



Overview of Fetal Alcohol Spectrum Disorders (FASD)

IRETA

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NYS OASAS

Bureau of Prevention Services

Course Objectives:

Participants will learn to:

- Learn the causes of FASD and why women consume alcohol during pregnancy
- Understand the effects of prenatal alcohol use on a developing fetus, and across the lifespan;
- Learn about FAS and the importance of a diagnosis
- Understand the challenges presented by raising a child with an FASD
- Identify resources to help professionals and caregivers



Poll question #1



A Pregnant Woman Never Drinks Alone

VOL 181, No.2.National Geographic *THE WORLD AS THEY SEE IT*
Text and photographs by GEORGE STEINMETZ



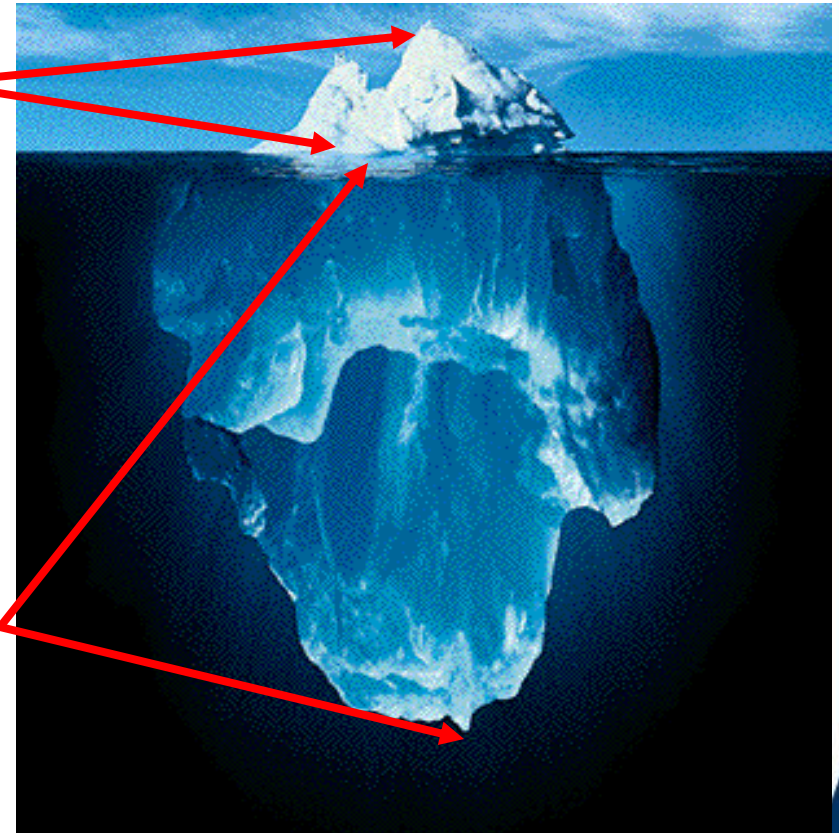
Fetal Alcohol Syndrome

- ✓ **Term first used in 1973 by Dr. David Smith and Dr. Kenneth Jones at the University of Washington**
- ✓ **One of the diagnoses used to describe birth defects caused by alcohol use while pregnant**
- ✓ **A medical diagnosis (760.71) in the International Classification of Diseases (ICD)**



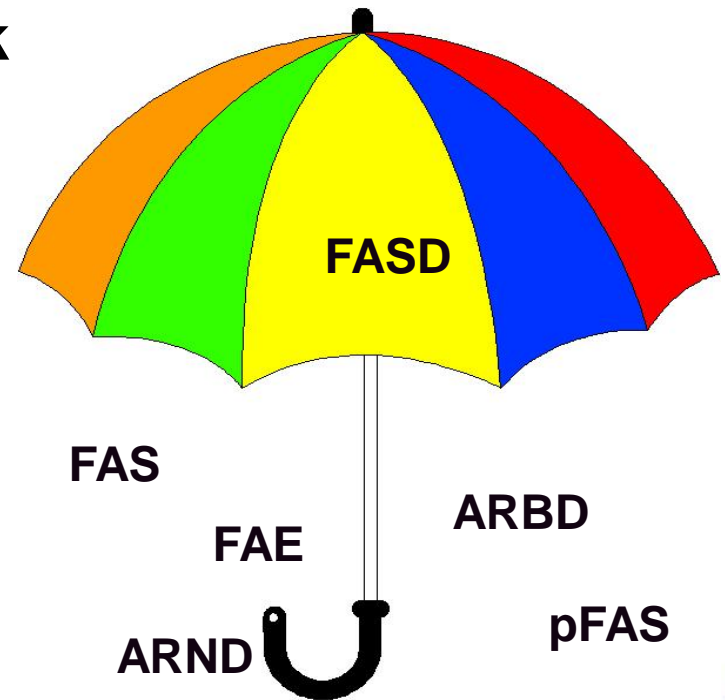
Fetal Alcohol Syndrome is only the tip of the iceberg.

- For every child born with full FAS, there are **FIVE** children born with invisible yet serious Fetal Alcohol Spectrum Disorders (FASD).
- Together FAS and FASD make up what is called Fetal Alcohol Spectrum Disorders (FASD).



Fetal Alcohol Spectrum Disorders (FASD)

- Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy
- May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications
- Not a clinical diagnosis



FASD Facts

- **100 percent preventable**
- **Leading known cause of preventable mental retardation**
- **Not caused on purpose**
- **Can occur anywhere, anytime pregnant women drink**



Cause of FASD

Alcohol is a teratogen

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

—IOM Report to Congress, 1996

The sole cause of FASD is women drinking alcoholic beverages during pregnancy.



Can the Father's Drinking Cause FAS?

- No, only the mother's drinking
- A woman's drinking behavior is greatly influenced by the drinking behavior of her partner, family, and friends.
- FAS prevention is not just a women's issue. Many pregnant women need support from their partners, extended family members and community in order to abstain from alcohol.



Poll question #2



Number of Women Drinking During Pregnancy

www.cdc.gov

December 15, 2011

- The number of women who drink alcohol while pregnant **has not changed substantially** over time, according to a 15-year study by the Centers for Disease Control and Prevention. About one in eight women drank alcohol while pregnant.



Why do Pregnant Women Drink Alcohol?

