by Linda N. Coakley

PREVENTABLE Birth Defects

One in 8 pregnant women **report drinking** during pregnancy.

A Golden Teaching OPPORTUNITY

Fetal alcohol syndrome (FAS) is the leading preventable cause of mental retardation in the United States. Why? Because the only risk factor for FAS is alcohol use during pregnancy. However, despite public education, FAS continues to be a major public health problem, with approximately 12,000 children afflicted each year (American Academy of Pediatrics, 2000). Interventions by nurses for improvement in prevention education and for increased awareness of FAS can help achieve the goal of Healthy People 2010 to decrease the numbers of children born with FAS (U.S. Department of Health & Human Services, 2000).

Along with FAS, other common birth defects can be prevented or lessened through proper education. As nurses, we are in an excellent position to have an impact on the problem of birth defects. We encounter women during their childbearing years in every arena of professional nursing practice and in relationships with children and families in multiple life venues. The caring art of nursing is demonstrated through health promotion interventions that are protective for the unborn child. Furthermore, the life of each child is precious, and nurses are blessed with golden opportunities to have an impact on the lives of individual children through education regarding preventable birth defects. Fetal alcohol syndrome is one birth defect for which many women unknowingly put their children at risk, and it is completely preventable.

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UNDERSTANDING FAS

Almost two centuries have passed since a committee report to the British House of Commons identified the effects of alcohol upon the unborn child. The report stated that infants born to mothers who drank excessively appeared shriveled and abnormal. Decades have passed since 1973, when scientists officially recognized the effects of alcohol upon the unborn child and named these effects "fetal alcohol syndrome" (Jones & Smith, 1973). The U.S. Surgeon General first recommended in 1981 that women not drink alcohol during pregnancy

