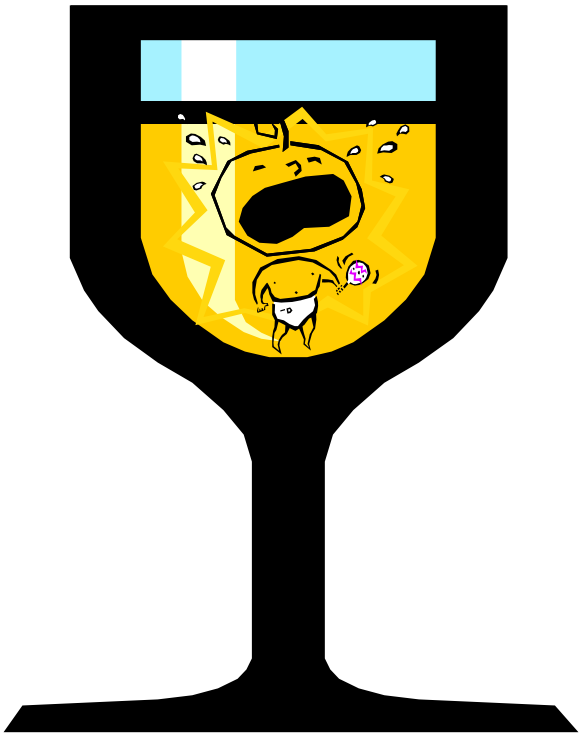
TCHP Education Consortium

Fetal Alcohol Syndrome



Introduction/Purpose Statement

Fetal Alcohol Spectrum Disorders (FASD) are the single largest cause of mental retardation in the Western world. It is all the more tragic given that FASD are the only congenital cause of mental retardation that is 100% preventable. The cost to society as well as the individuals and families dealing with this disorder is staggering. Why is it that it persists? Why is it that despite all that's known about FASD, health care professionals are still not particularly savvy in this area? As health care professionals there is a lot we can do to educate our patients and connect families with resources to deal with this disorder. The purpose of this home study is to help you educate yourself so you can make a difference in the lives of the families you deal with.

Target Audience

This home study was designed for nurses who have no familiarity with Fetal Alcohol Spectrum Disorders; however, other health care professionals are invited to complete this packet.

Content Objectives

1. Define Fetal Alcohol Spectrum Disorder (FASD) and Fetal Alcohol Syndrome (FAS).
2. Describe the risk factors that can lead to FASD.
3. Identify five traits of a child with FASD.
4. Explain why the neurodevelopmental disorders that occur with FASD can be devastating.
5. Describe how the timing of prenatal alcohol exposure during pregnancy affects the development of disorders in the child.
6. Identify three ways that health care professionals can decrease the impact of FASD.
7. List three points to include in patient education with a family dealing with FASD.

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Contact Hour Information

For completing this **Home Study**, you are eligible to receive:	**2.5 contact hours** (calculated using the Minnesota Board of Nursing 50 minute contact hour). **OR** **2.08 contact hours** (calculated using the WNA-CEAP criteria for certified nurses needing ANCC-approved contact hours). ***Criteria for successful completion:*** You must read the home study packet, complete the post-test and submit it to TCHP for processing.

Please see the last page of the packet before the post-test for information on submitting your post-test for contact hours.

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Overview

As a former pediatric nurse I thought I knew quite a bit about Fetal Alcohol Syndrome. I had held and taken care of many kids in the hospital with this disorder. I thought it was a fairly rare disorder that seemed to strike deep in the Native American community. I started reading to prepare to write this booklet and was shocked to find out what a common and devastating disorder this is and that it knows no boundaries in terms of race, socioeconomic status, or educational level. Even "Minnesota nice" doesn't help--Minnesota ranks 7th highest in the nation for frequent drinking in women of childbearing age.(1) After you are done reading this I hope you feel the same imperative I do to get the word out about the toxic effects of alcohol on a developing fetus.

I wanted to put a "face" to this syndrome, so I have created a fictitious character named Jill. Her story is a composite of cases and stories I have encountered along the way.

Let's Meet Jill…

Jill is the 19 year-old daughter of Bill and Kate, an upper middle class couple living in an outer ring suburb. Jill has always been a good student and is currently pre-law at the local college. Jill enjoys attending many parties that are a part of the social life at her college. What Jill doesn't know yet is that she is pregnant.

What is Fetal Alcohol Spectrum Disorder (FASD)?

Fetal Alcohol Spectrum Disorder

FASD is not a diagnosis but an umbrella term used to describe the range of effects that can result from prenatal alcohol exposure. FASD may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

The term FASD refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), fetal alcohol effects (FAE) or partial fetal alcohol syndrome (pFAS), and alcohol-related birth defects (ARBD). (35)

Fetal Alcohol Syndrome

More than 30% of babies born to alcoholic mothers sustain enough damage from in utero exposure to alcohol to be diagnosed with full FAS. (2)

Fetal Alcohol Syndrome (FAS) is a term that was first used in 1973 to describe birth defects caused by alcohol use while pregnant. FAS is a disability characterized by facial anomalies, low birth weight, mental handicaps or learning disabilities, central nervous system dysfunction (poor coordination, hyperactivity, attention problems, etc.), and varying degrees of damage or malfunction of internal organs.

To receive a clinical diagnosis of FAS, deficits must be seen in each of these three areas:

1. **Growth retardation**, either in utero or postnatally
2. **CNS damage** (irreversible brain damage, learning and behavioral disorders, deficits in memory and attention, hyperactivity, speech and language delays, poor coordination)
3. **Head and facial abnormalities** (small head circumference, abnormally small and widely spaced eyes, epicanthal folds, flat midface, short and upturned nose, smooth and wide philtrum, thin upper lip, underdeveloped jaw)

Not all children with FAS are alike. Some will be more severely affected than others and in different ways. Each child will have his or her own special needs, problems, and potential.

ARND, Partial FAS, or FAE

Sometimes children have deficits but do not meet all three of the criteria listed above and, therefore, do not receive a diagnosis of FAS. These children may lack the outward physical appearance of alcohol damage and have a higher IQ, but the internal damage to the brain and other organs can be just as serious as full FAS. Their mothers are found to drink smaller daily amounts of alcohol than mothers who have children with FAS, however, these children do not necessarily have a less severe form of FASD.

Fetal Alcohol Effects (FAE) is a term first used in 1978 to describe deficits similar to FAS bit did not meet all the criteria for a FAS diagnosis. The term Partial Fetal Alcohol Syndrome (pFAS) describes those with alcohol-related prenatal damage but without all the facial abnormalities. There is also Alcohol-Related Neurodevelopmental Disorder (ARND), which describes

those with alcohol-related prenatal damage but with little or no facial abnormalities. All of these terms are still out there in the current literature and may be used for diagnosis. (35, 36)

For the purposes of this packet, the terms used in a quoted source will used as they were presented or the term ARND will be used. My recommendation is to not get hung up on the words—all 3 terms (FAE, pFAS, and ARND) describe pretty much the same thing: someone who has deficits caused by prenatal exposure to alcohol but who does not meet all the criteria for a FAS diagnosis. The usual deciding factor is the facial abnormalities. In other words, they don't "look" like they have FAS.

It is estimated that the incidence of ARND is 3-10 times that of those diagnosed with full FAS. The lack of specific criteria for ARND makes estimation of incidence and diagnosis difficult.

Other Terms

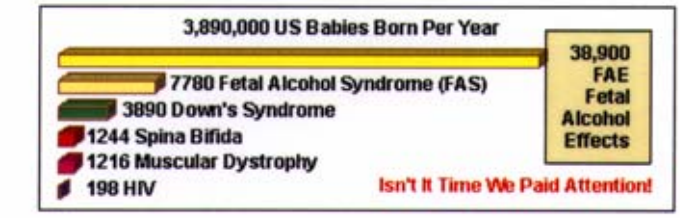
Other terms you may encounter that relate to disorders caused in children exposed in utero to alcohol are:

- **Static Encephalopathy (SE)**, which refers to a brain injury that will not change (won't get worse, won't get better). In the case of FAS, the SE is related to prenatal exposure to alcohol.
- **Alcohol Related Birth Defects (ARBD)**, which refers to certain abnormalities such as heart defects, sight and hearing problems, joint anomalies, etc. that can occur with prenatal exposure to alcohol.

What is the Scope of the Problem?

FASD is the leading cause of mental retardation in the USA. The incidence of FASD worldwide is 1.9 cases per 1,000 births, a rate that is 20 times the rate of infantile HIV. Figure 1 very graphically shows that FASD is far and away a much more pervasive problem than HIV, Spina Bifida, Muscular Dystrophy, or even Down's Syndrome.

