

# Closing the Gap

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## Maternal Mortality *African Americans Remain at Higher Risk*

Kauthar B. Umar, M.A.

In a decade-long study, the Centers for Disease Control and Prevention (CDC) found that African American women die three times more often from pregnancy-related complications than non-Hispanic White women. This gap, which has persisted for more than 60 years, is the largest and most difficult disparity to understand in the area of maternal and child health.

"Any pregnancy-related death is one too many," said Secretary of the Department of Health and Human Services (HHS) Tommy G. Thompson, in a February 20, 2003, press release. "We must focus our research on finding ways to reduce these deaths."

Data from CDC's Pregnancy Mortality Surveillance System (PMSS) from 1991 to 1999 indicate that although maternal mortality is rare, on average 12 women die each year for every 100,000 live births. For African American women, though, the rate is 30.0 deaths per 100,000 live births compared with 8.1 deaths for White women.

African American women are three times more likely to die from ectopic pregnancies, (when the placenta and fetus develop outside of the uterus) and preeclampsia (a combination of hypertension, fluid retention and protein loss in the urine). African American women are also two times more likely to leak amniotic fluids during pregnancy, which leads to infection, according to the Almanac, the University of Pennsylvania's faculty news journal. These three conditions account for 59 percent of all maternal deaths in the United States.

According to a 2002 CDC study, it is the limited access that minority communities have to health care that possibly leads to higher maternal mortality rates. The study revealed that African American women were more than twice as likely as White women to receive delayed or no prenatal care. Moreover, the majority of women in the study said they wanted earlier prenatal care but were hindered by

outside barriers like a lack of money or insurance and the inability to obtain an appointment.

Removing barriers to and actively promoting the use of prenatal services is key to reducing maternal mortality according to Dr. Audrey Saftlas, professor of epidemiology at the University of Iowa College of Public Health. In a study published in the "American Journal of Epidemiology," Saftlas argued that the health care system should make comprehensive reproductive health services more available to African American women while ensuring that women are able and willing to use services.

"With current medical knowledge and technology, more than half of maternal deaths can be prevented," Saftlas said. "We need to develop strategies to improve the content of and access to prenatal care for all Black women—not just Black women at high risk, but also those considered at low risk."

Indeed, there is a misconception that by focusing on high-risk women, incidents of pregnancy-related deaths will be easier to prevent, according to Dr. Margaret A. Harper, primary author of "Pregnancy-Related Death and Health Care Services."

But she said that about 10 to 15 percent of women who are thought to be at risk for a complication actually go on to have a problem. As a result, focusing on risk factors can give patients and providers a false sense of security, leaving them ill prepared if complications arise, Harper said. If lack of prenatal care and known risk factors don't fully explain the causes of maternal mortality then what needs to be done?

Dr. Luigi Mastroianni, Jr., professor of Obstetrics and Gynecology at the University of Pennsylvania School of Medicine, argues for a "need to speed up the development of superior methods to predict risk, achieve timely intervention and develop effective therapies."



Dr. Sara Whitehead, a reproductive health epidemiologist at CDC agrees that there is a need to expand public health monitoring of pregnancy-related death.

“We need to examine issues such as access to care, quality of care, health insurance status, language and cultural barriers to care, immigration issues and socioeconomic status,” she said.

In order to reduce maternal mortality to achieve the nation’s Healthy People 2010 objective of no more than

## Maternal Deaths in 2001

**White, Non-Hispanic**  
6.5 maternal deaths  
per 100,000 live births

**Hispanic**  
9.5 maternal deaths  
per 100,000 live births

**Black, Non-Hispanic**  
24.7 maternal deaths  
per 100,000 live births

Source: Healthy People 2010  
<http://wonder.cdc.gov/data2010/>

3.3 maternal deaths per 100,000 live births, the CDC has called for improved surveillance efforts to pinpoint exactly why Black women are dying in greater numbers.

In order to get a better understanding of such efforts, New York State, where the maternal mortality rate among African Americans exceeds the national average, launched an initiative in 2002 with a goal to increase awareness of maternal mortality, improve birth outcomes, and reduce pregnancy-related deaths and racial disparities.

The initiative introduced a uniform statewide protocol form to be used by Regional Perinatal Centers (RPCs) to document and review pregnancy-related deaths.