Holly Graham, RN,BA,BScN, MN

- **Unaware that they are pregnant**
- **Social norm - common when celebrating festive seasons or special events**
- **Know other women who drank during pregnancy & who have children who appear outwardly to be healthy.**
- **May not know how much harm alcohol can cause**
- **Use alcohol to cope with difficult life situations such as poverty, violence, isolation, despair, or depression**
- **Struggling with addiction**



The Cause of FASD

FASD does not occur **only** in children of women who are alcoholics



Who is at Risk of Giving Birth to a Child with an FASD?

- Women with co-occurring disorders
- Families with a history of multigenerational alcohol use
- Women who have experienced stressors that increase the risk of alcohol use or abuse
- Women who have an FASD
- Women who have given birth to a child with an FASD

All women of childbearing age who drink

Dan Dubovsky- FASD Specialist



Prevention is the Best Cure

Ask all women of childbearing age about alcohol use:

- Ask routinely at every medical appointment.
- Ask at appointments in various systems.
- Ask in a nonjudgmental, respectful manner.
- Use effective screening tools.
- Ask about possible prenatal exposure.

Indicate that stopping drinking at any time during pregnancy will help the fetus.

Convey the message: If you're pregnant, don't drink. If you drink, don't get pregnant.



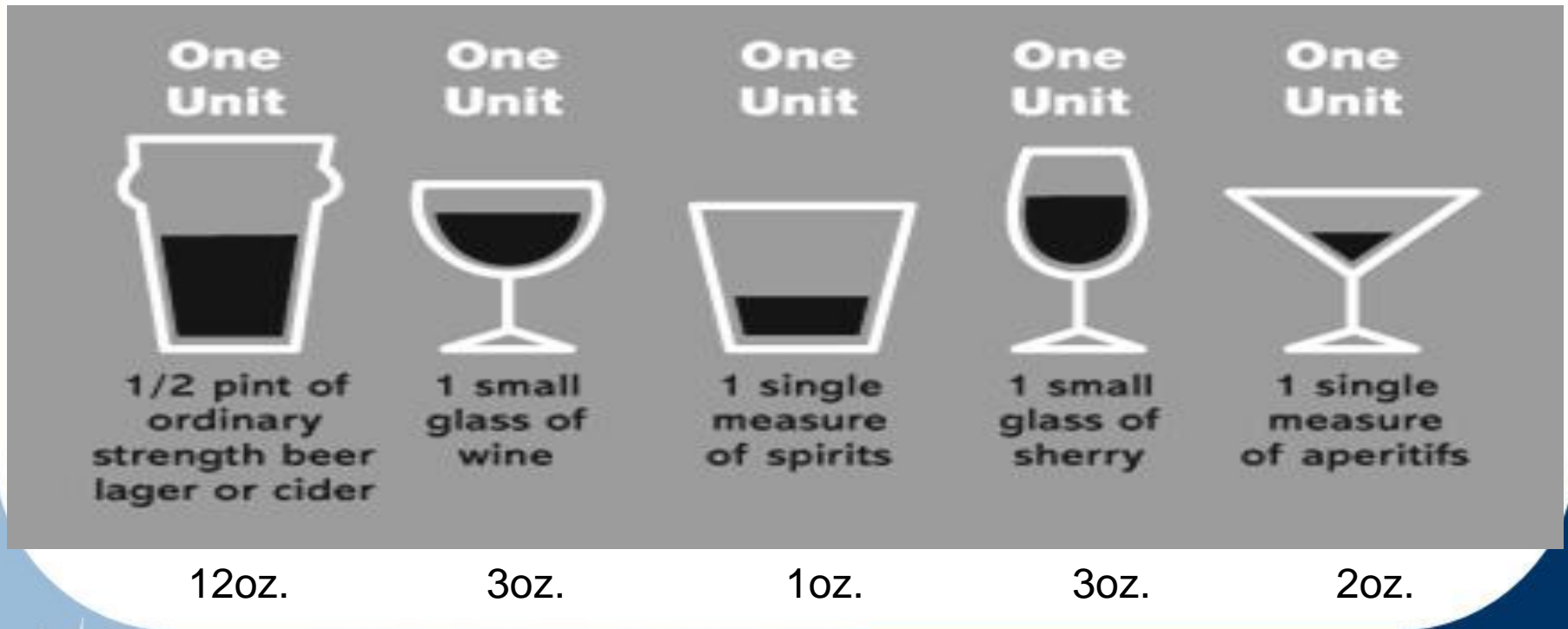
FASD and Alcohol

- All alcoholic beverages are harmful.
- Binge drinking is especially harmful.
- There is no proven safe amount of alcohol use during pregnancy.



FASD and Alcohol

- **Binge = 4 or more drinks on one occasion for a women, 5 or more for a man**
- **Drink = 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of hard liquor**



What *Is Not* a Standard Drink?

- Martini/Appletini
- White Russian
- Long Island Iced Tea
- Margarita or Daiquiri

A mixed drink made with two or more liquors **is not** a standard drink.

The alcohol content is **2- to 5- times more than a standard drink.**

A “**40**” bottle of beer or malt liquor or a beer stein is not a standard drink!

A balloon glass of wine contains **2- or 3-times more alcohol than a standard drink.**



Size does matter!

My Doctor said "Only 1 glass of alcohol a day". I can live with that.



How Much Alcohol Causes Damage?

- There is no way to predict how much alcohol will cause how much damage in any one individual
 - People absorb and metabolize alcohol differently
 - The ability of the liver to process alcohol has an effect
 - Genetics has an effect
 - The presence or absence of certain gene pairs
 - Age of mother
 - Parity (number of previous children)
 - Co-occurring issues e.g., tobacco use, other substance use; nutrition