Figure 1: Incidence of FAS and FAE in the USA Compared to Other Disorders
(Duplicated with Permission: Better Endings/ New Beginnings)



Alcohol damage to the fetus will vary greatly due to the volume of alcohol ingested, the time alcohol is ingested during the pregnancy, peak blood alcohol levels, genetics, and environmental factors. All fetuses will suffer some effects because it takes very little alcohol to cause serious damage. Alcohol is toxic at all concentrations to a developing fetus. In fact, the U.S. Surgeon General has warned that: ***There is no known safe level of alcohol consumption during pregnancy***.(3) It has been estimated that more than 10% of children born have been exposed to high levels of alcohol in utero. The lifetime cost of one baby with FAS could be as high as $4 million.(4) Taxpayers are currently estimated to be spending $5 million per day on FAS.(5) The mental retardation associated with FAS has by itself been estimated to account for as much as 11% of the annual cost for all mentally retarded institutionalized residents in the U.S. and may account for as many as 5% of all congenital anomalies.(6) Perhaps the saddest thing about this incurable, pervasive, devastating, and expensive syndrome is that it is 100% preventable.

Being a good student, Jill paid attention during the drug and alcohol abuse education program at her high school. Her parents also warned her about the harmful effects of drugs but did not include alcohol in their warnings other than "don't drink and drive." Jill has grown up in a household where wine is sometimes served with dinner and cocktails, beer, and wine coolers are part of entertaining. Her school hosts wine and cheese social gatherings and her sorority frequently sponsors parties where alcohol is served. In short, alcohol is not viewed in the same way as other drugs and carries with it social acceptance and respectability. Jill does not consider her frequent partying to be a problem at all since she doesn't drive while intoxicated and it is not affecting her grade point average. Bill and Kate are very proud of their daughter. Jill maintains good grades, is popular, and dates several young men from her college.

As Jill parties with her friends, she is unaware that the alcohol she is ingesting is altering and damaging the

neural crest cells in her 18 day-old fetus, affecting the facial bones and cartilage, and parts of the brain and heart of her child. Jill doesn't know it, but a single exposure to high levels of ethanol can potentially kill millions of neurons in her child's developing brain. (7)

Risk Factors

Maternal Factors

No doubt about it, FASD are 100% preventable. All that needs to be done is to avoid alcohol. Unfortunately, things are never quite that simple. Alcohol is an accepted social drug and drinking patterns and sexual experimentation are usually formalized in the teen years and progress into the college setting. Research has indicated that regular alcohol consumption has increased alarmingly among the female population, and particularly among younger women and teenage girls. (8) The Journal of Obstetrics and Gynecology (August 1998) published a study about drinking during pregnancy, which included more than 100,000 women.(9) The study indicated that certain groups of women were **more** likely to drink during pregnancy:

- College Educated
- Unmarried
- Employed or students
- Annual household income >$50,000
- Smokers

Pregnant women who are at high risk for frequent alcohol consumption during pregnancy are more likely to be unmarried and smokers. In fact, smoking and alcohol use together increase the potential for alcohol-related damage in the fetus. (10, 11)

The health risks for women who consume alcohol are greater than they are for men. There are several reasons why women are at greater risk. First of all, women absorb alcohol significantly faster than do men because they have less of the enzyme, alcohol dehydrogenase, in their stomachs. Having less of this enzyme means that women metabolize less alcohol in the stomach than a man does, thus more alcohol ends up in their bloodstream. The more alcohol in a person's bloodstream, the greater the impact on the body. Second, women tend to weigh less and have less body water than a man, making the total volume of alcohol distribution lower. This concentrates the alcohol. What all this means is that women tend to get drunk faster than a man who is drinking exactly the same thing. This also means that women are more vulnerable to the negative health effects of alcohol, such as alcohol-related liver damage.

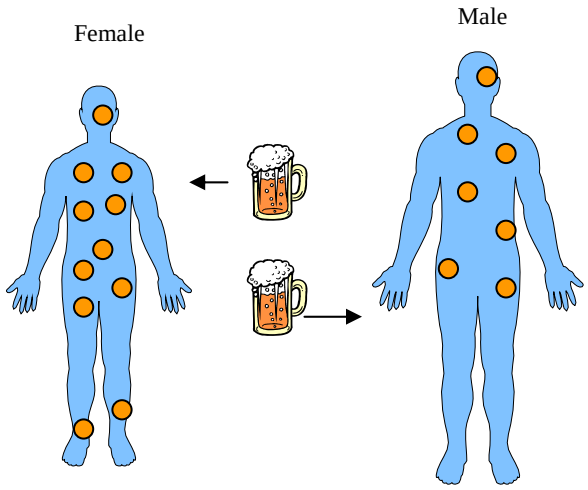


Figure 2: Lower weight and less body water concentrates the alcohol into a smaller area, raising the blood alcohol level in most females. Less alcohol dehydrogenase allows more alcohol to enter the bloodstream of a woman.

Ethnicity

There is also evidence of ethnic differences in rates of FASD. According to the CDC catchment study, incidences of FAS per 10,000 total births for different ethnic groups were as follows: Asians 0.3, Hispanics 0.8, Caucasians 0.9, African Americans 6.0, and Native Americans 29.9.

Within the United States, the incidence of FAS is 10 times higher at sites characterized by low socioeconomic status, and African American or Native American background compared to sites with predominantly middle to upper socio-economic status and Caucasian background. (13)

With Native Americans, the incidence of FAS varies among different cultures. Health units serving principally Navajo and Pueblo tribes report an FAS prevalence similar to that for the overall U.S. population, while for Southwest Plains Indians, a much higher prevalence was reported (1 case per 102 live births). (12)

The incidence of FAS among African Americans appears to be about seven times higher than among Caucasians, although more African Americans than Caucasians abstain from drinking. The reasons for this difference in FAS rates are not yet known. (12, 14)

While pregnant, 23% of White, 16% of African American, and 9% of Mexican American women will continue to drink during their pregnancies.

(Source: Theresa Kellerman, FAS Notes)

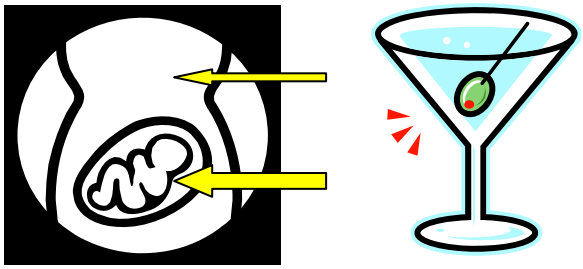


Figure 3: When alcohol is consumed quickly, the fetus may actually have a **higher** blood alcohol level than the mother.

After missing two periods, Jill has begun to suspect that she may be pregnant and visits her doctor. Finding out that she is with child has turned Jill's life upside-down. Jill does not know what to do and hides her pregnancy from her parents and friends for several more months. In the meantime, Jill limits her drinking to weekend parties but continues to binge on Saturday nights. Even though Jill is drinking less than eight drinks a week, she is drinking them all at once, which is having a devastating effect on her developing child.

Alcohol Consumption Pattern

Approximately half of all women of childbearing age are drinking alcohol regularly at the time that they get pregnant. Between 15-25% of pregnant women will knowingly drink during pregnancy. (15)

The maternal alcohol consumption pattern greatly affects the developing fetus. Heavily drinking during pregnancy (5 or more drinks per day) places the fetus at high risk for FAS. Binge drinking (> 5 drinks on one occasion) and drinking during the first 2 months of pregnancy are considered to be the two strongest maternal predictors of neurobehavioral deficits (hyperactivity, distractibility, speech and language problems). This is especially disturbing considering that the prevalence of binge drinking among pregnant women increased significantly between 1991 and 1995. (16)

The drinking pattern in African Americans, Native Americans, and Caucasian women is also different. The former two groups tend to binge drink, whereas Caucasian alcoholics tend to drink constantly throughout the week. Since it has been shown that peak blood alcohol level, rather than the total daily consumption, is the critical factor affecting neurodevelopment in children, this could put the infants of African American and Native American women at a higher risk for FAS. (17)

For the most part, ethanol passes from the mother to the fetus readily via the placenta to a point where the fetal blood alcohol level is almost the same as the mother's. If the mother drinks quickly (2 or more drinks within one hour), the fetal blood alcohol level can actually be **higher** that the mother's because the baby's system is immature and it takes longer to metabolize the alcohol. Again: ***There is no safe amount of alcohol that can be consumed during pregnancy.***

Paternal Factors

Women aren't the only ones who can impact the health of their offspring. Men play a part as well. Certain drugs (including alcohol, tobacco, marijuana, and cocaine) enter the testicles through the bloodstream to lower a man's sperm count and diminish the sperm's motility. This can interfere with reproduction by changing the process by which sperm are selected for fertilizing the egg. It has been established that approximately 80% of chronic alcoholic men are sterile (18) and that alcohol is one of the most common causes of male impotence.(19) A study published in the June, 1996, issue of the American Journal of the American Academy of Child and Adolescent Psychiatry suggests that alcoholism in fathers increases their child's risk of both alcoholism and mood disorders (especially major depression and bipolar disorder).(20) The semen of alcoholics is shown to contain aberrant sperm forms resulting in low birth weight in a significantly greater number of offspring.(21) Additionally, the number one factor of whether maternal drinking stops in pregnancy is related to the father. If the father abstains from alcohol, the mother is much more likely to abstain from alcohol as well. Men are advised to stop using alcohol and other drugs at least 3 months before conception and to remain alcohol and drug free throughout the pregnancy.