With uniform information, the state was then able to identify instances and causes of maternal death. There is hope that this data will yield some explanation of why a racial disparity in maternal mortality remains, so that programs can be created to keep mothers safe nationwide.

For more information on the Centers for Disease Control maternal mortality study, go to <http://www.cdc.gov/od/oc/media/pressrel/r030220c.htm> ♦

For more information on the Pregnancy Mortality Surveillance System, go to <http://www.cdc.gov/reproductivehealth/index.htm> ♦

## Safe Motherhood *Preventing Pregnancy-Related Illness and Death*

The Safe Motherhood Program provides national leadership and coordinated action by bringing together states and many other partners devoted to safeguarding the health of mothers. The Safe Motherhood Program’s mission is to promote the health of women before, during and after pregnancy. The Centers for Disease Control and Prevention and its federal partners work with state and local health departments and other organizations to collect and analyze data on maternal health, conduct research and translate the findings into high-quality, effective programs.

- ❖ Approximately 6 million American women become pregnant each year, and more than 10,000 give birth each day.
- ❖ Each day in the United States, between 2 and 3 women die of pregnancy-related causes. A pregnancy-related death is one that occurs during pregnancy or within 1 year after pregnancy and is caused by pregnancy-related complications.
- ❖ The risk of pregnancy-related complications has not decreased since 1982.
- ❖ The risk of death due to pregnancy varies greatly in different racial and ethnic groups. African American women are 4 times more likely and Hispanic women are 1.7 times more likely than White women to die of pregnancy-related complications.
- ❖ Among women who become pregnant in the United States each year, at least 30 percent have a pregnancy-related complication.
- ❖ Childbirth is the most common reason for hospitalization in the United States, and pregnancies with complications lead to more costly hospitalizations.

For more information on the Centers for Disease Control and Prevention Safe Motherhood Program, go to [http://www.cdc.gov/nccdphp/bb\\_motherhood/](http://www.cdc.gov/nccdphp/bb_motherhood/) ♦

*Closing the Gap* is a free newsletter of the Office of Minority Health, Office of Public Health and Science, U.S. Department of Health and Human Services. The Office of Minority Health Resource Center provides free information on various health issues affecting U.S. minorities.

Send an e-mail to [info@omhrc.gov](mailto:info@omhrc.gov) to join our mailing list or to update your address. Or, write to OMHRC, P.O.Box 37337, Washington, DC 20013.



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# Health Prevention and Promotion

## *National Women's Health Week, May 9-15, 2004*

**N**ational Women's Health Week, coordinated by the U.S. Department of Health and Human Services, is a national effort by an alliance of government organizations to raise awareness about manageable steps women can take to improve their health. The focus is on the importance of incorporating simple preventive and positive health behaviors into everyday life.

It encourages awareness about key health issues among all women, and especially African American, Asian/Pacific Islander, Hispanic/Latina and American Indian/Alaska Native women, since research has shown there are significant health disparities among these groups compared to White women.

Kick off the National Women's Health Week by participating in the second annual National Women's Check-Up Day on Monday, May 10, 2004, the nation's largest preventive care check-up event! Community health centers, hospitals, and other health care providers across America will participate in this event.

### **What is National Women's Check-Up Day?**

National Women's Check-Up Day is a nationwide effort to encourage women to visit health care professionals to receive regular, preventive check-ups and screenings.

### **When is National's Women's Check-Up Day?**

The second annual National Women's Check-Up Day will be held on Monday, May 10, 2004, which is the day after Mother's Day, the start of National Women's Health Week.

### **What is the purpose of National Women's Check-Up Day?**

The purpose is to emphasize the importance of getting regular check-ups and asking a doctor about screenings for heart disease, diabetes, cancer and sexually transmitted diseases (STDs). Maintaining regular check-ups is one of five health habits that can contribute to the betterment of women's health along with exercise, a healthy diet, not smoking and following general safety rules.

### **Why is it important for women to participate in this effort?**

Many of the leading causes of death among women, such as heart disease, cancer, stroke and diabetes, can be successfully prevented or treated if the warning signs are caught early enough.

