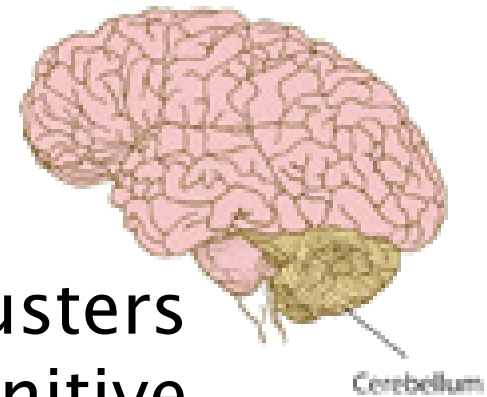
# The Hippocampus



- The Hippocampus is involved in memory. Children and adults with FAS may have deficits in spatial memory and other memory functions associated with the hippocampus. The hippocampus also acts as a mood control centre. Damage to the hippocampus can affect the ability to respond appropriately to emotions, such as anger.<sup>7</sup>

[http://fasdcenter.samhsa.gov/educationTraining/courses/FASDTheCourse/module2/mod2\\_ct\\_at\\_pg1.cfm](http://fasdcenter.samhsa.gov/educationTraining/courses/FASDTheCourse/module2/mod2_ct_at_pg1.cfm)

# Basal Ganglia and Cerebellum

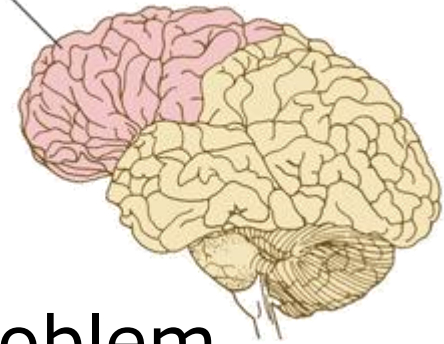


- The Basal Ganglia are nerve cell clusters involved in motor abilities and cognitive functions. This can affect skills related to perception, or inhibit inappropriate behavior.
- The Cerebellum is involved in both motor and cognitive skills. The cerebellum tends to be smaller in people with FASD. Damage to the cerebellum can cause learning deficits and problems with motor skills, such as balance and co-ordination.

[http://fasdcenter.samhsa.gov/educationTraining/courses/FASDTheCourse/module2/mod2\\_ct\\_at\\_pg1.cfm](http://fasdcenter.samhsa.gov/educationTraining/courses/FASDTheCourse/module2/mod2_ct_at_pg1.cfm)