Jill talks to her boyfriend and family about her pregnancy. Jill's parents, while supportive, are very disappointed and concerned that Jill's "bright future" is ruined. Jill herself is extremely worried about the future and has become depressed and withdrawn. Jill's boyfriend has agreed to help where he can but continues to attend parties, drinking heavily nearly every night. This has put Jill in an awkward position. If Jill parties with her boyfriend she almost always ends up drinking herself, but Jill suspects that drinking during her pregnancy may not be the best for her baby.

Other Factors

Alcohol-induced malnutrition is an important secondary factor that can affect the developing fetus. Nutritional deficiencies occur frequently with alcohol intake due to reduced appetite and alcohol's interference with nutrition utilization, digestion and absorption, as well as greatly increasing urinary excretion of both vitamins and minerals. Alcohol-induced zinc depletion has been well documented. There is a correlation between zinc depletion and low birth weight and fetal malformations. Folic acid deficiency, which results from alcohol-induced urinary excretion, has been linked directly to spina bifida. However, animal studies indicate that even when nutritional status is well controlled, offspring will still exhibit the damaging effects of alcohol. (22) Improving nutrition in mothers may help to reduce the development of other malformations, but is not likely to affect the development of FASD itself.

Metabolic disturbances due to alcohol consumption may also affect the developing fetus. Alcohol-induced hypoglycemia, ketoacidosis, alterations in both lipid and amino acid metabolism all can lead to adverse outcomes in the mother as well as the child.

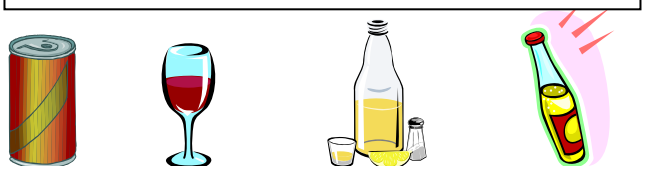
The doctor has urged Jill to eat right, take her vitamins, and stay away from all drugs and alcohol. While Jill comprehends the directions given by her physician, she does not understand the absolute importance of them. Jill has stopped going to parties and her boyfriend no longer stops by or calls. Jill stays at home most evenings and drinks several glasses of wine to help her relax. Jill has heard that drinking red wine is good for you.

A Drink is a Drink

People often tend to associate "problem" drinking with shots of liquor and "social" drinking with beer, wine, and wine coolers. The trouble is, your body does not distinguish between these beverages. What's important is the absolute alcohol content of the beverage. A can of beer, a glass of wine, a shot of liquor, and a wine cooler all contain approximately ½ ounce of absolute alcohol. None of these are safe to consume during pregnancy.

Consumers often receive confusing and mixed messages (i.e., red wine is good for your heart, "lite" beer or wine generally refers to calories but not necessarily alcohol content). High-impact advertising can add to this confusion and tends to overshadow public messages about responsible drinking.

Figure 4: Each of these Beverages contains about ½ ounce of absolute alcohol



Characteristics of a Child with FASD

We've all seen the advertisement with the egg frying in the pan as the actor tells us that "this is your brain on drugs, any questions?" Even today there is a misperception that illegal street drugs produce the most devastating effects in the fetus. In the words of the Institute of Medicine in their 1996 report to Congress (23):

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

In fact, all of the other drugs of abuse combined don't produce the numbers of affected babies as does alcohol. (10) So what are these devastating effects? Damage can occur on almost every level possible.

Let's take a "systems approach" to looking at what kinds of damage can occur from in utero alcohol exposure.

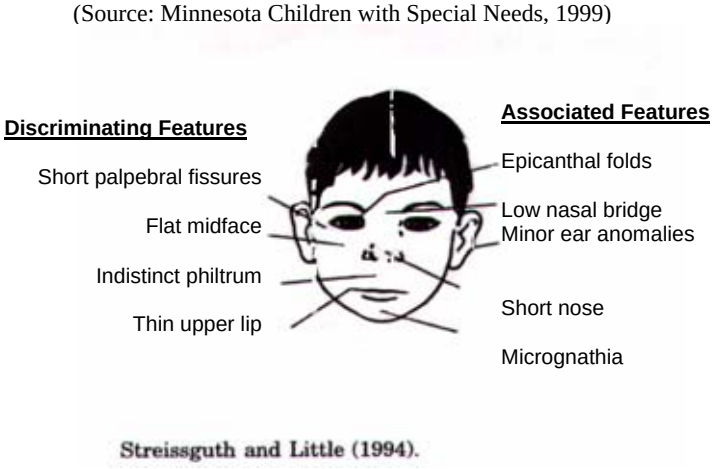
Physical Appearance

So what features make a child "look" like a child with FAS? The following facial features are associated with FAS.

- Nearsightedness
- Short eye slits (short palprebral fissures)
- Droopy eyelids (epicanthal folds)
- Widely spaced eyes
- Crossed eyes
- Short, upturned nose
- Low and/or wide bridge of the nose
- Thin upper lip
- Smooth or flat area between the nose and lip (indistinct philtrum)
- Flat midface
- Small, underdeveloped jaw (micrognathia)

The facial characteristics of FAS are sometimes not as noticeable at birth and are less obvious in adolescence and adulthood. The facial anomalies will be most noticeable between the ages of 2-10 years. (24)

Figure 5: The Face of Fetal Alcohol Syndrome
(Source: Minnesota Children with Special Needs, 1999)



Other physical features related to FASD include:

- Low birth weight
- Failure to thrive
- Small size for age in weight and length
- Small head for age (microcephaly)
- Large or malformed ears
- Underdeveloped fingernails or toenails
- Short neck
- Joint and bone abnormalities

The child with FAS will have some or all of these physical features. Children with ARND will most likely appear normal, making diagnosis more difficult. The effects of prenatal exposure to alcohol may become more apparent in pre-school and school age due to behavioral and performance issues. (10)

Hearing Disorders

Children with FAS will often suffer from hearing deficits. The severity of the hearing disorder will vary from child to child. Some may suffer from chronic ear infections that persist into adulthood. There are 4 main types of hearing disorders associated with FAS:

1. **Delayed auditory function**; associated with speech and language disorders
2. **Sensorineural hearing loss**; a sensory nerve problem (occurs in the inner ear or auditory pathways)
3. **Intermittent conductive hearing loss**; conduction of sound vibration is interrupted (occurs in the outer or middle ear)
4. **Central hearing loss**; most have normal hearing acuity but something happens to disrupt the sound vibrations from turning into electrical impulses that can be interpreted by the brain.

All children with FAS should have periodic hearing tests.

Eye Disorders

Three visual disorders are commonly associated with FAS:

1. **Strabismus**; a muscle disorder that causes eyes to point in different directions
2. **Optic nerve hypoplasia**; underdevelopment of the optic nerve during pregnancy, it is not progressive, inherited, or curable
3. **Posterior haze of the cornea**; cornea is hazy instead of clear, blurs vision

Children with FAS should see an ophthalmologist or optometrist to evaluate and treat eye conditions.

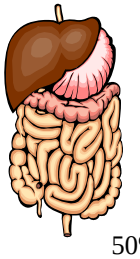
Dento-facial Disorders

Children that have the facial characteristics of FAS may also suffer from temporomandibular joint disorder (TMD) and malocclusion. TMD is a condition where the chewing muscles and jaw joints do not work together correctly. Malocclusion is a condition where the teeth don't meet together correctly.

Immune Disorders

Research is currently being conducted about the effect of alcohol on the fetal immune system. There appears to be a relationship between alcohol exposure and the reduction of T-cells. T-cells are important because they augment and potentiate immune responses and help kill certain tumor cells, viral-infected cells, and sometimes parasites.

Internal Organs



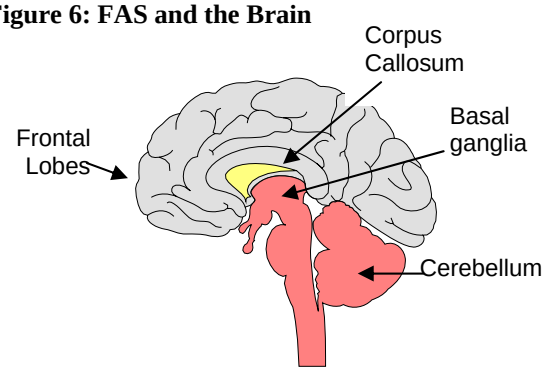
By the end of the 36th day of pregnancy, most of the rudimentary organs have already been formed, such as limbs, heart, brain, eyes, mouth, and digestive tract. If alcohol is consumed during this critical period of organ formation, a number of malformations can occur. Congenital heart disease is found in 29-50% of reported cases. Defects are commonly atrial or ventricular septal defects. The kidneys, brain, nervous system, and other organs may all have congenital anomalies due to prenatal exposure to alcohol.

Neurodevelopmental Disorders (Primary)

Primary neurodevelopmental disorders are disabilities a child is born with. There are many neuro-developmental disorders that can occur in children with FASD. These disorders are the most debilitating part of FASD because they are permanent and can prevent the child with FASD from growing up to live a normal and independent life. These neurodevelop-mental disorders occur because the brain has been irreversibly damaged by alcohol. There are four areas of the brain that are seriously affected by prenatal alcohol exposure: the frontal lobes, basal ganglia, corpus callosum, and cerebellum.