- ◆ Heart disease is the number one killer of American women. Often thought of as a man's disease, more women die of heart disease each year than do men.
- ◆ Cancer is the second leading cause of death of American women. Lung cancer is the top cancer killer among American women, with an estimated 65,000 deaths in 2002, followed by breast cancer and colorectal cancer.
- ◆ Stroke is the number three killer of American women. Each year, 30,000 more women than men have strokes.
- ◆ Diabetes is the sixth leading cause of death in women. An estimated 18 million Americans have diabetes (9 million women), of which an estimated 5 million are undiagnosed.
- ◆ HIV and sexually transmitted diseases also have a major effect on women's health. There are an estimated 40,000 new HIV infections each year in the United States, with about 30 percent of reported infections occurring in women.

### **How can women participate in this important event?**

To participate in National Women's Check-Up Day, women should contact their

existing health care providers or one of the participating health care providers to schedule check-ups and screening services that day. Screening tests, such as mammograms and Pap smears, can find diseases early, when they are easier to treat. Some women need certain screening tests earlier, or more often, than others. During their check-ups, women should discuss with their health care professionals which of the tests are right for them, when they should have them, and how often.

### **How can women prepare for Check-Up Day?**

Women can prepare themselves for their check-ups with "A Checklist for Your Next Check-up," developed by HHS' Agency for Healthcare Research and Quality, which can be found at <http://www.ahrq.gov/ppip/healthywom.htm>.

### **Where can women and health care providers get more information about participating in National Women's Check-Up Day and National Women's Health Week?**

For information about hosting or participating in this and other National Women's Health Week activities, visit the National Women's Health Week Web site at <http://www.4woman.gov/whw> or call 800-994-WOMAN or 888-220-5446 (TTY). ◆

Contact the Office of Minority Health Resource Center for more information on National Women's Health Week and women's health issues at 800-444-6472 or <http://www.omhrc.gov>

# Fetal Alcohol Syndrome

## *Efforts Underway to Reduce Rates*

Lisa Troshinsky

For more than 30 years, doctors, nurses and other health care providers have worked to alert women about the dangers of drinking during pregnancy. Yet, prenatal exposure to alcohol is one of the leading causes of mental retardation and preventable birth defects today.

Fetal alcohol syndrome (FAS), a medical term first identified in 1973, describes a lifelong, physically and mentally disabling condition in children whose mothers drank alcohol while pregnant. FAS is characterized by (1) abnormal facial features, (2) growth deficiencies, and (3) central nervous system problems. People with FAS may have problems with learning, memory, attention span, communication, vision and/or hearing. These problems often lead to difficulties in school and problems getting along with others.

### Those Most Affected

FAS affects one in every 500 live births in the United States, the equivalent of 8,000 to 12,000 cases each year. And, the disease disproportionately affects American Indian communities where the incidence of alcoholism is the highest.

The National Organization on Fetal Alcohol Syndrome (NOFAS) says FAS affects American Indian and Alaska Native communities at least 10 times more frequently than it does the broader population. FAS rates vary between different American Indian tribes, but appear to be worse for those located in the southwestern part of the United States.

Though there are no exact statistics, according to a Centers for Disease Control and Prevention (CDC) surveillance study conducted from 1995 to 1997 in four U.S. states, the rate of FAS births for American Indian and Alaska Natives was 3.2 percent, compared with the rate of 0.2 percent for Whites, and a rate of 0.4 percent for the general population. The second highest incidence rate was for African Americans, with a rate of 1.1 percent.

### FAS Not Confronted? Experts Differ

Though FAS is an escalating health concern, related primarily to the rate of alcoholism increasing among women of childbearing ages, experts maintain that the disease has not been taken seriously by the medical community and that there are very few comprehensive programs that exist for its prevention and treatment.

"There isn't really good surveillance data on FAS anywhere in the United States," said Callie Gass, project director for the FAS Center for Excellence, a new project started by the Department of Health and Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA). "We have a mandate from Congress to identify exemplary systems for comprehensive prevention, treatment and appropriate intervention, and we found out there

**"...We don't know any safe level of alcohol consumption for pregnancy..."**

Callie Gass, Project Director, FAS Center for Excellence

aren't any. We don't know any safe level of alcohol consumption for pregnancy, yet, medical doctors don't routinely tell

women not to drink during pregnancy and we don't have intervention programs for women who are drinking."