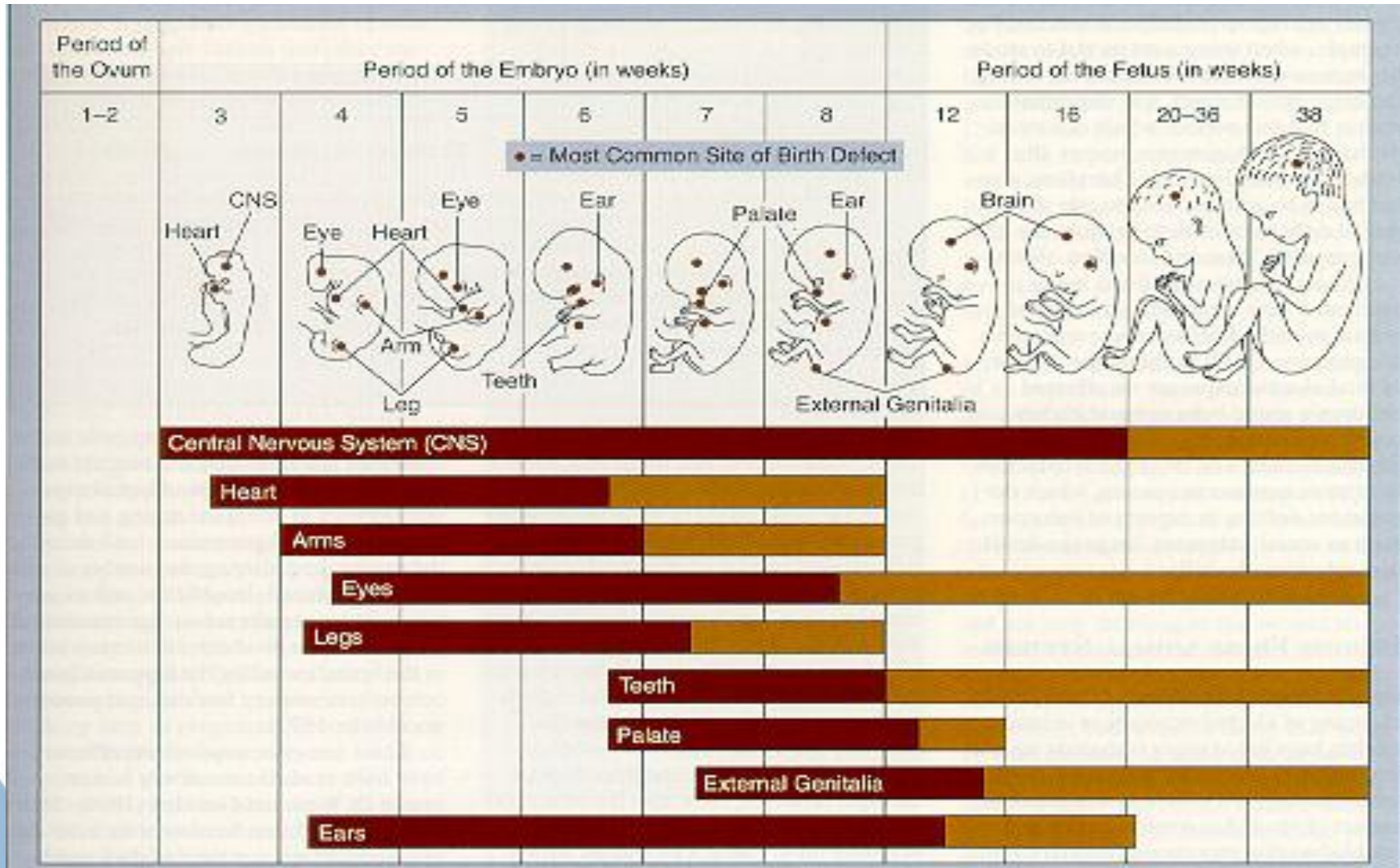
Dan Dubovsky-FASD Specialist



A Variable: Gestational Timing Coles C.

Critical periods for prenatal alcohol exposure. *Alcohol Health Res World*. 1994;18:22-29.)

Dark bars-most sensitive periods of development; Lighter bars represents periods of development during which psychological defects and minor structural abnormalities would occur.



Associated Anomalies

- Cardiac anomalies
- Joint and limb anomalies
- Neurotubal defects
- Anomalies of the urogenital system
- Hearing disorders
- Visual problems
- Severe dental malocclusions



Medical Costs

Djesika D. Amendah □ , Scott D. Grosse, Jacquelyn Bertrand

- Children with FAS incurred annual mean medical expenditures that were nine times as high as those of children without FAS during 2005 (**\$16,782 vs. \$1,859**).



Benefits of Identification and Diagnosis of FASD

- The individual is recognized as having a disability, which may decrease anger and frustration among individuals, families, providers, and the community.
- The individual may feel relieved that he or she is not just “lazy” or “a bad person.”
- We can set realistic goals, focus on why people are not succeeding in a program and how we can help them “succeed.”
- We can access health/support services and improve treatment outcomes.
- We can prevent future births of children with FASD.

“Knowledge is Power”



Poll question # 3



Who Can Diagnose FASD?

- **Trained team of professionals**
- **Physicians**
 - Developmental Pediatricians**
 - Pediatric Neurologists**
 - Pediatricians**
 - Family Physicians**
- **Psychiatrist**
- **Dysmorphologists**
- **Clinical Geneticists**



Identifying FAS: What to Look For



This patient is microcephalic, underweight, and of short stature. He has the typical facial features of FAS. With his foster mother's permission he will attend an anthroposophical special school because of behavioral difficulties.

- **Damage to the central nervous system**
- **Evidence of mother drinking while pregnant**
- **Growth deficiency in height and/or weight**
- **Specific differences in facial characteristics**