CE 2 contact hours

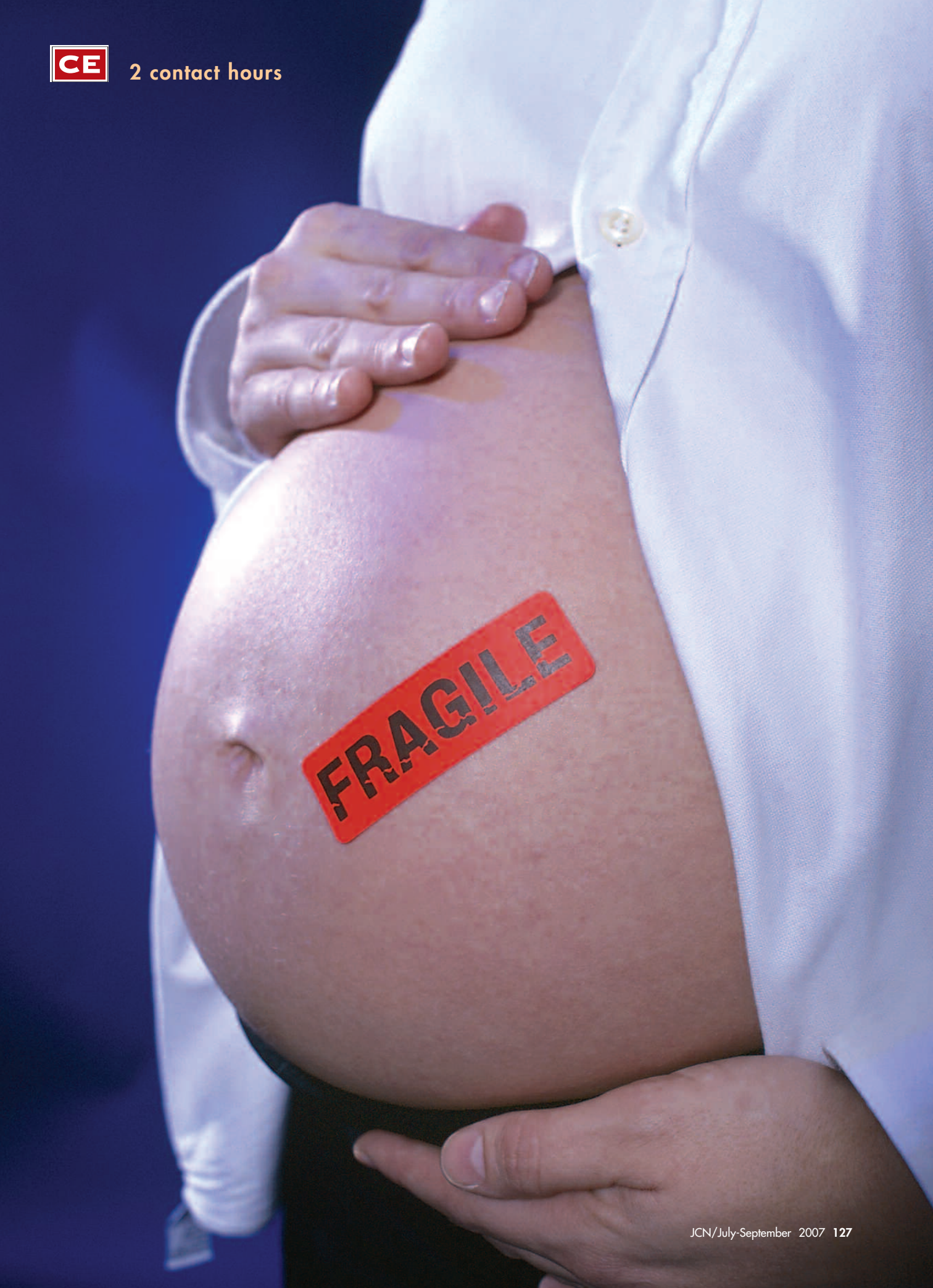

TABLE 1 Fetal Alcohol-Related Terms (American Academy of Pediatrics, 2000)

- *Fetal alcohol syndrome* (FAS) is a syndrome affecting physical, behavioral, mental, and cognitive abilities, resulting in abnormalities of one or all of these aspects of the affected person. The effects of FAS range from very mild behavioral effects to severe physical and mental disability. There is no cure. The mental and physical damage from FAS are permanent.
- *Alcohol-related neurodevelopmental disorder* (ARND) is the term used to describe children with learning or behavioral disorders but without the full spectrum of FAS effects.
- *Fetal alcohol effects* (FAE) refers to children affected by prenatal alcohol exposure who do not present with the full syndrome of effects. These children lack the major facial dysmorphology associated with FAS.
- *Fetal alcohol spectrum disorder* (FASD) is a term used to describe the full range of disorders that result from prenatal exposure to alcohol. FASD includes FAS and ARND.
- *Teratogenic* refers to any substance that causes harm to the unborn fetus.

or when planning a pregnancy (Streissguth, 2002). The fact that the health of children is still threatened in the 21st century by this potentially catastrophic syndrome underscores the need for increased awareness and prevention of FAS.

A national leading researcher on FAS, Ann Streissguth, founder of the Fetal Alcohol and Drug Unit at the University of Washington School of Medicine, states, "If women didn't drink during pregnancy, there would never be another baby born with fetal alcohol syndrome or effect" (Association of Retarded Citizens of Atlantic County, 2004).

Despite dissemination of educational information about prevention of FAS, women continue to drink during pregnancy, exposing the unborn fetus to the teratogenic effects of alcohol. Children exposed to alcohol during pregnancy are identified as at high risk for mental retardation and central nervous system damage, physical malformation including facial anomalies, and growth retardation. The effects of alcohol on the developing child range from mild developmental delays to severe brain damage. Alcohol-related neurodevelopmental disorder (ARND) and fetal alcohol effects (FAE) describe children with some effects of FASD, but without the characteristic facies. Recently, fetal alcohol spectrum disorder (FASD) has been used to describe the full range of disorders including FAS, ARND, and FAE that may result from prenatal exposure to alcohol (Sokol, Delaney-Black, & Nordstrom, 2005).

Reports regarding the prevalence of FAS vary widely, depending on the population studied and the surveillance methods used. The Centers for Disease Control and Prevention (CDC) studies show FAS rates ranging from 0.2 to 1.5 per 1,000 live births in different areas of the United States. Other FASDs are believed to occur approximately three times as often as FAS (CDC, 2006).

Because the amount of alcohol that causes FAS is unknown, national guidelines recommend that women avoid all alcohol during pregnancy and for any period during which they are trying to or might conceive. No one knows why some children of mothers who report very heavy drinking habits are born with mild effects whereas other children of mothers with minimal drinking habits are born with severe damage. Current guidelines from the American Academy of Pediatrics, the U.S. Department of Health and Human Services, and the American College of Obstetricians and Gynecologists recommend preconception counseling for health promotion and prevention of FAS.