One of the main problems in fighting FAS is that it is easily misdiagnosed. Unless a person has the characteristic facial defects, the syndrome can be mistaken for attention deficit disorder, or just plain laziness or intentional "acting out." A cultural stigma is another barrier to FAS identification and intervention, experts say.

Dr. Kathy Masis, medical officer for behavioral health, Billings Area (Montana), Indian Health Service (IHS), contends that though stigma, embarrassment and resistance associated with FAS exists, there is less of a cultural barrier to facing the problem in American Indian communities.

"IHS was a pioneer in discovering FAS in 1973," Masis said. "Ascertainment within the American Indian community is better than in other communities; they don't have the level of stigma. American Indians are already stigmatized just for being Indians, for living on a reservation. They don't have the same need to look good for society. There is more of a willingness to talk about FAS and report it."

But Sharon Asetoyer, executive director of the American Indian Women's Health Education Resource Center, located in South Dakota, says fighting FAS in American Indian communities has a long way to go.

"Some communities have treatment centers, but they are few and far between," Asetoyer said. "The government spends millions on treatment services, but fails to provide after-care services. Without those, women go back into the same environments and start drinking again."

"There is a disparity of funding for the American Indian community because we are tucked out here in rural communities and reservations, and we haven't had the voting power in the past," Asetoyer said. "Luckily, that is starting to change in South Dakota, and now there is a consortium that includes Minnesota, Nebraska,

Oklahoma, Arizona, New Mexico, Montana and Idaho, that is dealing with the problem.”

### Some Hope—More Money, More Initiatives

Efforts by government and private organizations to prevent, identify and treat FAS in American Indian communities are starting to gather steam, say FAS experts. IHS, SAMHSA, CDC, the National Institutes of Health, and NOFAS are among those that have received funding to fight the disease.

“In the last two years, activity around the country toward reducing FAS has been phenomenal,” Masis said. “There is more funding from CDC, IHS recently hired key people, and SAMHSA started the FAS Center for Excellence a few years ago.”

“I think more attention has been put on fighting FAS in the American Indian communities because of Congressional support,” said Kathleen Mitchell, NOFAS program director and national spokesperson.

One piece of significant legislation, the Children’s Health Act of 2000, requires the HHS Secretary to make awards to public, non-profit and private organizations to establish up to four centers for excellence to study techniques to prevent FAS and alcohol-related birth defects.

As a result of that legislation, for the purpose of combating FAS, SAMHSA was appropriated approximately \$12 million for fiscal year (FY) 2001, \$11 million for FY 2002, \$9.7 million in FY 2003, and \$10 million is expected for FY 2004, Stone said.

“Before these appropriations, SAMHSA was getting nothing for FAS,” Stone said.

“There have been some funding increases within CDC for state-based grants for FAS awareness and training,” said Candice Jalonen, a health scientist at the CDC National Center on Birth Defects and Developmental Disabilities.

“For FY 2003, CDC received \$12.4 million, and for FY 2004, \$12.5 million was appropriated for FAS prevention. CDC also heads up a federal FAS Task Force, and contracts non-profits and community organizations to conduct FAS prevention.”

“NOFAS also has grown due to increased investment for this issue over the last three-year-period,” said NOFAS executive director Tom Donaldson.

### Projects are Beginning

“The SAMHSA FAS Center for Excellence is still in its research stage,” said center project director Callie Gass. “We’re going around the country conducting town hall meetings to identify what the American Indian communities need regarding FAS, particularly in the southwest. We’re developing a strategic plan—trying to figure out how to get around lack of resources in those areas, and discovering which best practices and models are required.”

Gass went on to say, “We want to increase recognition of women at risk, and after someone is diagnosed with FAS, we want to encourage early intervention, which could include occupational, speech, and behavior therapy.”

NOFAS recently received \$175,000 from the Weinburg Foundation for a three-year Indian youth project to fight FAS, and \$150,000 from the CDC for a Cherokee Nation project in Oklahoma, Donaldson said.

“The goal of the Cherokee Nation project is to conduct prevention and intervention work,” said Mitchell. “The Cherokee Nation will form an advisory committee that will drive our activities, and we will develop a public awareness campaign to serve women and children and develop workshops for health clinics and addiction treatment centers.”

NOFAS just completed a similar three-year, public awareness campaign in Washington, D.C., funded by the National Institutes of Health that targeted African Americans. NOFAS also is continuing to increase FAS awareness in the medical community.