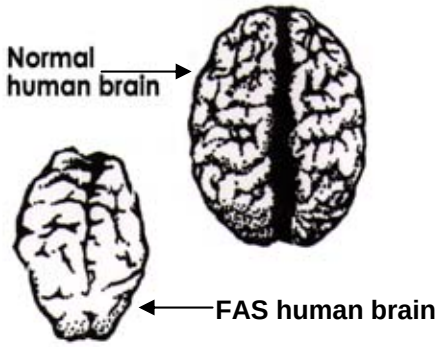
Prenatal alcohol exposure causes the most serious damage to the frontal lobes of the brain. This is where the brain maintains control of impulses and inhibitions. This is a permanent neurologic condition that impedes the person's ability to form healthy relationships. (25)

Figure 6: FAS and the Brain



1. **Cerebellum:** Controls coordination and movement (balance, gait, posture).
2. **Basal Ganglia:** Controls spatial memory and behaviors like perseveration (repetition of an activity to an extreme, to the point where it interferes with other activities).
3. **Corpus Callosum:** Passes information back and forth from the right side of the brain (impulse, feelings) to the left side of the brain (rules, logic).
4. **Frontal Lobes:** Controls judgment, inhibition, concentration, self-control, conscience, personality, and emotional traits as well as cognition and memory, motor speech, and movement skills.

Figure 7: Normal versus FAS Brain (Source: Minnesota Children with Special Health Needs, 1999)



- Smaller
- Not fully divided into right and left hemispheres
- Smooth surface and fewer folds indicate lack of development

Damage to any of these structures causes very poor and inappropriate responses. For example, if the corpus callosum cannot access the appropriate information quickly enough (or at all), the reaction to incoming information will be completely spontaneous and impulsive. With prenatal alcohol exposure, the physical structures, "wiring", and brain chemistry are all damaged. Primary neurobehavioral disabilities occur because of this damage to the brain and secondary disabilities often surface as children get older. Primary disabilities include:

1. **Loss of Intellectual function (IQ)**. The average IQ in children born with FASD is 65-80, depending on which source you read. A normal IQ is 100, with a standard deviation of 15. In general, IQ below 85 indicates mental retardation, with scores less than 70 indicating severe retardation.

2. **Behavior disorders.** About 70% of children with FASD are severely hyperactive, frequently engaging in disturbing self-stimulating behaviors such as body rocking, head banging, or head rolling. Behavior problems may include hyperactivity, stubbornness, impulsiveness, passiveness, fearlessness, irritability, sleep difficulties, and teasing or bullying of others.

3. **Learning disabilities**. With FAS the average academic functioning does not seem to develop beyond early grade school level, even with constant remedial help at school. Arithmetic and abstractions like time and space, cause and effect, as well as generalizing from one situation to another are particular deficits.

4. **Speech and language disorders**

5. **Sensory Integration issues.** Individuals with FASD are often overly sensitive to sensory input. They are upset by bright lights or loud noises, clothing tags, and seams in socks. Certain food textures may also be objectionable.

6. **Coordination impairment**. Many children with FAS have impaired fine motor coordination, impaired hand-eye coordination, and are "clumsy" and "accident-prone."

7. **Musculoskeletal abnormalities.** Variable musculoskeletal and limb defects are found in approximately 40% of cases, ranging in severity from minor problems such as contractures of the finger joints to more severe lesions, such as congenital hip dislocations and thoracic cage abnormalities.

8. **Social impairment.** In general, children with FAS do not consider consequences for their actions, lack responses to appropriate social cues, lack reciprocal friendships, withdraw socially, are sullen with mood lability, exhibit teasing and bullying behavior, and have periods of high anxiety and excessive unhappiness. These characteristics impair the child's ability to form satisfying and lasting relationships.

> Research indicates the social maturation of individuals with FAS is **arrested**, and not just delayed, at the level of a 4-6 year-old child. (26)

9. **Executive Function Deficits**: Executive function deficits lead to a number of typical difficulties for the individual with FASD. They may go with strangers, break rules repeatedly, have trouble with money and time, and give in to peer pressure. They do not learn from their mistakes or natural consequences and frequently do not respond to point, level, or sticker systems.

10. **Information Processing Problems.** Individuals with FASD have problems with:
    - Taking in information
    - Storing information
    - Recalling information when needed
    - Using the information appropriately in a given situation

Individuals with FASD have very concrete, literal reasoning. To them, "straightening up their room" may mean to move the bed or chair so it is straight rather than picking up their things. They have difficulty with:

- Completing tasks or chores and may appear oppositional.
- Following multiple directions.
- Knowing what to do in a given situation.

- Asking questions (won't ask because they want to fit in). They will say they understand when they do not. Often their verbal expressive skills will exceed their understanding.
- Correctly interpreting others' words, actions, or body movements.

These information processing problems make the individual with FASD socially vulnerable.

Secondary neurodevelopmental disorders can occur if there is a failure to properly deal with the primary disabilities. Secondary disabilities include:

1. Mental health problems
2. Disrupted schooling
3. Legal problems
4. Confinement (jail or juvenile detention, inpatient treatment for mental health)
5. Alcohol and drug problems
6. Inappropriate sexual behavior
7. Dependent living
8. Employment problems

The most common secondary disability in FASD is mental illness, occurring in 94% of adults. Clinical depression is the most common diagnosis. (27)

There are so many primary and secondary disabilities that can result from FASD that they could not be covered here in detail. *Figure 8* lists the multitude of disabilities that are linked to FASD. There are good clinical data showing that if the primary disabilities of FASD are addressed, the incidence and severity of the secondary disabilities can be reduced. Because only about 11% of individuals with FASD are diagnosed by age 6, every effort should be made to provide an early diagnosis.(27)

Figure 8: Primary and Secondary Disabilities That Can Occur From Alcohol Exposure In Utero

Primary Disabilities
(Disabilities a child is born with)

- Developmental speech and language disorders
- Developmental coordination disorder
- Central auditory processing disorder
- Severe loss of intellectual potential
- Decreased cranial size
- Structural brain abnormalities
- Mental retardation
- Problems in social perception
- Poor capacity for abstraction or meta-cognition
- Eye disorders
- Deafness
- Cleft palate
- Night terrors
- Sleep disorder
- Tourette's traits
- Precocious puberty
- Sociopathic behavior
- Serious maxillofacial deformities
- Extreme impulsiveness
- Dyslexia
- Hypersensitivity
- Tremors
- Immune system functioning
- Poor judgment
- Renal problems
- Musculoskeletal abnormalities
- Cerebral palsy
- Complex seizure disorder
- Developmental delay
- Height and weight deficiencies
- Tight hamstrings
- Cognitive perseveration (continuance of an activity after cessation of the causative stimulus)
- Heart failure and defects
- Attention deficit disorders (ADD/ADHD)
- Dental abnormalities
- Mild to severe vision problems
- Higher than normal to dangerously high pain tolerance
- Little or no capacity for interpersonal empathy
- Little or no retained memory
- Little or no capacity for moral judgment
- Echolalia (automatically repeating whatever is said)

Secondary Disabilities
(Disabilities that develop if the primary disabilities are not dealt with properly)

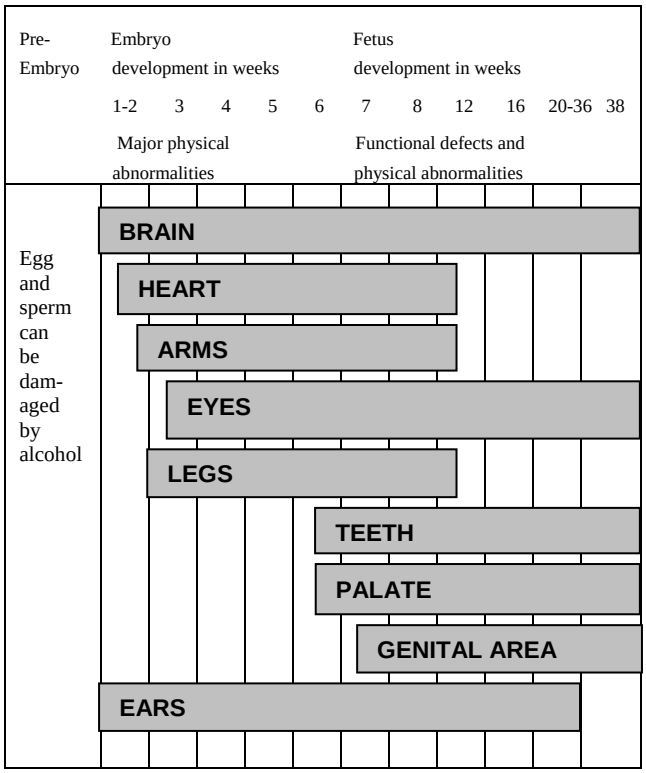
- Learning disabilities
- Early school drop-out
- Juvenile delinquency
- Poverty
- Chronic unemployment
- Sexual acting-out
- Social problems
- Behavioral problems
- Reactive outbursts
- Homelessness
- Violence
- Crimes against property
- Depression
- Prostitution
- Suicide
- Addiction
- Alcoholism
- Promiscuity
- Sexual assault
- Mental illness
- Early pregnancy

Adapted from: The Triumf Project by Bruce Ritchie and the Institute of Medicine's publication on Fetal Alcohol Syndrome (28, 29)

Timing of Alcohol Intake and its Relationship to Disorders

Because a fetus develops certain areas at certain times during pregnancy, the disorders that can occur with alcohol exposure also vary depending on when the exposure took place. *Figure 9* reviews the impact of alcohol on the fetus expressed in weeks of development.