A PREVENTABLE PROBLEM

Preconception counseling recommends that women abstain from drinking alcohol both before and after becoming pregnant. Dissemination of educational information about FAS has traditionally been delivered after the diagnosis of pregnancy. However, many women, especially first-time mothers and teenagers, may be pregnant for several weeks to months before becoming aware of their pregnancy.

Drinking during this crucial

at a Glance

- **Fetal alcohol spectrum disorder (FASD)** *describes a range of problems resulting from women consuming alcohol during pregnancy.*
- **Fetal alcohol syndrome,** *the most severe FASD, is the leading preventable cause of mental retardation in the United States.*
- **Nurses are in** *a strategic position to educate their patients and the public on preventable birth defects.*

Kristy's STORY

For 10 years, I served as a foster parent to Kristy, and then adopted her in December 2004. Kristy is severely disabled because of fetal alcohol syndrome (FAS).

In February 1995, Kristy had been with our family only 8 weeks when my husband announced he was leaving. My son was soon off to college, and I was working as an Air Force flight nurse with the Tennessee National Guard and teaching at Tennessee State University. When I picked Kristy up from day care that afternoon, I wondered how I would manage to care for her alone. As if reading my mind, Kristy began laughing, then extended her arms and with her eyes seemed to say, "Keep me!"

That afternoon I made her a promise that we'd stick together, and I'm glad I've been able to honor that promise. Kristy is a blessing. She's added to my life in countless ways. I love her dearly and am amazed at God's hand in our lives. Our story is as follows.

I loved my son but wanted a little girl. I had prayed for another child since my son was young. My prayers seemed to go unanswered. After 14 years of prayer, Kristy came to me. She was 4 months old when we brought her home on December 30, 1994. Immediately, and throughout the years, it became evident why I had needed to wait. Those long years of deep desire were preparing me for Kristy because I would need stored-up love to care for her.

During the ensuing months, Kristy was diagnosed with FAS. Kristy's infant appearance resembled the pictures in my nursing assessment text illustrating the faces of children with FAS. Kristy would soon experience the full-blown, major effects of FAS. These effects include growth retardation, facial dysmorphology, and neurodevelopmental defects. Kristy had other problems associated with FAS including cardiac septal defects, strabismus, hearing deficits, and hemangiomas. Kristy has suffered greatly as a result of FAS. Sadly, all her suffering could have been prevented.

At 5 weeks, Kristy was found to have congestive heart failure. She also had a ventriculoseptal defect (VSD). She underwent surgery for the VSD repair and was in the neonatal intensive care unit (NICU) at Vanderbilt during her early weeks of life. She was placed in state custody after her release from Vanderbilt showing a common factor associated with FAS. Research shows that almost one-third of children with FAS are raised by parents other than their birth parents. Kristy came to me with an apnea monitor and needing Lanoxin. It seemed as if we had an ICU in my home. Kristy was sick most of the time, and I slept fewer than 5 hours per night for 4 years.

Kristy's problems began to manifest themselves as the weeks, months, and years passed. She was a medically fragile child who often had severe respiratory distress and required inhalation treatments and frequent corticosteroid treatment because of reactive airway disease.

Kristy suffered growth retardation. She weighed only 11 pounds at 4 months. She's been on nutritional supplements throughout the 12 years she's been with me. Brain damage from exposure to alcohol in utero left Kristy, like many children afflicted with FAS, disabled. Kristy began leg scissoring movements early and was diagnosed with cerebral palsy. Kristy's pediatric neurologist described her brain structures viewed on the MRI as "thin." When she was 2 years old, it was reported that Kristy's corpus callosum was missing. According to the prognosis, Kristy would require help with all activities of daily living for her entire life.

The impact of FAS for Kristy has been cumulative and devastating. She's endured 13 surgical procedures, many for correction of severe scoliosis. She wears a back brace and orthotics. A wheelchair and walker provide Kristy some mobility, and she sleeps in a special hospital bed to protect her from falls.

Kristy is just one child with FAS. The impact of Kristy's FAS includes, but is not limited to, open heart surgery, chronic lung problems, and frequent exacerbations of asthma with upper respiratory infections, poor endurance, brain damage, cerebral palsy with handicapping conditions, and many surgeries. The lifetime costs of FAS are estimated to be 5 million dollars per child. The costs in terms of human suffering and the lifetime impact on quality of life are inestimable.