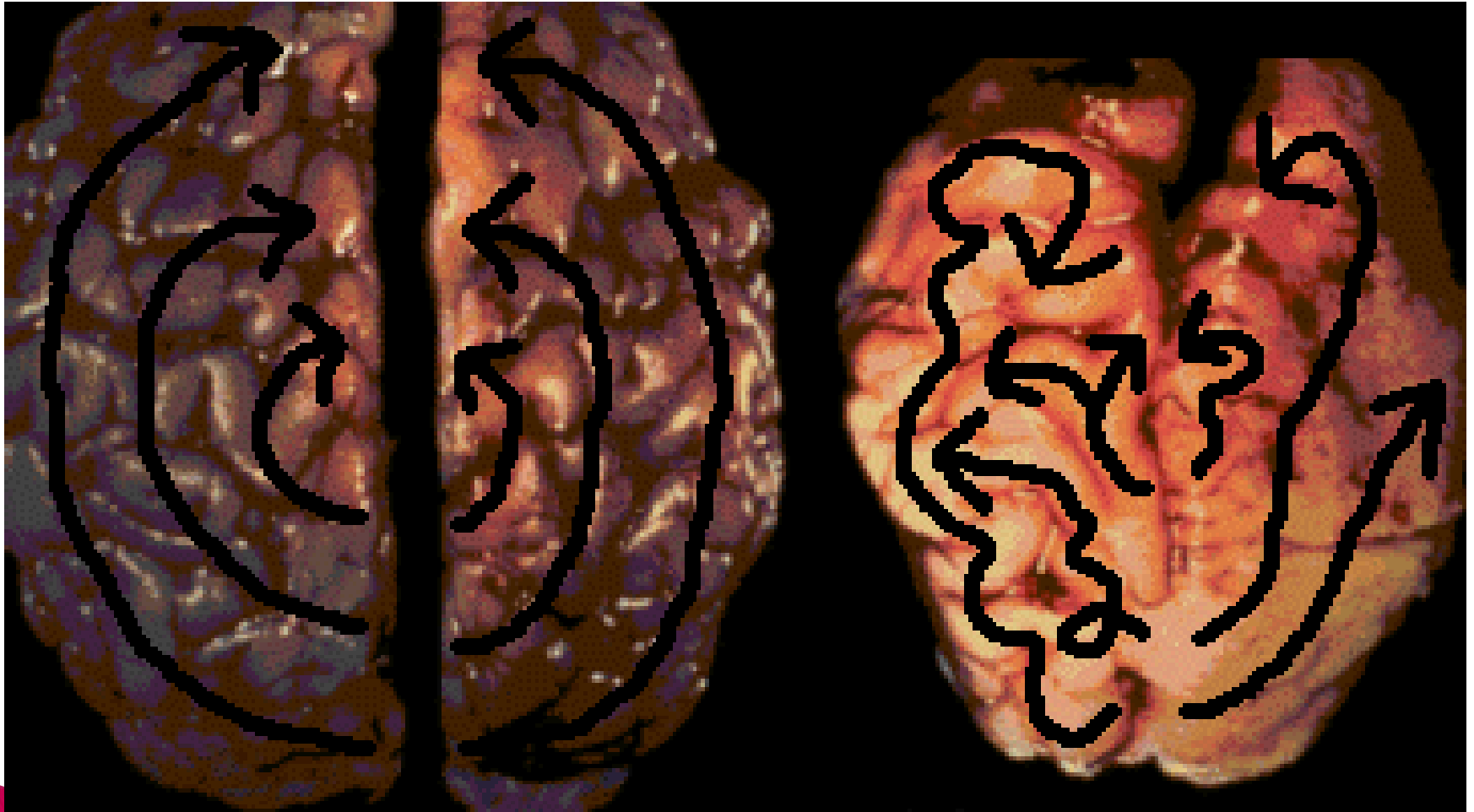
# Frontal Lobes

Frontal Lobes



- The frontal lobes control executive functions, such as planning and problem solving. They also control impulses and judgment. Frontal lobes can be smaller in teenagers and young adults prenatally exposed to alcohol. Persons with FASD may have poor impulse control & self-monitoring. They might engage in risky or illegal activity to fit in with peers.

[http://fasdcenter.samhsa.gov/educationTraining/courses/FASDTheCourse/module2/mod2\\_ct\\_at\\_pg1.cfm](http://fasdcenter.samhsa.gov/educationTraining/courses/FASDTheCourse/module2/mod2_ct_at_pg1.cfm)



"No alcohol for all nine months of pregnancy is best for baby"

# Signs & Characteristics: The FASD – MESS!

**Mental;** Memory deficit, struggles with school or work, maths & time, unable to link consequences to action, attention deficit; IQ can be 70 – 130. Needs an external brain; a reminder

**Emotional;** emotional outburst; withdrawn or anger, tantrums. Low self esteem. Doesn't know how they feel.

**Social;** trusting strangers, unaware of social rules – personal space, undiscerning of public & private spaces, easily lead. Acts young for age. Isolated.

**Skills;** impairment in gross & fine motor skills, master a skill one day unable the next day, delayed toilet training – bed wetting. Clumsiness & poor balance.

# Preventable Secondary FASD Issues

- Ⓜ Disrupted School Experience\* (60%)
- Ⓜ Mental Health Issues\* (90%)
- Ⓜ Trouble with the law\* (60%)
- Ⓜ Alcohol & drug problems\* (30%– 40%)
- Ⓜ Inappropriate Sexual Behaviour\* (40% - 50%)
- Ⓜ Unemployment & homelessness
- Ⓜ Vulnerability to physical, sexual, financial, social, and emotional abuse
- Ⓜ Isolation & loneliness
- Ⓜ Unsafe partnering and volatile relationships



Many mothers who have children with FASD have also been effected prenatally by alcohol so they have great difficulty parenting their children. NOT because they choose to be poor parents but rather they don't know how to be effective parents

(Fetal Alcohol Spectrum Disorder (FASD) The Preventable Disability: nofasard; [www.nofasard.org](http://www.nofasard.org))



# ADD/ADHD vs FASD

## Can you tell the difference?

ADD/ADHD	FASD
Have trouble focussing & sustaining focus	Can focus & sustain focus
When focused, student can learn & problem solve, etc	When focused, has trouble problem solving & using newly learned info
Student can shift focus when necessary	Has difficulty shifting focus
May act impulsively without forethought	May act impulsively
When things go wrong student is able to:	When things go wrong student is unable to (or slow) to:
•Process	•Process
•Understand what happened	•Solve the problem
•Problem solve	•Take responsibility

Adapted from FAS Times, Summer 1997: Fetal Alcohol Exposure & Attention: Moving Beyond ADHD

# FASD is Permanent!

## FASD is a lifetime disability

Early diagnosis is essential for both child and the family for

- ④ Early Intervention & prevention of secondary issues.
- ④ Appropriate treatment & support.
- ④ Reason for the child's behaviour; not a label.
- ④ Lets others understand the child's behaviour eg. teachers.
  