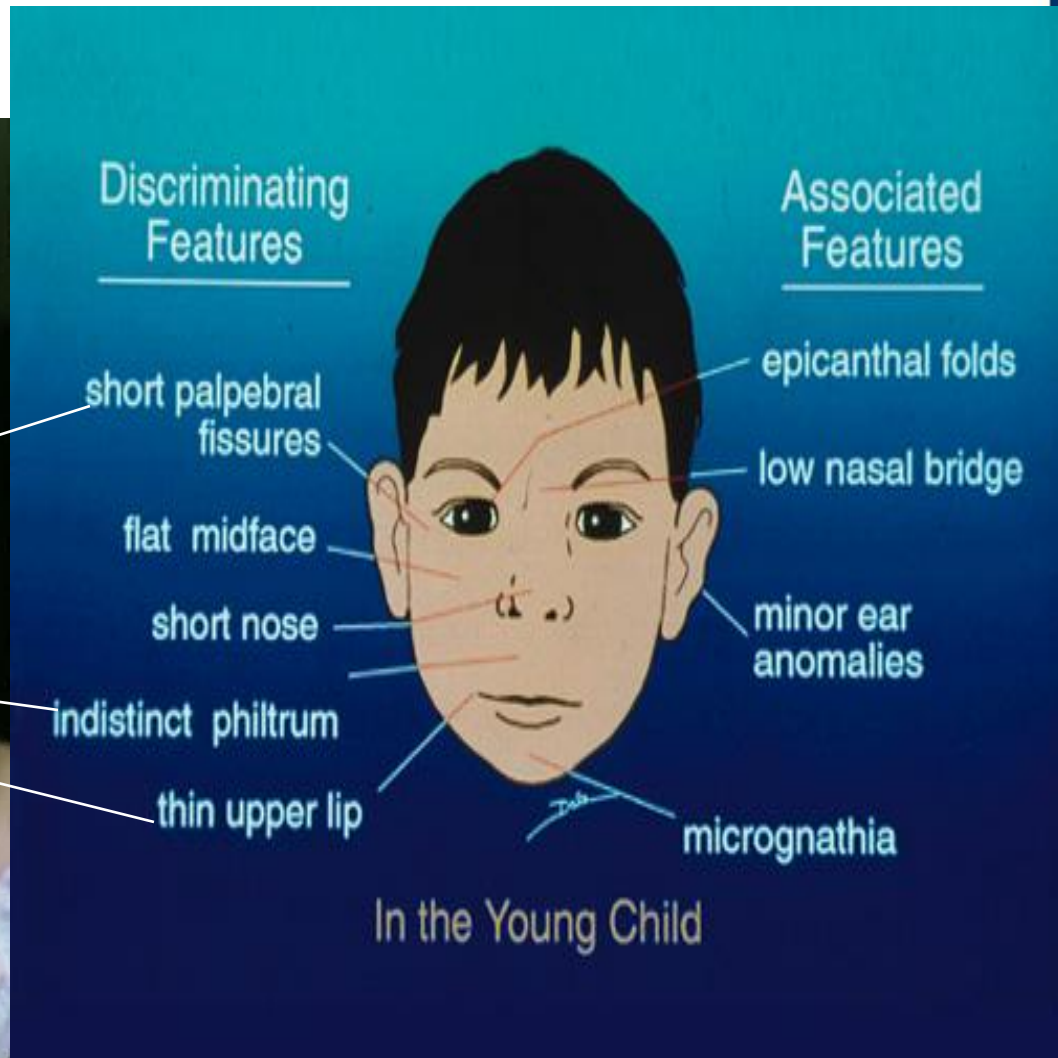
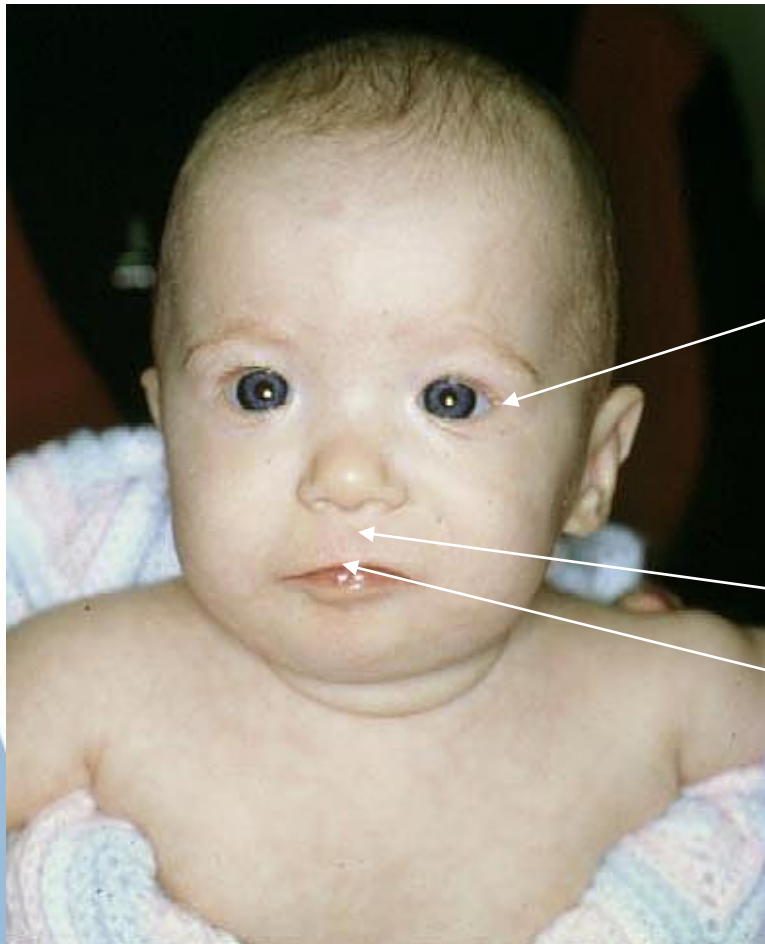