Figure 9: Impact of Alcohol Use on the Developing Fetus
(Source: Minnesota Children with Special Health Needs, 1999)



During the first trimester (the first 12 weeks), the third week of pregnancy is considered a critical period for the teratogenic actions of alcohol to produce the most severe and characteristic features of FAS. The nervous system develops in the first 8 weeks and vulnerability to brain damage is highest at 15-25 days. The CNS, heart, eyes, legs, arms, teeth, ears, palate, and external genitalia are all vulnerable to alcohol in the first trimester. This damage may be taking place before the mother is even aware that she is pregnant. Therefore, any woman thinking of becoming pregnant should not use alcohol.

Alcohol can still have negative effects in the second trimester (weeks 13-24), as the fetus continues to grow and develop. Alcohol can impair brain development, cause miscarriage, or damage muscles, skin, teeth, glands, and bones. Research indicates that women who discontinue alcohol use mid-pregnancy fare better than continuous drinkers, though the damage caused by 1st trimester alcohol use will not be reversed.

There is another critical period of brain development in the third trimester (25 weeks to term). Alcohol use during this time can impair brain and lung development, prevent adequate fetal weight gain, and cause early labor and delivery. Heavy drinkers who reduce or abstain from alcohol in the third trimester have a lower incidence of birth defects than those who continue to drink throughout their pregnancy, though again, earlier damage will not be reversed.

Research has indicated that there is a critical period for the development of the characteristic head and facial anomalies that make a child "look" like a child with FAS. If alcohol of sufficient quantity is not ingested during this critical period (15 to 22 days), then the head and facial characteristics may not develop. Unfortunately the quantity required is variable and cannot be delineated. Research also indicates that it takes a lot more alcohol to cause head and facial deformities than it takes to cause neural and behavioral problems. This is important because children must have the head and/or facial deformities to receive a clinical diagnosis of FAS. Many children with prenatal alcohol exposure don't meet the criteria for treatment because they don't exhibit symptoms in all three categories required for the diagnosis of FAS: CNS damage, growth retardation, and head and facial abnormalities.

The big day is here and Jill has delivered a 4-lb. 14-oz. baby boy named Ryan. As the pediatrician examines Ryan, she notices that Ryan is small for a full-term infant and exhibits poor sucking responses. Jill is sent home with instructions to encourage feeding and visit the pediatrician often to follow Ryan's weight gain. Jill tries breastfeeding Ryan but it hasn't worked out very well. After 2 weeks of feeding problems, Jill switches to bottle feeding Ryan.

Breast feeding and Alcohol

Although the amount of alcohol ingested by infants through breast milk is low, it can be sufficient to cause a slight motor delay. When alcohol has been used at moderate levels during pregnancy, the child's sucking reflex may be impaired at birth, making breast feeding a challenge. Drinking regularly while breastfeeding may inhibit prolactin, a hormone necessary to maintain lactation. (30)

As the weeks go on Ryan becomes very irritable, arching stiff as a board and crying inconsolably. Ryan doesn't sleep very long at a time and Jill is exhausted from walking him around day and night. The pediatrician initially thinks that Ryan has colic, but after 6 months begins to wonder if something else may be wrong. As the months pass, Ryan grows slowly and is delayed in walking and talking.

Ryan develops into a child that gets frequent ear infections, is hyperactive and impulsive, clumsy, and never sleeps a night all the way through. Jill must watch Ryan like a hawk because he is fearless and will do things like climbing and jumping off of high places, walking in front of speeding cars, and playing with sharp knives. After 5 years, Jill has given up on the idea of returning to school or even working because she cannot find anyone willing to watch Ryan. He bullies smaller children and will not follow the rules in a daycare setting. At the last daycare center Jill tried, Ryan broke the arm of another child by pushing her off the monkey bars.

It has become obvious that Ryan has a learning disorder when he fails pre-school screening. On the recommendation of the school staff, Jill takes Ryan to a doctor that specializes in developmental disorders. After a barrage of tests, Ryan is diagnosed with FAE. Jill is devastated to learn that her drinking caused Ryan's problems. Jill learns that no amount of remorse will change what has happened to Ryan and that she needs to focus her energies on keeping more problems from occurring. Jill does her best to get the help that Ryan needs.

What Can We Do?

Being in a helping profession, most of us wonder, "What can we do to help Jill and Ryan? How can we prevent this from happening to other women and children?" Although it can be difficult to diagnose (especially ARND) in the neonatal period, an early diagnosis is a critical factor in lessening secondary disabilities and in primary prevention of future affected children.

Educate Ourselves

To prevent FASD from occurring, greater emphasis needs to be placed on education. Health care professionals need to become better educated in this area so that they can do a better job of detecting FASD and teaching and counseling their patients. According to the National Organization on Fetal Alcohol Syndrome, fewer than 10% of medical schools require students to complete a course on the proper diagnosis and referral of patients with alcoholism and other drug addictions. (31) This organization maintains that most health care providers are unfamiliar with and untrained in the issues of substance abuse among pregnant women. There also seem to be some differences in care depending on the mother's race. A National Center for Health Statistics study found that doctors appear less likely to tell a black woman to quit drinking and smoking during pregnancy than they are to tell a white woman. Pregnant black women were 30% more likely than white women to report that they had never been told to quit drinking. (32) It is imperative that **all** women who are pregnant or planning to become pregnant be told to abstain from alcohol and other drugs.

When FAS has been diagnosed in a child, the parents need counseling about the risk of having another FAS child because the recurrence risk is as high as 25% more than the normal population. Presumably, this occurs because the mother of a child with FAS is more likely than the general population to drink alcohol while pregnant. With increasing age and parity the incidence of FAS rises occurring 85 times more frequently in older siblings of FAS children and 350 times more frequently in the younger siblings of FAS children than in the general population. **The risk of having another child with FAS is zero if the mother abstains from alcohol during her pregnancy.**

Educate the Public

Every physician and nurse should advise their patients of the hazards of drinking during pregnancy, whether they are in their third trimester, newly pregnant, or just planning to become pregnant. Both men and women need to understand the risk alcohol poses and that it is important that neither of

> Only 39% of women of child-bearing age even know what Fetal Alcohol Syndrome is. (33)

them drink during the pregnancy. Reiterate that there is no safe level of alcohol consumption during pregnancy.

Encourage the development of educational programs regarding the damaging effects of alcohol on an unborn child. These programs should be integrated into mandatory curriculum for all elementary, middle, and high school students.

Support the development of print and broadcast advertisements, as well as a "Surgeon's General" warning on alcohol containers. Informational leaflets should be widely distributed in all doctors' offices, waiting rooms, and clinics.

In Minnesota, "Action Steps for Professionals" were included in the 1998 Governor's Task Force on Fetal Alcohol Syndrome.

Professionals Action Steps for Physicians and Nurses

- Be diligent in asking about alcohol use by other biological parents. Use a screening tool to identify women who drink during pregnancy.
- Participate in efforts to improve the identification of chemically dependent women and the provision of treatment for them.
- Work to incorporate fetal alcohol syndrome information into basic academic curriculums.
- Discuss family planning with women who are of childbearing age and use alcohol.
- Be more aware of fetal alcohol syndrome and effects and learn to recognize the signs early on. Become knowledgeable about prevention, intervention, and assistance resources.
- Caution mothers to abstain from alcohol when they are nursing.
- Educate practitioners who work with families, children and women via continuing education programs.
- Make public statements through professional associations and newsletters that define fetal alcohol syndrome as a social problem of significant proportion that calls for heightened awareness and action.

Source: Suffer the Children: The Preventable Tragedy of Fetal Alcohol Syndrome (1998), page 26.

Get Help For Those Children Who Have FASD

The child with FASD often requires services from a variety of health care providers and professionals. Parents should be encouraged to become actively involved in the planning and coordination of their child's care. Care team members may include:

- Primary health care provider (pediatrician, family doctor, or pediatric nurse practitioner)
- Developmental or Behavioral Pediatrician
- Child Psychologist or Developmental Psychologist
- Classroom Teacher(s)
- Dentist
- Occupational Therapist
- Ophthalmologist or Optometrist
- Otolaryngologist
- Public Health Nurse
- Registered Dietitian
- School Counselor
- School Nurse
- Social Worker
- Speech-Language Pathologist

We should encourage parents to be effective advocates and care coordinators for their child.

Important Tips for Parents:

Health Care

- Take your child in for regular, routine care and immunizations.

- A child psychologist or developmental psychologist should see your child to assess IQ, academic achievement and abilities, emotional and social development, and parent/child relationships. The psychologist may perform tests and will help to teach you about your child's condition, expected behaviors and interventions, and ways to cope with the stress and grief that goes along with this condition.

- Write down your questions before you visit the doctor, dentist, nurse, etc. so that you will not forget them.

- Write down the answers to your questions and other pertinent information in a notebook. Include the date, health care team member's name, and location.

- Keep good records of immunizations, test results, x-rays, medications and side effects, and developmental milestones.