In sharing Kristy's story, it is my hope that nurses reading this account will have an increased awareness of FAS and the importance of teaching prevention. Fetal alcohol syndrome is preventable. Let's work together to eradicate this disease.

TABLE 2

CHARACTERISTICS of fetal alcohol syndrome (FAS) and other fetal alcohol spectrum disorders (FASDs)

- Small size for gestational age or small stature in relation to peers
- Microcephaly
- Facial abnormalities including small eye openings, epicanthal folds, low nasal bridge, flat midface, short nose, thin upper lip, micrognathia (small chin)
- Poor coordination
- Hyperactive behavior
- Learning disabilities
- Developmental disabilities (e.g., speech and language delays)
- Mental retardation or low IQ
- Problems with daily living
- Poor reasoning and judgment skills
- Sleep and sucking disturbances in infancy

time places the mothers at high risk for giving birth to a child with FAS. Therefore, it is best to teach prevention of FAS before pregnancy and during the preconception period (Floyd, Ebrahim, and Boyle, 1999).

Research at the CDC indicates that women continue to drink at such high levels during pregnancy that 1 in 30 could produce a child with FAS. Although the CDC reports a decrease in the overall rate of alcohol use during pregnancy, 1 in 8 pregnant women, or 130,000 per year, still report drinking during pregnancy (CDC, 2006). Recommendations from the CDC call for improvement in educational programs to teach prevention of FAS. In February 2005, the U.S. Surgeon General issued an Advisory on Alcohol Use in Pregnancy to help raise public awareness about this critical health concern. The advisory recommends that for a comprehensive reduction of prenatal alcohol exposure, prevention efforts should target all women who could become pregnant yet are drinking at high-risk levels and having unprotected sex, as well as pregnant women (CDC, 2005).

LONG-TERM EFFECTS OF ALCOHOL

Fetal alcohol syndrome is at the severe end of a spectrum of effects that can occur when a woman drinks alcohol during pregnancy. The most prominent feature of FAS is abnormal facial features. Children with FAS also experience growth and central nervous system problems, and in severe cases, mental retardation. Fetal death is the most extreme outcome. Children with FASDs are at risk for secondary conditions such as cognitive disorders, psychiatric illness, and psychological dysfunction. The most frequently diagnosed disorders are attention problems, including attention-deficit/hyperactivity disorder (ADHD). Sadly, children with FAS can experience conduct disorder, alcohol or drug dependence, depression, and even psychotic episodes. Other psychiatric problems such as anxiety disorders, depression, eating disorders, and posttraumatic stress disorder also have been reported.

In turn, these problems can lead to a disrupted school experience for children with FASDs. Such children are more likely to be suspended or expelled, or to drop out of school because of difficulty getting along with other children. They more frequently are characterized by truancy and poor relationships with teachers. Many children with FAS remain in school but have negative experiences because of their behavioral challenges. Teenagers and adults with FAS are more likely to have interactions with police, authorities, or the judicial system. Those with FAS have difficulty controlling anger and frustration, combined with problems understanding the motives of others. Other long-term sequelae of FAS are alcohol and drug problems, inappropriate sexual behavior, and difficulty sustaining employment or living independently as adults. In summary, FAS can result in poor judgment and poor impulse control as a result of primary brain dysfunction. Children with ARND but without full FAS may demonstrate learning and behavioral problems such as difficulties with mathematical skills, difficulties with memory or attention, poor school performance, and poor impulse control and/or judgment (Streissguth, Barr, Kogan & Bookstein, 1996).

Although these conditions can be serious, studies have shown that certain protective factors can significantly help children with FASDs. For example, a child whose FASD is diagnosed early can be placed in appropriate educational classes and given access to social services. Children with FASDs who receive special education are more likely to achieve their potential. In addition, children with FASDs need a loving, nurturing, and stable home life to avoid disruptions, transient lifestyles, or harmful relationships.

PRECONCEPTION Risk Factors for Birth Defects

The Bible records the first preconception counseling. Judges 13 documents this message delivered by an angel to the mother of Samson before she conceived her son. The message instructed, "Now see to it that you drink no wine or other fermented drink and that you do not eat anything unclean, because you will conceive and give birth to a son" (Judges 13:4-5, NIV). Today, we know from science and research that promoting the health and wellness of women and couples before pregnancy improves birth outcomes.