“We’ve had an FAS curriculum at several medical institutions, including Northwestern and Georgetown, for more than 13 years, and we’re working with the CDC to develop a general FAS curriculum for medical students and practitioners,” Mitchell concluded.

*For more information on the Substance Abuse and Mental Health Services Administration Fetal Alcohol Spectrum Disorders Center for Excellence, go to <http://www.fascenter.samhsa.gov/>* ♦

Number and Prevalence Rate\* of Fetal Alcohol Syndrome Cases • Fetal Alcohol Syndrome Surveillance Network, 1995-1997

Race/ethnicity	Alaska			Arizona			Colorado			New York			Total		
	Births	Cases	Rate	Births	Cases	Rate	Births	Cases	Rate	Births	Cases	Rate	Births	Cases	Rate
White, non-Hispanic	19,007	5	.3	114,851	15	.1	63,653	11	.2	68,932	18	.3	266,443	49	.2
Black	1,341	0	-	7,054	4	**	5,508	5	.9	13,455	21	1.6	27,358	30	1.1
Hispanic	1,287	0	-	80,626	16	.2	21,579	8	.4	3,635	0	-	107,127	24	.2
Asian/Pacific Islander	1,493	0	-	4,371	1	**	2,556	0	-	1,693	0	-	10,113	1	**
AI/AN++	7,117	40	5.6	15,685	39	2.5	1,744	1	**	627	1	**	25,173	81	3.2
Other/Unknown	39	0	0	456	0	-	96	0	-	447	0	-	1,038	0	-
<b>Total</b>	<b>30,284</b>	<b>45</b>	<b>1.5</b>	<b>223,043</b>	<b>75</b>	<b>.3</b>	<b>95,136</b>	<b>25</b>	<b>.3</b>	<b>88,789</b>	<b>40</b>	<b>.4</b>	<b>437,252</b>	<b>185</b>	<b>.4</b>

\* Per 1,000 population/\*\* Rates were calculated when the number of cases was <5/ ++American Indian/Alaska Native  
Source: *Morbidity and Mortality Weekly Report (MMWR)* May 24, 2002 / 51(20):433-5

# No Cost, Big Benefit

## *Breastfeeding Promotes Health and Prevents Disease*

Kauthar B. Umar, M.A.

New moms can keep their money in their pockets. Without spending a dime, mothers can improve their baby's health, and their own, by taking advantage of the one thing that can not be bought off the shelf—breast milk.

“When a mother breastfeeds, it strengthens the bond between her and her baby,” said Carol Huotari, manager of the Center for Breastfeeding Information at La Leche League International. “There are benefits for the child, and there are benefits for the mother.”

As long as women across the country continue to neglect breastfeeding, they are placing themselves and their babies at-risk, experts say. That's why all women, and minorities in particular, are being encouraged to exchange rubber nipples for the real thing.

According to the United Nations Special Session on Children and the World Health Organization (WHO), breastfeeding is the most cost-effective way to promote health and prevent disease. Research shows that breastfeeding, for the mom, leads to an earlier return to pre-pregnancy weight, decreases postpartum bleeding, and possibly reduces the risk of ovarian cancer. Among American Indians, the incidence of obesity, which contributes to high rates of type 1 and 2 diabetes, has decreased when breastfeeding among new mothers has increased, according to Sue Murphy, breastfeeding program coordinator at the Diabetes Center of Excellence at the Phoenix Indian Medical Center.

The health benefits children receive from breast milk are equally promising. Breast milk enhances an infant's cognitive development, neurodevelopment, immune system, and nutritional and mental health.

### Why Women Don't Breastfeed

Despite the benefits of breastfeeding, HHS studies show that too few women commit to exclusive breastfeeding, while many remain unaware of its importance.

“I don't think most women know about the benefits of breastfeeding for their children and for themselves,” said Dr. Suzanne G. Haynes, chairwoman of the HHS Subcommittee on Breastfeeding and senior science advisor to the Office of Women's Health (OWH). “Still today, in developed countries like ours, breastfeeding is viewed as old fashioned.”