Stunted Growth in a Child



Facial Characteristics: FAS

Panel: Streissguth, 1994, 1996

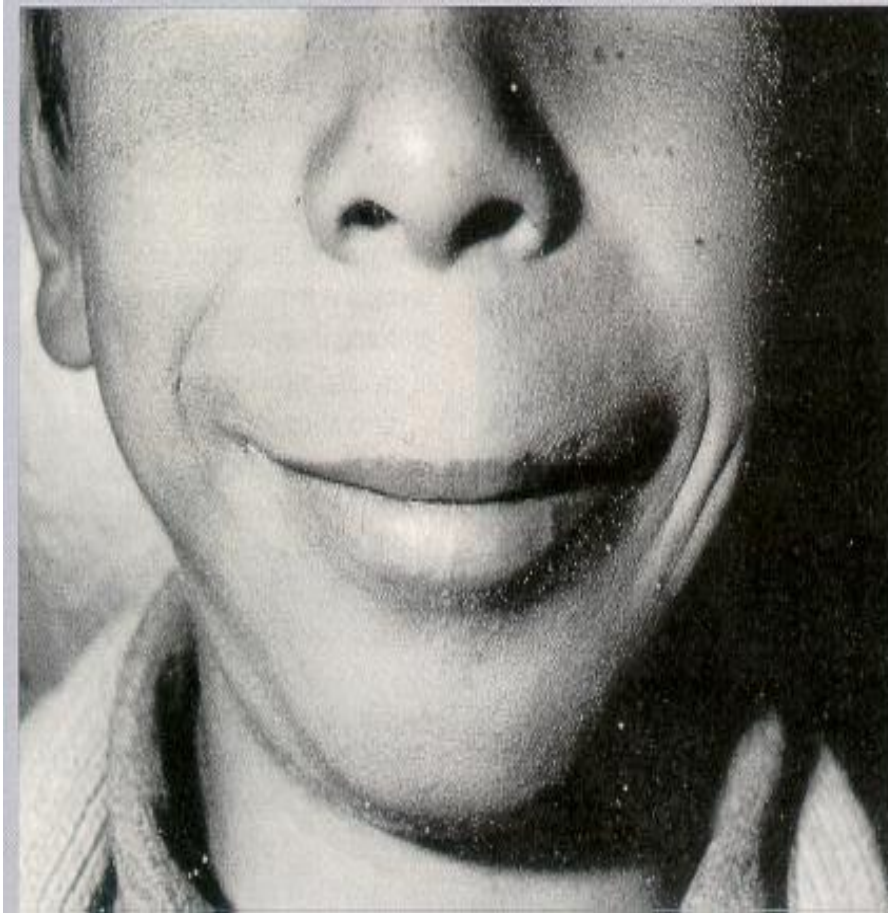


Short Palpebral Fissures

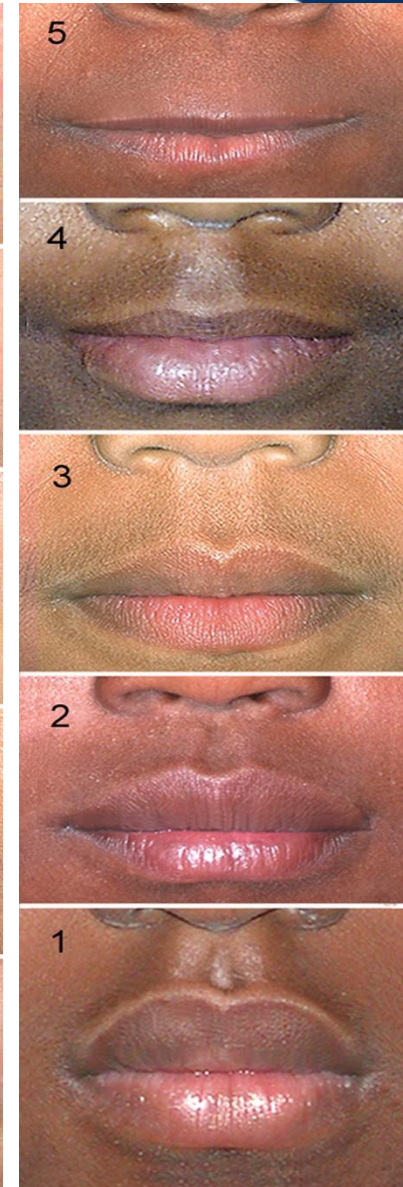
<http://www.cdc.gov/ncbddd/fas/default.htm>