Preconception care is defined as a set of interventions that aims to identify and modify biomedical, behavioral, and social risks to a woman's health or pregnancy outcome through prevention and management. The March of Dimes Foundation has created a series of nursing education modules to assist nurses in working with women and families to help them make healthy decisions to decrease birth defects. The modules can be obtained in writing or online and offer professional continuing education credit (March of Dimes, 2007).

Maternal and child health researchers and providers have recommended that health risks and behaviors be addressed during any encounter with the healthcare system because approximately half of the pregnancies in the United States are unintended. Clinical trials have indicated that provision of preconception care can increase pregnancy planning and intention. This finding is vital because studies have consistently demonstrated that planned pregnancies typically have improved outcomes for both the women and the infants.

The Centers for Disease Control (CDC) and its partners have developed specific recommendations and action plans designed to reach four preconception goals: improve knowledge/behaviors about preconception health; assure women of childbearing age receive preconception care; reduce risk through interventions during the interconception period; and reduce disparities in adverse pregnancy outcomes. The CDC also has released 14 preconception interventions which have proven to be effective in improving pregnancy outcomes (CDC, 2006, April 12):

1. Isotretinoins. The use of isotretinoins (e.g., Accutane) in pregnancy to treat acne can result in miscarriage and birth defects. Effective pregnancy prevention should be implemented to avoid unintended pregnancies among women with childbearing potential who use this medication.
2. Alcohol intake. At no time during pregnancy is it safe to drink alcohol, and harm can occur early, before a woman has realized that she is or might be pregnant. Fetal alcohol syndrome and other alcohol-related birth defects can be entirely prevented if women cease intake of alcohol before conception.
3. Antiepileptic drugs. Certain antiepileptic drugs are known teratogens (e.g., valproic acid). Recommendations suggest that before conception, women receiving a regimen of these drugs who are contemplating pregnancy should be prescribed a lower dosage.
4. Diabetes (preconception). The threefold increase in the prevalence of birth defects among infants of women with types 1 and 2 diabetes mellitus is substantially reduced through proper management of diabetes before and during pregnancy.
5. Folic acid deficiency. Daily use of vitamin supplements containing folic acid has been demonstrated to reduce the occurrence of neural tube defects by at least 50%.
6. Hepatitis B. Vaccination is recommended for men and women at risk for acquiring hepatitis B virus (HBV) infection. Preventing HBV infection in women of childbearing age prevents transmission of infection to infants and eliminates the risk to the woman of HBV infection and sequelae including hepatic failure, liver carcinoma, cirrhosis, and death.
7. HIV/AIDS. If HIV infection is identified before conception, timely antiretroviral treatment can be administered, and women (or couples) can be given additional information that can help prevent mother-to-child transmission.
8. Hypothyroidism. The dosages of medication (Levothyroxine) required for the treatment of hypothyroidism increase during early pregnancy. Levothyroxine dosage needs to be adjusted for proper neurologic development of the fetus.
9. Maternal phenylketonuria (PKU). Women diagnosed with PKU as infants have an increased risk for delivering neonates/infants with mental retardation. However, this adverse outcome can be prevented if mothers adhere to a low-phenylalanine diet before conception and continue it throughout their pregnancy.
10. Rubella seronegativity. Rubella vaccination provides protective seropositivity and prevents congenital rubella syndrome.
11. Obesity. Adverse perinatal outcomes associated with maternal obesity include neural tube defects, preterm delivery, diabetes, cesarean section, and hypertensive and thromboembolic disease. Appropriate weight loss and nutritional intake before pregnancy reduces these risks.
12. Oral anticoagulant. Warfarin, used to control blood clotting, is demonstrated to be a teratogen. To avoid exposure to warfarin during early pregnancy, medications can be changed to a nonteratogenic anticoagulant before the onset of pregnancy.
13. Sexually transmitted diseases. *Chlamydia trachomatis* and *Neisseria gonorrhoeae* have been strongly associated with ectopic pregnancy, infertility, and chronic pelvic pain. Sexually transmitted diseases during pregnancy may result in fetal death or substantial physical and developmental disabilities, including mental retardation and blindness. Early screening and treatment prevents these adverse outcomes.
14. Smoking. Preterm birth, low birthweight, and other adverse perinatal outcomes associated with maternal smoking in pregnancy can be prevented if women stop smoking before or during early pregnancy. Because only 20% of women successfully control tobacco dependence during pregnancy, cessation of smoking before pregnancy is recommended.—JCN

Centers for Disease Control and Prevention. (2006, April 12). *Preconception care questions and answers: Professionals.* Retrieved March 25, 2007 at http://www.cdc.gov/ncbddd/preconception/QandA_providers.htm.