- Keep copies of assessments, performance reports, and the Individual Family Service Plan (IFSP),

Individual Education Plan (IEP), and Individual Health Plan (IHP).

The sections labeled "Important Tips for Parents" are points for patient education.* Parents are going to need a lot of help. Anyone who has cared for a child with FASD can tell you that it is unbelievably challenging, with caregivers frequently reaching the limits of their patience. You will need to check with parents at every visit to see how they are doing with their living situation. Encourage parents to seek respite and take their own "time-out" if they feel their anger rising. Anyone who has walked a crying baby around for hours will tell you that anger and frustration do occur. Parents need to recognize when this is happening and to take a break from it before it gets out of control. I had one dad tell me that the way he dealt with his inconsolably crying daughter was to slip on the headphones and listen to some music. Just blocking out the sound of her crying helped him enormously in dealing with his child.

The types of problems and care needed are going to vary depending on the age of the child. Let's review by age, common problems and suggestions for handling these problems.

Infants and Toddlers with FASD (Ages 0-3 years)

Infants born with FASD may have a difficult first few months. Some infants show behaviors related to withdrawal symptoms from alcohol. These symptoms can include seizures, sleeping disorders, stomach upsets and extreme fussiness. Some infants are unable to screen out unwanted noise and distractions. This may cause overstimulation, frustration, and irritability.

Many infants with FASD are born with low birth weight. Some have difficulty getting adequate nourishment due to poor sucking and swallowing or mouth abnormalities. There may be failure to thrive or height/weight growth deficiencies. Nutritional assessments and monitoring may be needed.

*If you are interested in other helpful hints for parents including how to manage hyperactivity, discipline issues, providing structure, encouraging self esteem, and behavior issues, check the end of this packet to see how you can order a copy of "*Guidelines of Care for Children with Special Health Care Needs: Fetal Alcohol Syndrome and Fetal Alcohol Effects."* The bulk of the important tips for parents in this independent learning activity were selected or adapted from this booklet.

Most infants with FASD show:

- Irritability, jitteriness, nervousness
- Sucking or feeding problems
- Poor muscle tone
- Sleep disorders
- Sensitivity to sound and light
- Excessive crying
- Decreased alertness

As they get older, the infant with FASD may tend to:

- Be easily upset
- Be easily distracted
- Be hyperactive
- Have a short attention span
- Have developmental delays
- Have problems using muscles
- Have problems with attachment to parents (they do not differentiate between a parent and someone they just met)

The health care team members must assess the child's physical, mental, emotional, and behavioral development. This will help to identify special needs that the child with FASD has. Early intervention is the first step to an improved prognosis, by diminishing secondary disorders.

Important Tips for Parents

Health Care

- Infants and toddlers often have problems with growth. Diet needs to be monitored and height and weight graphed to follow progress.
- Flu shots may be given to prevent influenza.
- Upper respiratory and ear infections may occur frequently due to an impaired immune system.

Development

- Because of hypersensitivity to sound and touch, try to reduce sensory stimulation by:
  - Keeping the lights low
  - Keeping noise levels down
  - Introducing stimuli one at a time
  - Using calming measures when overstimulation occurs (warm shower or bath, listening to quiet music, swaddling, rocking)
  - Providing calm, consistent bed routines (darkened room, soft clothing, few distractions in the bed and room: avoid mobiles, use plain bumper pads, have simple room decoration, no

clutter or busyness, use white noise such as a fan or soft music if needed).

- Make healthy eating a daily goal. Try to make mealtime a positive experience. Here are a few suggestions for feeding:
  - Learn hunger signs and serve food when signs are first exhibited.
  - Serve small, frequent, high calorie meals and snacks. Four to six meals a day may be needed for adequate nourishment.
  - Reduce distractions while feeding. This helps the infant focus on eating. Feed in a quiet and slightly darkened room. Do not rock or talk while feeding. Do not turn on a radio or television.
  - Never prop a bottle or leave a child unattended while eating.
  - Allow ample time for eating. Have reasonable expectations on portion size. Serve food warm. Avoid hot or cold foods. It may help to reduce the texture of foods offered.
  - Limit choices.
  - Seek help from a nutrition professional.

Finding Child Care:

- If you use childcare, choose a provider who is willing to learn about caring for a child with FASD. Be sure you feel confident in your provider's ability to understand and carry out your instructions. Smaller settings usually work best.

- Your child may need extra supervision to keep them safe. Choose a location where caregivers are consistent, have established routines, have good child to adult ratios, and value attachment, predictability, flexibility, and nurturing.

- Know the law; the Americans with Disabilities Act (ADA) provides that childcare facilities may not refuse a child because of a special health need. This is true regardless of childcare size or whether they receive public funds.

- Make sure your child care provider and helpers do not smoke if your child has allergies, asthma, or frequent ear infections.

School

- Schools are required to provide early intervention services. Services are provided to children who have special health needs which affect learning or who have developmental delays. Children from birth to age 3 are entitled to these services. Contact your local school district and ask to speak with the Early Childhood Intervention Coordinator to find out how this program works in your area.

Preschool Children with FASD (Ages 3-6 years)

Preschool children with FASD are usually friendly, outgoing, highly social, and talkative. Verbal skills are often better than thinking skills. Cognitive, motor, and complex speech development are usually slow.

Signs of hyperactivity are seen in many children with FASD. Sensitivity to sensory stimulation may continue. There may be difficulty making a transition from one activity to another and adjusting to change in routines. Frustration and temper tantrums often occur, especially as children get older. Children with FASD often have no real sense of "stranger danger." Close supervision is usually required.

Important Tips for Parents

Health Care

- Continue to keep a close watch on growth and diet. A nutritional assessment may be done.

- Poor gross motor coordination can lead to injury. Frequently the child does not recall how he or she got hurt. Suspicion may fall unjustly upon the caregiver. The child may not be able to identify pain or know how to tell you about it. Children with FASD may also have a high tolerance for pain. They may not complain. Injuries can go untreated. Teach children what to do when their body hurts.

- Extra care may be needed to treat ear infections which can lead to hearing loss.

- An impaired immune system may continue. It places the child with FASD at greater risk for opportunistic infections.

- Flu shots are usually given in the fall to prevent influenza.

Development

- Provide your child with simple information about FASD. Help them tell their own story and identify feelings.

- Provide your child with opportunities to:

- Play with other children the same age. However, some children with FASD are more comfortable playing with children one to two years younger.
- Play outdoors in a safe area.
- Succeed and gain self-confidence.
- Maintain a balance between structured activities and free time.

♦ Offer assistance or aids to help your child overcome difficulties that may hinder progress. For example, a computer may help a child who has difficulty writing.

♦ Irregular sleep patterns may continue. Stay with an established evening routine and bedtime. Routines help children who have difficulty predicting and organizing. Music, singing or reading can help to calm or soothe. Naps may be needed; however, many children with FASD will not nap at all.

♦ Mealtime is an opportunity for socialization. it helps in bonding and developing relationships. A positive mealtime should be a priority. Children with FASD may lose interest in eating before completing a meal. They may need to be reminded to eat. They often need to move about while eating.

♦ Children with FASD may have difficulty making and keeping friends. Plan brief play periods with one or two friends. Teach friendship and sharing. Friends may be the same age or younger. Supervise and structure activities. Lack of friendships may result in increased dependency on caregivers.

♦ Most children this age love to pretend. They may act out things they have seen or that have happened to them. Usually this type of play, with friends or stuffed animals, can help the child learn. Parents can help children understand experiences through this type of play. Sometimes parents will need to teach the child how to play and how to separate fact from fiction.

School

♦ Schools must provide Early Intervention services as part of the Individuals with Disabilities Education Act. Children 3 to 5 years of age who have FASD are usually entitled to these services. Contact you local school district to find out how this program works in your area.

♦ At the beginning of each school year, meet with your child's teacher and the school nurse. Inform them of your child's development and any special needs related to FASD. It is often a good idea to write out these special needs so that they can be copied and given out to other personnel such as teacher's aides, playground supervisors, and Special Education staff. Keep them informed of changes throughout the year.

♦ Make sure the school has instructions from your health provider about use of medication if needed. The school nurse will need a pharmacy label on all medications given at school. Ask your health care provider to write medication administration instructions for the school and to specify on the prescription that two labeled bottles be given with each refill (one for home, one for school). It is best to hand deliver the written instructions with medication(s) to the school nurse before the start of school.

♦ If your child has asthma or allergies, ask about pets and plants in the classroom.

The School-Age Child with FASD (Ages 6-13)

School-age children with FASD may continue to grow slowly. They may appear thin and malnourished even though the diet is adequate. Their slow growing head size is related to slow brain growth and development.

The elementary school years mark the time when additional problems may begin to show. Children with FASD may have difficulty "fitting in" and making friends. They may want to play with younger children or adults. It is important for parents to teach their child social skills. Skills must be taught early and repetitively to become habits.

Children with FASD may not be able to learn from experience. They may also have difficulty following rules. Rules may be known, but cannot be applied. They may lack understanding of action and consequence. The complex school environment can be especially challenging. Children may feel overwhelmed which can result in problems with learning. Anger, frustration, temper tantrums and refusals can be signs your child is having difficulty. Listen to the child's complaints. The school environment may need to be modified to suit special needs. It is important for parents to work closely

with the school to assure that the child's needs are being met.