Breastfeeding is least common among young, low-income ethnic minorities who work full time, according to a literature review by Cindy-Lee Dennis in the January/February 2002 issue of the “Journal of Obstetric, Gynecologic, and Neonatal Nursing.” Most lack proper support, decide to breastfeed during or late in their pregnancy, feel negatively about breastfeeding, and have low confidence in their ability to breastfeed.

This holds true for many African American women. HHS statis-

tics show that African Americans have the lowest rate of breastfeeding among all ethnic groups—only 45 percent during the early postpartum period, compared to 68 percent of White women, who breastfeed most often.

A NIH study conducted by Dr. Yvonne Bronner, director of the MPH/DrPH program at Morgan State University, found that lack of support from partners and families was a major deterrent to breastfeeding. As a result, breastfeeding has lost its importance in African American culture said Katherine M. Barber, executive director and founder of the African American Breastfeeding Alliance Inc. (AABA).

“The shift in the family structure from two-parent to single-parent families, as well as infant formula companies and their ability to mass market to the African American community, has influenced this change,” Barber said.

Such cultural trends continue to lure women away from breastfeeding. For many Asian American and Pacific Islander (AAPI) women, breastfeeding is not popular in their countries of origin, so when they migrate to the United States they bring the bias with them.

Exposure to bottle feeding in hospitals has also been highly influential, especially for new AAPI immigrants.

“When the baby's crying, the nurse will pop in the bottle and that gives mothers the wrong message,” said Madeline Ritchie, center director of the Chinatown Public Health Center in San Francisco.

Language barriers and a lack of cultural competence among medical staff also affect a new mother's choice to breastfeed exclusively. While Hispanic women often breastfeed initially, they tend to introduce formula into their babies' diets early on, leading to early weaning, according to Dr. Lucia Kaiser, community nutrition specialist at the University of California, Davis, Department of Nutrition.

Part of the problem, research conducted by the University of California, Berkeley indicates, is that Mexican Americans receive breastfeeding advice less often because they are frequently less educated, of lower socioeconomic status and unmarried.

“Some of it simply has to do with how hospital staff delivers care and what kind of practices they have in the hospital that can support breastfeeding in that population,” Kaiser said.

For American Indians, who tend to have positive cultural views about breastfeeding, the loss of traditional birthing practices has contributed to lower breastfeeding rates.

“Anthropologic research on the Navajo Nation by Dr. Anne L. Wright, associate director of the Arizona Respiratory Sciences Center at the University of Arizona Medical Center, suggested that the loss of the traditional ‘women helping women’ in childbirth has contributed to the loss of the art of breastfeeding among Native Americans,”

Phoenix Indian Medical Center's (PIMC) Murphy said. "In the general population, this traditional circular nurturing is described as 'mothering the mother so that she can mother her baby.'"

### Breaking Down Barriers

In an attempt to eliminate barriers to breastfeeding, OWH and various cultural organizations are working toward reaching the Healthy People 2010 national health objectives: increasing breastfeeding rates among all women to 75 percent in the early postpartum period, from 29 percent to 50 percent at six months, and from 16 percent to 25 percent at one year. To reach the goals, OWH developed the, "Blueprint for Action on Breastfeeding," an action plan and a comprehensive breastfeeding policy for the nation.

Because the decision to breastfeed is usually made within the first three months of pregnancy, the Blueprint focuses on education for women, their partners and other significant family members during both the prenatal and postnatal visits.

The Blueprint also calls for culturally appropriate strategies to promote breastfeeding and eliminate racial and ethnic disparities. Toward that end, programs are being developed to give mothers access to comprehensive, up-to-date and culturally specific lactation services.

In partnership with the Alliance, HHS developed interventions to educate African American mothers about breastfeeding. The interventions include teaching moms the importance of pumping and freezing breast milk to promote spousal involvement in feeding and strategies to help mothers transition back to work. AABA also provides intervention, support groups, home and hospital visits and breastfeeding classes for and by African American women.

"Because our information is coming from African Americans, it tends to help," Barber said. "Whether it's a poor community or an affluent one, peer counselors that Black women can relate to, that can teach them about breastfeeding one-on-one, tend to make a big difference."



Efforts to increase rates among American Indians have focused on culturally sensitive promotional material. Together with various tribal communities, PIMC and NIH created "An Easy Guide to Breastfeeding for American Indians and Alaska Natives."

"We hope that our intervention's progress is a reflection of providing readily available, consistent and reliable information," said PIMC's Murphy.