Smooth Philtrum, Thin Upper Lip



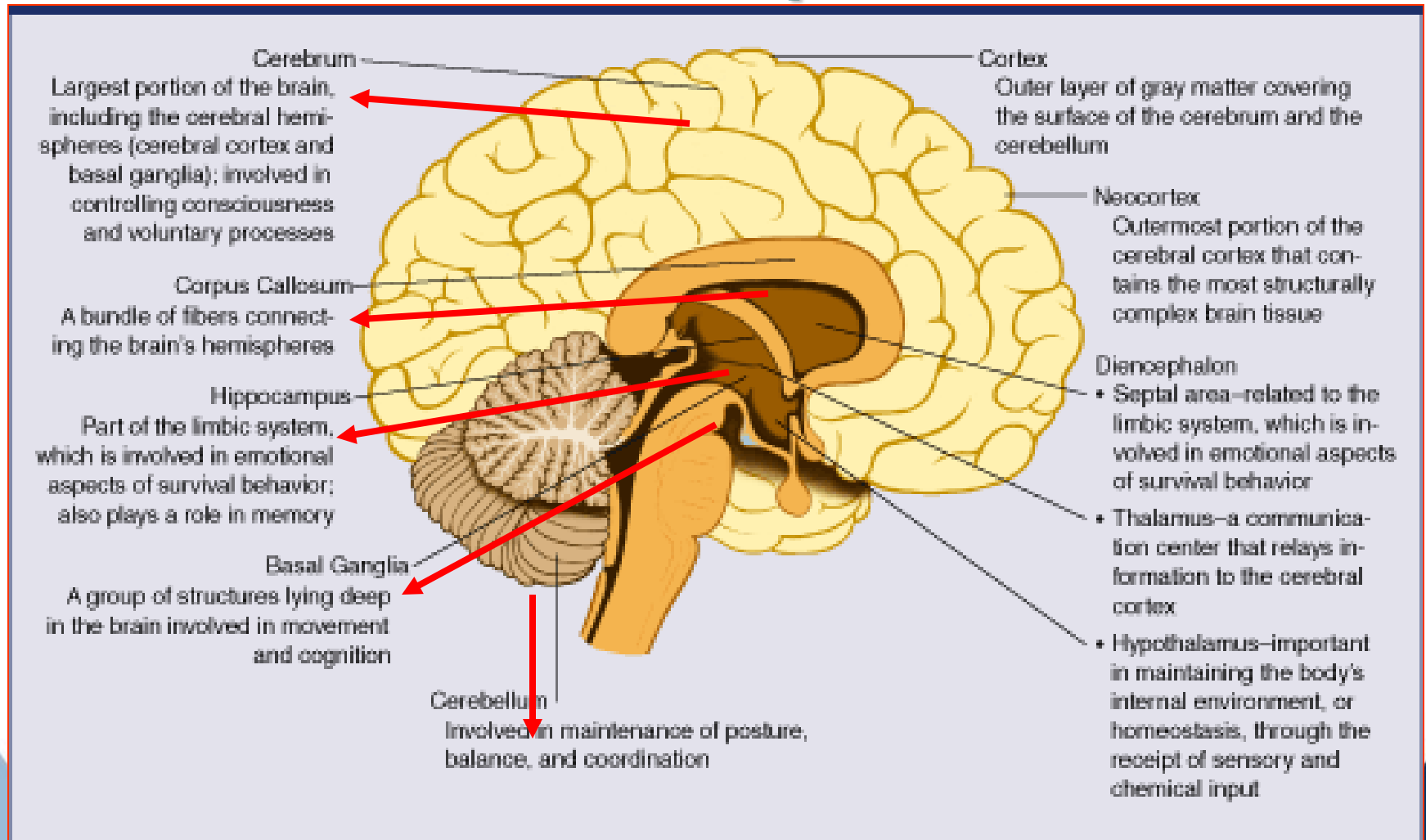
Lip-Philtrum Guide 1



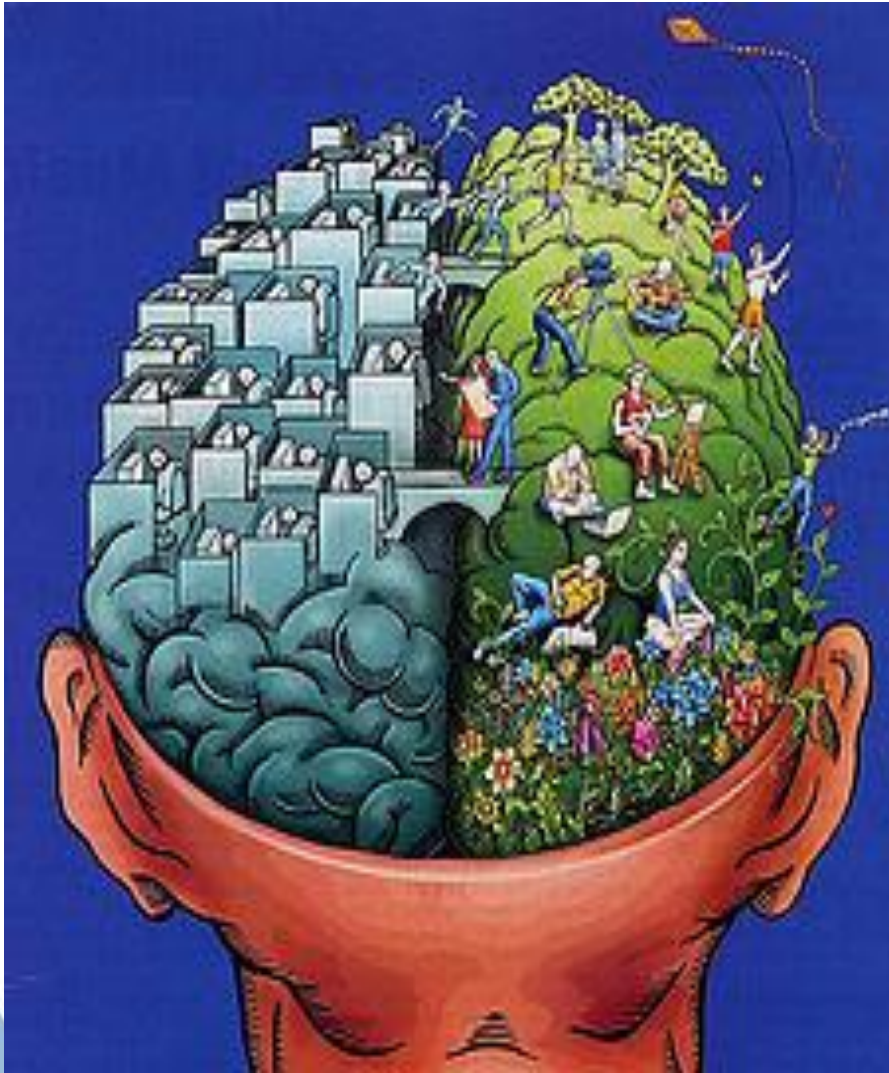
Lip-Philtrum Guide 2



Brain areas that can be affected by alcohol exposure



Left Brain - Right Brain



Left Brain-

- Details
- Categorizes
- Thinks in language
- Connects internal to external
- Calculates intelligence
- Voice that says "I am"
- Linear, methodical