Due to problems with short-term memory, skills must be taught over and over again. This can be frustrating for parents and teachers. However, repetition and practice help in learning.

Important Tips for Parents:

Health Care

- Continue to follow growth and nutritional status.
- Make sure your child is getting enough exercise. Find activities or sports that fit your child's abilities.

Development

- Provide your child with specific information about FASD and related conditions. Encourage questions. Remind him or her that concerns can be discussed with parents, health care providers, and other professionals.
- Children with FASD may have difficulty with abstract concepts such as time, money, and math. They may not be able to tell time even by the age of 12. Problems understanding the concept of time may continue after mastering the skill. The value of money is also a difficult concept to grasp. Your child may not associate value to items. For example, $5.00 for a piece of candy or for a television may seem acceptable. Monitor your child's money. Limit access to money when you cannot directly supervise its use. Give your child money only in small amounts. Do not expect understanding of equal values such as four quarters being the same as a dollar.
- Teach your child about ownership. A child with FASD will often take something that catches his or her eye. The concept of stealing may not be understood. Teach your child to ask before taking anything that does not belong to him or her.
- Use gestures to help your child understand directions. Limit directions to 5-10 seconds. Use eye contact. Direct one task at a time. Avoid using words with more than one meaning. Be specific when telling your child what to do. Repeat directions as needed.
- There is a great difference between physical maturity and emotional and social development. As children with FASD get older, problems crop up when adults and other children expect them to "act their age." THINK YOUNGER. For example, an individual of 18 years of age with FASD may have a much lower developmental age *(see figure 10).* Problems can occur if age-appropriate behavior is expected but cannot be met.

Figure 10: Skills Often Do Not Match the Developmental Age of the Child With FASD

Skill	Expected Developmental Age Equivalent
Expressive Language	20 years
Physical Maturity	**18 years**
Reading Ability	16 years
Living Skills	11 years
Money, Time Concepts	8 years
Social Skills	7 years
Comprehension	6 years
Emotional Maturity	6 years

(D. Malbin, 1994)

School

- Continue to meet each year with school staff as described under "school" in ages 3-6 years. Call your child's teacher often to see how things are going in the classroom. Do not wait for the teacher to call you after problems arise.
- An Individual Education Plan (IEP) will be developed if your child has special education needs.
- Let your child's teacher know that children with FASD frequently have learning difficulties that prevent them from remembering and applying information. Learning may occur in spurts with easy periods of learning followed by harder periods of learning. This does not mean that they aren't trying. Inconsistent learning is a result of their FASD, not a result of laziness or stubbornness.

Adolescents with FASD (Ages 13 to 18)

Typically, the thin build of children with FASD begins to change during adolescence. Girls tend to become obese. After puberty, the facial features of FASD are more difficult to recognize.

Teenagers with FASD may develop problem behaviors such as lying and stealing. They may have poor judgement and difficulty with peer relationships. Alcohol and drug abuse are common. There is also a greater risk for depression and suicide.

Teenagers with FASD usually look like typical adolescents. However, their developmental level may only be that of a six-year-old. Extra guidance and protection may be needed.

In guiding adolescents with FASD, consider the following:

1. **Structure**. Create a structured environment that includes limited choices. Have clear and set routines. Adjust the environment for slower development and understanding.

2. **Supervision**. Carefully supervise adolescents so they do not place themselves in dangerous situations.

3. **Simplicity**. State instructions briefly and clearly. Use simple directions and orders.

4. **Steps**. Break tasks down into small steps. Teach each step through repetition. Lists may be helpful. Use rewards as incentives.

5. **Setting**. Teach desired skills in the way in which they will be used. Adolescents with FASD may not have the ability to transfer skills from one setting to another.

Important Tips for Parents/Patients:

Health Care

- Continue to follow growth, nutritional status, and adequacy of exercise.

- You will need to discuss a variety of topics dealing with health promotion/problem prevention. Topics may include: Drug and alcohol use, depression and suicide, physical/sexual/emotional abuse, high blood pressure, high cholesterol, infectious diseases, learning problems, puberty and adolescence, healthy eating habits/ prevention of obesity or eating disorders, safety and injury prevention, physical fitness, parent's ability to respond to the health needs of their adolescent, anger and violence management, ruling out diagnoses such as depression or personality disorders, self-esteem, birth control, sexually transmitted diseases, inappropriate sexual behavior, and becoming a victim or victimizing others.

- Information shared with health providers is personal and confidential.

- Health care providers need to be aware that the teenager with FASD may have memory gaps that make them unable to report symptoms or take medication independently.

Development

- Teenagers understand factual information about FASD. Give them specific information about their condition. The information can be more detailed than for younger children. Encourage your teen to read about FASD.

- Teenagers may need encouragement to ask questions. Remind them that concerns can be discussed with parents, health providers, and professionals.

- Allow your teen increasing control over when to take medication or do other treatments. Encourage him or her to be responsible for remembering these things. Mastering self-care skills gives all teens a feeling of control and accomplishment. It may still be necessary to remind a teen to take their medication.

- Some teenagers may be vulnerable to pressure to be sexually active or to use alcohol and drugs. They may seek acceptance from their peers through these activities. Parents can help prevent these behaviors by discussing concerns with their teen.

- Independence is necessary for teenagers to develop responsible behavior. They will need encouragement to increase their independence and make the transition to adult life.

- It is important to remember that teenagers will not outgrow the effects of FASD; it lasts a lifetime. Regardless of age, mental and emotional functioning may be much lower than the norm. Teens may continue to require supervision to keep out of trouble and dangerous situations.

According to a research study, 18% of adults with FASD were able to achieve independent living, but fewer than 10% were able to live independently and without employment problems.(34)

School

- Career counseling is available to teenagers during high school. Career options should be realistic and relate to the skills of the individual. Transition planning (i.e., planning what will happen after high school) and applying for developmental disability services are important. Many individuals with FASD may not be able to maintain a job or live independently.

Young Adults with FASD (Ages 18 to 21)

FASD continues throughout life. Short stature and small head size may remain. However, facial features and growth deficiency may be less visible. Limited reasoning and judgement abilities persist. Mental illness is common and includes depression, withdrawal, isolation, and unpredictable behavior. Alcohol and drug abuse may add to problems.

Some young adults with FASD continue to need supervision and support. Many will have problems with employment. They may be capable of performing a job, but often have difficulty keeping it. They may be age 21 physically, yet have the ability of a 12 year old. Help may be needed to perform household tasks successfully. The simple tasks of daily living may need to be taught. Routines that do not vary day to day are best. Using lists is often helpful.

Young adults with FASD may not be able to manage money or parent the children they have. Independent living may not be possible. Special living arrangements may be needed which provide supervision, support, and guidance. Home health aides may be helpful.

Stress frequently increases with the age of the young adult. Coping may be difficult. Often, the entire family needs support and understanding from others. Support groups may be helpful.

Important Tips for Parents/Patients:

Health Care

- Continue to discuss topics related to health promotion and disease prevention (see adolescent section for list of topics). Information shared is personal and confidential.
- Young adults with FASD may still have problems with memory gaps and the ability to report symptoms and take medications.
- When moving away from home or finding a job, many young adults find they are no longer covered by their parent's health insurance. Many policies only cover dependents that are full-time students. Discuss health care coverage with the insurance company. You may also want to talk with your social worker, public health nurse, or doctor. Help young adults learn the details of their policies. If they do not have health insurance, help them to find low cost coverage.

Development

- Young adults need to understand their condition. They may need encouragement to ask questions.
- Encourage your young adult to be as independent in activities as possible.
- Young adults need to understand how FASD may affect their sexual and reproductive lives. Provide sexually active young adults with information to protect them from pregnancy and sexually transmitted diseases.
- Encourage your young adult to be an advocate for him or herself.

School and Employment

- Many individuals with FASD may not be able to maintain a job or live independently. They may also need help managing money. Mentoring and job coaching are helpful.
- Some young adults with FASD may be eligible for vocational rehabilitation services. The Minnesota Department of Economic Security, Division of Rehabilitation Services (DRS), can help young adults with disabilities. For information on counseling, assistive technology, job training, or job placement contact your area WorkForce Center or call 1-888-438-5627.
- The American with Disabilities Act (ADA) prohibits discrimination in employment practices against a qualified person with a disability. This is a person who can perform the "essential functions" of the position with or without reasonable accommodation.

Support Groups, Networks, and Resources

Parents may need help accessing the resources that are available to them. Provide them with literature, telephone numbers, web site addresses, and other means of finding out more about FASD and resources that can help. It might be a good idea for families to consult with a social worker to help identify and access resources.

The Minnesota Department of Health, Minnesota Children with Special Health Needs (MCSHN) publishes a reproducible booklet, "*Guidelines of Care for Children with Special Health Care Needs: Fetal Alcohol Syndrome and Fetal Alcohol Effects*," that covers many of the topics discussed in this packet and has an extensive list of references and resources at the end. To obtain your own copy, call:

(651) 215-8956 (voice or TDD)*
(800) 728-5420 (voice or TDD)*

**You can request this information in another form such as Braille, large print, or audiotape by requesting it from the project supervisor at these numbers.*

The Minnesota Organization on Fetal Alcohol Syndrome (www.mofas.org) provides education and support services.