- ④ **FASD is not curable (No solution just strategies)**
- ④ Effective support includes
- ④ Special education and vocational programs, tutors,
- ④ Structured environments and life long care.

With support persons affected by FASD can achieve at school and find employment in the open market place!

(Fetal Alcohol Spectrum Disorder (FASD) The Preventable Disability: nofasard; [www.nofasard.org](http://www.nofasard.org))

# FASD is Prominent!

- ④ FASD is the leading known cause of mental retardation in the Western World and is a major public health issue.
- ④ Streissguth (1997) study found nearly one per hundred babies grew up to have either FAS or alcohol-related neuro-developmental disorders (ARND)
- ④ Only about 10% of children with FASD receive a diagnosis of FAS

# FASD is Pervasive!



“FASD pervades many places, many races, many faces! FASD does not respect culture, class or race; FASD is not just a concern for indigenous communities; Where ever alcohol is consumed, FASD has the potential to raise it’s face! With all pregnancies there is a man involved. Lets face it FASD is a concern for all Australians!”

– Ps Warren “Wazza” Harvey

Australian Research shows that:

50% of childbearing women drink. \*

30% participate in risky drinking.\*

50% of pregnancies are unplanned;\*

20 % went to doctors for support, 15% turned to family, 12% phone counsellors.\*

\*Marie Stopes International –

What Women Want When Faced With An Unplanned Pregnancy: Nov 2006

# FASD is 100% Preventable!

1. Public Awareness
2. Potentially Pregnant Women
3. Pregnant Women
4. Professionals
5. Postnatal Care



# FASD is MEN's business too!

- ④ Mutual Support; encourage her 'not to drink a single drop' when trying to conceive & during all 9 months of pregnancy.
- ④ Educate yourself; about FASD & the lifetime effects of drinking alcohol during pregnancy.
- ④ Notify your family & friends; about your decision & enlist their support, when announcing your pregnancy. Also, when you are invited to parties, dinner occasions and bbq's. Any where you think, your spouse might be offered a drink!

# Donuts are a great FASday treat

## They remind us that.....

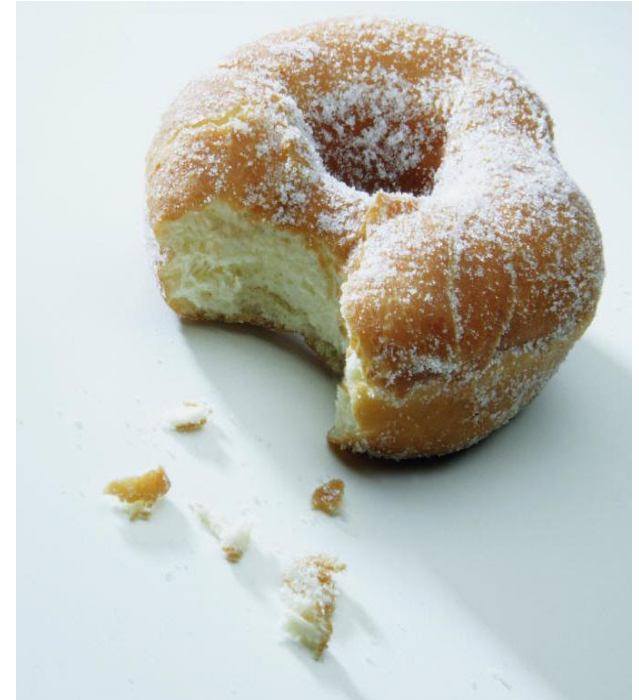


- ④ FAS kids look like every other kid but some thing is missing!
- ④ Their brain is damaged. FAS has been called the invisible disability.
- ④ But who focuses on what's missing when you eat a donut, so neither must we when speaking about kids with FASD.

# Looking at the sweeter side of FASD

## Common strengths of FASD kids

- ▶ Highly verbal
- ▶ Bright in areas
- ▶ Artistic, musical, mechanical
- ▶ Athletic
- ▶ Friendly, out going, affectionate
- ▶ Determined, persistent
- ▶ Willing
- ▶ Helpful,
- ▶ Generous



As a parent if you focus on what's missing you may miss the joy of raising a child with FASD!



# Where to from here!

- Do what you can to promote FASD awareness in your field of influence.
- Mark FASday in your diary and plan to host a FAStastic Event at your work place next year.
- FAS Awareness Week; 1 - 9 September
- FAS Day: 9/9