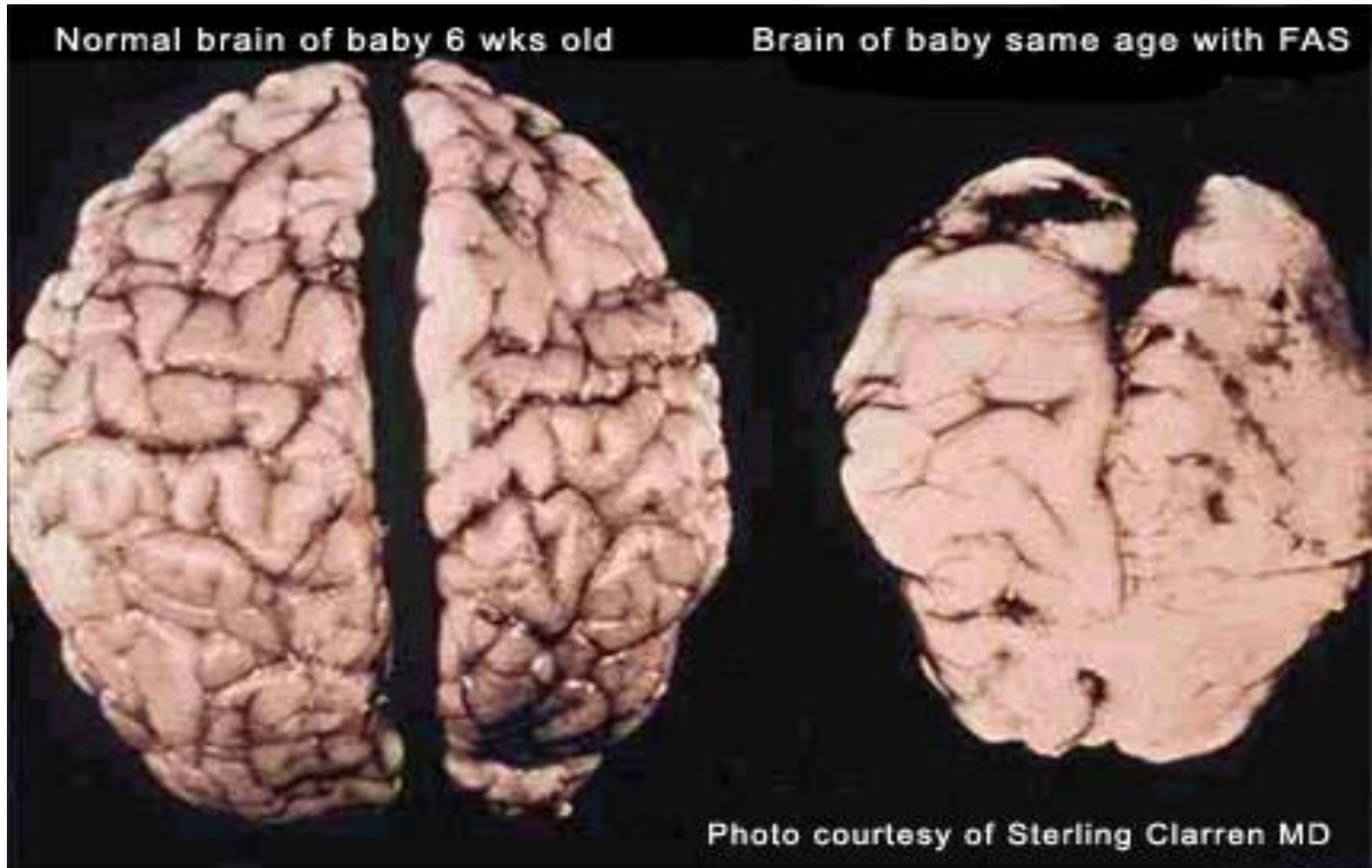
Right Brain-

- Right here, right now
- Thinks in pictures
- Kinetic, sensory
(looks, smells, feels, hears)
- Energy-all connected to others
- The life force, power of the universe
- More peaceful

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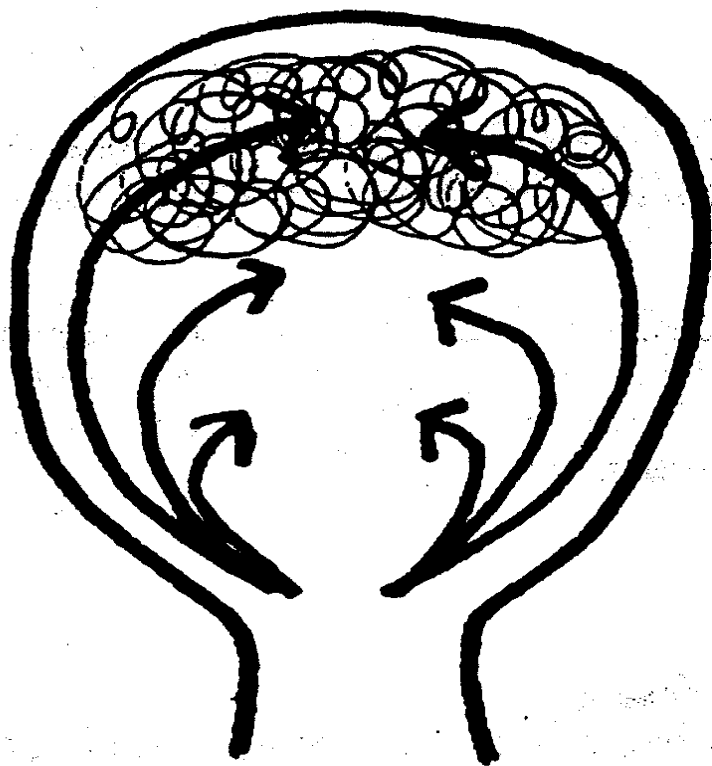
FAS and the Brain



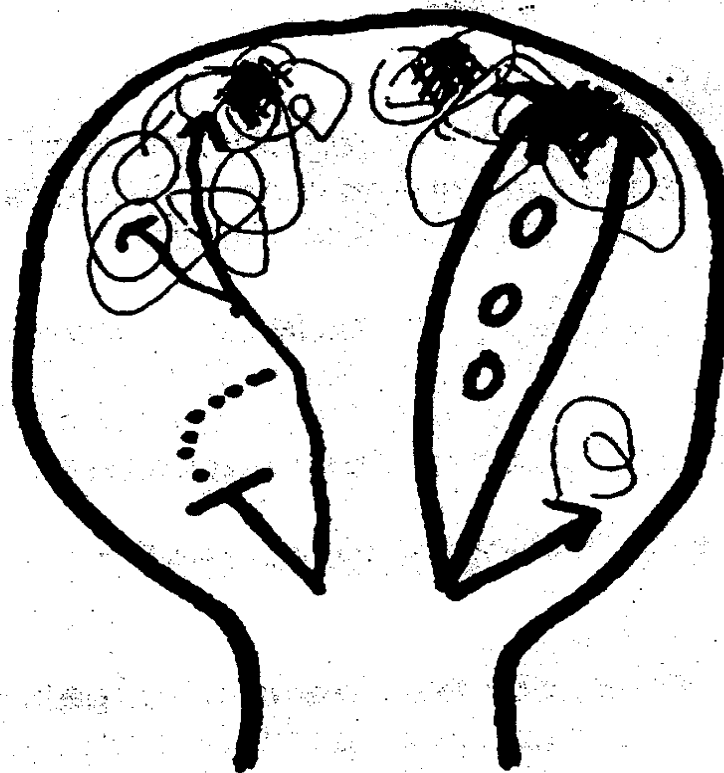
Prenatal alcohol exposure causes brain damage. Effects of FASD last a lifetime. People with an FASD can grow, improve, and function well in life with proper support.



Visual Model of Brain Differences



Normal brain development is complex, orderly, and sequential. Rich neural networks provide mechanisms for basic abilities: Storing, remembering, integrating, and retrieving information.



FAS/ARND: There is often undergrowth, overgrowth, gaps and tangles. Fewer cells, the brain structure and chemistry may be altered affecting basic cognitive abilities and sensory responses.