Summary

Over the years Ryan gets special help in school, medication for ADHD and depression, OT and PT, and career counseling but never gets beyond a grade school level intellectually. Ryan is now an adult and unable to live independently. He has tried many jobs but cannot maintain employment for more than a few weeks at a time. However, thanks to Jill's persistence and a number of resources, many of the secondary neurodevelopmental disorders have been avoided. Jill has made arrangements for Ryan's placement in an assisted-living facility. Ryan is excited to try things on his own. Jill continues to wrestle with her feelings of guilt over her role in Ryan's FAE and worries what will happen to Ryan if anything were to happen to her.

This may be the end of the story and the end of this packet, but hopefully not the end of your learning about FASD. Please continue to read and inform. Good luck to you in your practice!

Acknowledgements

Thank you to the Minnesota Children with Special Health Needs division of the Minnesota Department of Health for providing so much information on Fetal Alcohol Syndrome and Fetal Alcohol Effects in a reproducible form. The ability to include information, tables, and figures without wrangling with copyright issues made the development of this independent learning activity much easier.

Thank you to Better Endings New Beginnings for granting permission to use information from their web site. You may want to check it out if you have internet access: www.betterendings.org (for Minnesota-specific information visit: www.mofas.org).

Thank you to Teresa Kellerman, FAS Community Resource Center in Tucson, AZ, for developing an awesome web site on FAS. Great for health care professionals, parents, and kids. She even has a presentation that kids can print out for school reports. Check it out: http://come-over.to/FASCRC.

Directions for Submitting Your Post Test for Contact Hours

To obtain a certificate of completion for this home study program, please complete the post-test on the next page.

HCMC, MVAMC & Regions Hospital Employees

If you are an employee of HCMC, MVAMC, or Regions Hospital, simply send the post-test to TCHP for processing.

Paid Participants

If you are not an employee of one of the TCHP hospitals, please send the post-test to TCHP with a check for $12.50. Please make check payable to **Regions Hospital** and mail to:

TCHP Education Consortium
Capitol Office Building
525 Park Street, Suite 120
St. Paul, MN 55103

Your post-test will be returned to you with the certificate of completion.

References

Due to the temporary nature of information on the internet, some website references may no longer be available. Printouts of online references are kept on file in the TCHP office.

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Suggested Reading

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2. Dorris, M. (1989). The Broken Cord. New York: Harper & Row Publishers.

   One family's experiences raising a child with FAS.

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   A comprehensive report on fetal alcohol syndrome.

6. Governor's Task Force on Fetal Alcohol Syndrome (Feb. 1998). Suffer the Children: The Preventable Tragedy of Fetal Alcohol Syndrome. To obtain a copy call Minnesota Planning at 651-296-3985.

   Results of a study and professional recommendations regarding fetal alcohol syndrome.

7. Minnesota Children with Special Health Needs, Minnesota Department of Health (1999). Fetal alcohol syndrome and fetal alcohol effects.

   Thorough booklet available free from MCSHN. Covers lots of information that health care providers and parents need to know. Call 651-215-8956 to order your own copy.

8. Miller, Kay (Sunday, April 16, 2000) "Damaged for Life." Minneapolis Star Tribune. Available on line at: http://www.startribune.com.

   An article on FASD and how it has affected the life of Emma Pohl and her family.

9. Web site: http://www.betterendings.org. Sponsored by the Minnesota Organization on Fetal Alcohol Syndrome.

   Wonderful web site with tons of information on FASD for professionals and families. Lots of links to other sites.

10. Web site http://come-over.to/FASCRC: Developed by Teresa Kellerman, Director for the FAS Community Resource Center in Tucson, AZ.

    Wonderful web site chock full of information for health care providers, parents, and children. Many links to other sites.

11. Web site: http://www.nofas.org. Sponsored by the National Organization on Fetal Alcohol Syndrome.

    Provides information on FASD for health care professionals and families. Several studies referenced.

12. Web site: http://etoh.niaaa.nih.gov. Sponsored by the National Institute of Health.

    You can search their web site for information on FASD or other alcohol abuse topics and it will display a list of related article summaries.

13. Web site: http://www.fasalaska.com.

    Nice website with lots of information. Nice list of interventions for educators.

14. Web site: http://depts.washinton.edu/~fasdpn/Diag3.html. *On line guide for diagnosing FAS. Has a pictorial lip-philtrum guide to aid to improve measurement accuracy and precision.*

Post-Test
Fetal Alcohol Syndrome

Name_____

Date Completed_____

HCMC, MVAMC, or Regions Hospital employees:

Hospital _____Unit_____

Paid Participants: _____
Street address

_____
City State Zipcode

Multiple choice

1) Fetal Alcohol Syndrome is a disability characterized by:
   a) Growth retardation
   b) CNS damage
   c) Head and facial anomalies
   d) B & C only
   e) All of the above

2) What term or terms describe a disorder of prenatal alcohol-related CNS damage but without the head and facial anomalies?
   a) Partial Fetal Alcohol Syndrome
   b) Alcohol Related Neurodevelopmental Disorders
   c) Both of the above
   d) None of the above

3) What percentage of children born are exposed to high levels of alcohol in utero?
   a) 10%
   b) 5%
   c) 30%
   d) 2%

4) Which of the following characteristics make it more likely that a woman will consume alcohol during pregnancy?
   a) Smoker
   b) Married
   c) High school drop out
   d) A & C only
   e) All of the above

5) Which of the following defects can occur with prenatal alcohol exposure?
   a) Low birth weight
   b) Hydrocephalus
   c) Congenital heart defects
   d) A & C only
   e) All of the above

6) What is the most common secondary disability in children with FASD?
   a) Mental illness
   b) Homelessness
   c) Alcoholism

True or False (circle one)

7) T or F Fewer than 10% of medical schools require students to complete a course on the proper diagnosis and referral of patients with alcoholism and other drug addictions.

8) T or F Parents who have had a child with FAS are at much greater risk to have another child with FAS than the general population.

9) T or F Children with FASD get frequent upper respiratory and ear infections due to an impaired immune system.

10) T or F Children with FASD appear thin and malnourished throughout their lives.

11) T or F Alcohol Related Neurodevelopmental Disorder (ARND) is a less severe form of Fetal Alcohol Syndrome (FAS).

12) T or F Children with ARND don't “look" like a child with FAS.

13) T or F Social drinking does not increase the risk of having a child with FASD.

14) T or F Men are advised to stop using alcohol and other drugs at least 3 months before conception.

15) T or F The facial characteristics of FAS are most noticeable between the ages of 2-10 years.

16) T or F All children with FAS should have a hearing test.

17) T or F Because most of the damage to the fetus occurs before the end of the first trimester, you shouldn't continue to encourage a pregnant woman to stop drinking during the remainder of her pregnancy.

18) T or F Breast feeding may be impossible if a mother continues to drink regularly.

19) T or F It is a good idea for children with FASD to get a flu shot every fall.

20) T or F Children with FASD often have a social and emotional maturity many years behind their age in years.

21) T or F Children with FASD learn at a consistent but slow pace.

22) T or F Some teenagers may outgrow the effects of FASD.

23) T or F Fewer than 10% of adults with FASD are able to live independently without employment problems.

24) T or F If alcohol of sufficient quantity is not consumed during the critical period of development (15 to 22 days), then the head and facial characteristics of FAS may not develop.

25) T or F Children who do not exhibit the facial and head characteristics of FAS will not receive a clinical diagnosis of FAS, even if they have lots of other disorders associated with prenatal alcohol exposure.

26) T or F It is imperative that health care professionals become well educated on FASD and give clear, consistent messages about alcohol consumption during pregnancy (there is no known safe level of alcohol consumption during pregnancy).

Evaluation: Fetal Alcohol Syndrome

We'd appreciate it if you could take a moment to complete the evaluation for this program. Thank you!

1. Who do you work for?_____

2. How did you hear about this program?

   - ❑ brochure
   - ❑ co-worker
   - ❑ education department/clinical educator
   - ❑ TCHP website
   - ❑ Other _____

3. Were the objectives met?

Objective	Was the objective met?
Define Fetal Alcohol Spectrum Disorder (FASD) and Fetal Alcohol Syndrome (FAS).	Yes No
Describe the risk factors that can lead to FASD.	Yes No
Identify 5 or more traits of a child with FASD.	Yes No
Explain why the neurodevelopmental disorders that occur with FASD can be the most devastating.	Yes No
Describe how the timing of prenatal alcohol exposure during pregnancy affects the development of disorders in the child.	Yes No
Identify 3 ways that health care professionals can decrease the impact of FASD.	Yes No
List 3 points to include in patient education with a family dealing with FASD.	Yes No

4. Would you recommend this program?

   ❑ yes ❑ no

5. Was this educational activity…
   - ❑ too long
   - ❑ too short
   - ❑ just right

6. I can use the information from this activity in my job.
   - ❑ strongly agree
   - ❑ agree
   - ❑ disagree
   - ❑ strongly disagree

7. The information was….
   - ❑ easy to understand
   - ❑ difficult to understand