March of Dimes. (2007). *Preconception health & healthcare: Continuing education.* Retrieved March 25, 2007 at http://www.marchofdimes.com/professionals/19640.asp.

Children with FASDs who live in abusive or unstable homes or who become involved in youth violence are much more likely to experience secondary conditions (Streissguth et al., 1996). The National Center on Birth Defects and Developmental Disabilities (NCBDDD) has issued helpful guidelines for referral and diagnosis of FAS and FASDs. The free guidelines can be downloaded at www.cdc.gov/ncbddd (NCBDDD, 2004).

INFLUENCING HEALTHY DECISION MAKING

On the basis of these recommendations and personal experience raising a child severely afflicted with FAS, I conducted my dissertation research on *Teaching Prevention of Fetal Alcohol Syndrome: Relationship of Factors to Healthy Decision Making in Adolescents* (Coakley, 2006). High school students were the population chosen for the study, which aimed to deliver preventive health information for use at the preconception stage. Survey findings from this research showed that

- Adolescents are capable of using health information to make decisions regarding their health. A cross-tabs data analysis showed that 98% of students scored 75 or higher out of 100 possible points on the healthy decision-making survey.
- Religiosity is significantly related to healthy decision making in adolescents. A Pearson correlation coefficient run between the variables of religiosity and health decision making demonstrated $r(85) <eq> .32$ ($p <lt> .01$).
- According to bivariate correlation results, a significant interaction exists between the variables of parental support and peer support (Pearson $r(95) <eq> .21$; $p <lt> .05$).

Further research with larger populations is needed to determine how adolescents make decisions about their health. The sample population size for this project was 95 students. However, the findings of this study indicated that adolescents are capable of making healthy decisions, and this information is helpful in planning health education programs for this population. The significant correlation between healthy decision making and religiosity supports spiritual assessment by nurses and the encouragement of religious activity. The significant correlation between healthy decision making and peer and family support encourages nurses to facilitate positive peer and family relationships for adolescents in their care. Scripture supports the conclusion that training and influencing children in God's ways and the way of wisdom (Proverbs 22:6) contributes to health and well-being (Proverbs 3). Scripture also instructs about strong parental support and parent-child relationships (Ephesians 6:1-4).

Little children were important to Jesus. When little ones were brought to him, against the stern rebuke of his disciples, he stopping everything he was doing to take the children in his arms and bless them (Mark 10:13-16). He taught us that whatever we do for "the least of these" we do for him (Matthew 25:40). As Christian nurses, we can continue Christ's ministry to little ones by educating our patients and others with whom we have contact to prevent FAS.

American Academy of Pediatrics (AAP) Committee on Substance Abuse and Committee on Children With Disabilities. (2000). Fetal alcohol syndrome and alcohol-related neurodevelopmental disorders. *Pediatrics, 106*(2), 358-361.

Association of Retarded Citizens (ARC) of Atlantic County. (2004). *Everyone should know about FAS.* New Jersey: Author.

Web Resources

- FAS World: www.fasworld.com
- Fetal Alcohol Diagnostic & Prevention Network: www.depts.washington.edu/fasdpn
- Fetal Alcohol Disorders Society: www.acbr.com/fas
- Fetal Alcohol Syndrome Family Resource Institute: www.fetalalcoholsyndrome.org
- March of Dimes Preconception Health & Health Care: www.marchofdimes.com/professionals/19695.asp
- National Center on Birth Defects and Developmental Disabilities: www.cdc.gov/ncbddd/fas
- National Organization on Fetal Alcohol Syndrome: www.nofas.org

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U.S. Department of Health & Human Services (DHHS). (2000). *Healthy People 2010.* Retrieved February 29, 2004 at http://www.healthypeople.gov.