Adapted from Malbin (1999)



Steps to take after a Diagnosis

(A Manual for Community Caring, FAS/E Support Network, 2002)

- Explaining diagnosis (Brain works differently)
- Dealing with anger, grief and loss
- Finding necessary support & services
- Respite care
- Professional counseling
- Support groups



General Issues in FASD

- **Often undiagnosed, especially in adolescents, adults, and persons without facial features of FAS**
- **More difficulties seen in those without the facial features and with higher IQs**
- **Adaptive functioning significantly more impaired than IQ**



Primary Disabilities in Persons With FASD

- **General intelligence**
- **Mastery of reading, spelling, and arithmetic**
- **Do not complete tasks or chores and may appear to be oppositional**
- **Do not accurately pick up on social cues**



Poll question #4



FASD is mostly mental health

Some likely Co-Occurring Disorders

Source: Larry Burd, Ph.D., Director, North Dakota Fetal Alcohol Syndrome Center

- **ADHD**
- **Learning disabilities**
- **Depression**
- **Sleep Disturbances**
- **Substance abuse**
- **Schizophrenia**
- **Bipolar Disorder**



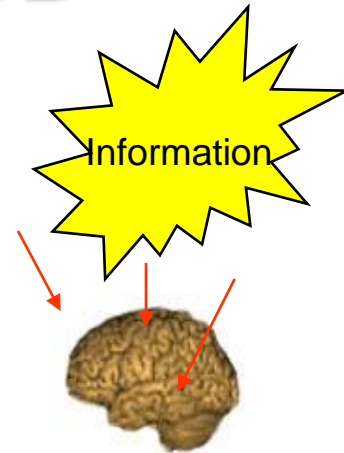
Likely Co-Occurring Disorders With FASD

- **Sensory processing disorder**
- **Reactive attachment disorder**
- **Separation anxiety disorder**
- **Posttraumatic stress disorder**
- **Traumatic brain injury**
- **Medical disorders (e.g., seizure disorder, heart abnormalities)**



Overall Difficulties for Persons With FASD

- Taking in information
- Storing information
- Recalling information when necessary
- Using information appropriately in a specific situation



Infancy & Early Childhood, Birth-5 *Challenges*



- Sensitivity to light, sounds, & touch
- Poor sucking response
- Failure to thrive
- Sleep disturbances
- Delays in walking, talking, toilet training
- Hyperactive
- Irritable
- Temper tantrums



Childhood, 6-11 years old

Challenges

- Easily influenced
- Attention & memory problems
- Difficulty with cause & effect, consequences
- Easily distracted
- Delayed physical & cognitive development
- Poor understanding of social rules & expectations
- No sense of boundaries
- Easily victimized by peers



Adolescence, 12-17 years old

Challenges



- Attention & memory problems
- Impulsive
- Inappropriate social skills
- Faulty logic
- Low self-esteem
- Easily victimized
- Depression, anxiety
- Risk of substance abuse
- Good expressive language/poor comprehension



Adulthood, 18+ years

Challenges

- Poor comprehension of social expectations
- Social, sexual &/or financial victimization
- Increased expectations by others
- Withdrawal & social isolation
- Daily obstacles—housing, employment, transportation, money



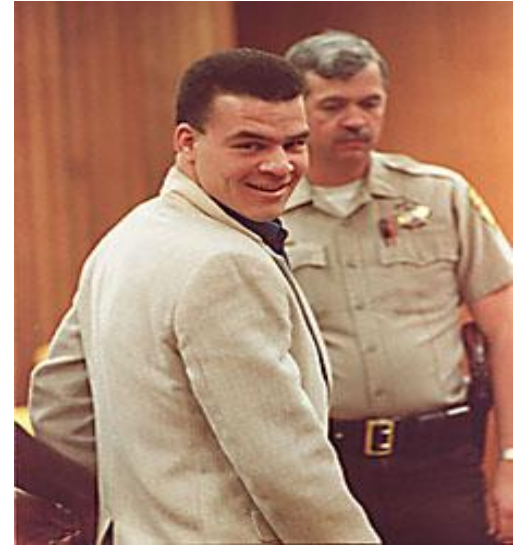
Developmental Skills At Age 18

Adapted from research findings of Streissguth, Clarren, et al., by Diane Malbin, 1994

Skill	Developmental Age Equivalent
Comprehension.....	6 years
Emotional maturity.....	6 years
Social skills.....	7 years
Money and time concepts.....	8 years
Living skills.....	11 years
Reading ability.....	16 years
Physical maturity.....	18 years
Actual age.....	18 year
Expressive language.....	20 years



When the primary brain injury is never acknowledged and addressed, the individual grows up believing he is “stupid” and “worthless.”



Secondary disabilities develop as a result of the failure to properly deal with the primary disability.



Secondary Disabilities in Persons With FASD

- **Mental health issues – 94%**
- **Dependent living – 83%**
- **Problems with employment – 79%**
- **Trouble with the law – 60%**
- **Confinement – 50%**
- **Inappropriate sexual behavior – 45%**
- **Disrupted school experience – 43%**
- **Alcohol and drug problems – 35%**

Streissguth, 1996



Protective Factors Against Secondary Disabilities

- Stable, good quality home
- Not having frequent changes of homes
- Not being a victim of abuse, neglect, or violence
- Receiving developmental disabilities services
- Diagnosed before the age of 6



Services/Supports That May Assist Children with FASD

“Sharing Stories...Finding Hope”, CDC/The Arc 2003

- Family support, including **respite care**
- Child care
- Education – early intervention, preschool, school aged special education
- Vocational & transition services
- Other basic services



<http://www.fassn.org/photos.htm>



8 Magic Keys for Successful Interventions



- **Be concrete**
- **Be consistent**
- **Use repetition**
- **Use routines**
- **Keep it simple**
- **Be specific**
- **Provide structure**
- **Provide supervision**

<http://www.fassn.org/>

Evensen & Lutke,
(1997)



FASD Prevention Strategies & FASD Treatment Interventions

More information:

On Wednesday, **April 18, 2012** from 2 - 4 pm I will be presenting a follow-up FASD Webinar (a “Part 2”) that will address evidence-based strategies for helping women with alcohol problems, as well as interventions to assist those living with an FASD.



Poll question #5



FASD Resources: Web Links

- **NYS Office of Alcoholism & Substance Abuse Services (NYS OASAS):** www.oasas.state.ny.us/fasd
- **SAMHSA FASD Center for Excellence:** www.fascenter.samhsa.gov

State Systems of Care:

<http://fascenter.samhsa.gov/statesystemsofcare/statesystemsofcare.cfm>

- **Centers for Disease Control and Prevention FAS Prevention Team:** www.cdc.gov/ncbddd/fas
- **National Organization on Fetal Alcohol Syndrome (NOFAS):** www.nofas.org
- **FASLINK (online forum):** <http://www.acbr.com/fas/faslink.htm>



Questions and Answers



Thank you for listening!!



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