Though breastfeeding has been ignored for far too long, it is finally reaching more women, according to Haynes.

"You have to educate every generation as they come along," she said. "We've got to make this a cool thing to do." ♦

Go to page 19 for breastfeeding resources.

# Making an Important Investment

## *Prenatal Care for the Uninsured*

Kauthar B. Umar, M.A.

Living without access to health care is not easy. Just ask the thousands of uninsured pregnant women in the United States today. Carrying a baby for eight months without a physician's exam can lead to preventable, life-threatening complications and far too many women are familiar with this reality.

States have recently begun tackling this issue, though, by taking advantage of a new Department of Health and Human Services (HHS) regulation that allows them, under the State Children's Health Insurance Program (SCHIP), to provide health coverage for prenatal care and delivery to mothers and their unborn children. HHS expects the expansion to maximize the availability of prenatal care, advancing the overall health of infants and children.

"Prenatal care is one of the most important investments that we can make to ensure the long-term good health of our children and their mothers," said HHS Secretary Tommy G. Thompson. "This is a common-sense, compassionate measure to make sure that all children born in this country come into the world as healthy as possible."

Currently, funding is distributed based on the number of uninsured children in each state whose family income is at or below 200 percent of the poverty level. For 2004, SCHIP will receive \$3.2 billion. According to the Center for Medicare & Medicaid Services, the federal government will pay around 70 percent of all SCHIP expenditures.

While all states operate SCHIP programs, each has different eligibility rules. Most cover children younger than 19 whose families earn up to \$36,800 a year for a family of four. Since its inception, the program has provided insurance to more than 4.6 million children of low-wage working parents.

In the past, states were required to apply for an SCHIP waiver, or use state funds, in order to provide care to pregnant women and their unborn children. Under the new regulation, states can offer similar health coverage as a state plan option under the federal SCHIP program. This allows states to easily and quickly expand coverage of prenatal care to pregnant women whose children otherwise would be eligible for Medicaid or SCHIP coverage only after they are born.

In April, Michigan and Rhode Island were the first of six

states to take advantage of the new regulation. In Michigan, pregnant women and their unborn children were offered limited coverage with state funds prior to the HHS expansion. But Logan Dreasky, a manager with Michigan Children's Health Insurance Program, expressed concern over servicing this population with state funds only, due to the possibility of budget cuts. He explained that new regulations have actually helped to increase enrollment for their program and secure service to unborn children.

"It has allowed us to maintain and modify our program," said Dreasky. "This is a good vehicle for women who normally wouldn't have access to that care."

Dreasky said enrollment has been increasing relatively steadily thus far, and the state expects to care for more than 5,000 women in the first year.

Prior to the new SCHIP regulation, Rhode Island also served pregnant women and unborn children with state funds. But nearly 700 pregnant women who otherwise would not qualify for services under Medicaid have been covered because of the new rule. Rhode Island's Rite Care program will extend SCHIP eligibility to those with family incomes of up to 250 percent of the poverty level, or \$17,969 for an individual and \$36,800 for a family of four.

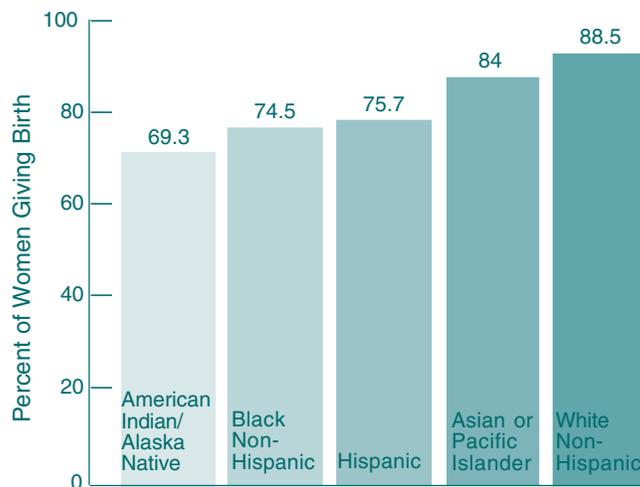
Not only is this an opportunity for the state to expand its services, but Jane Hayward, director of Rhode Island's Human Services Department, argues that prenatal care saves money and lives.

"Prenatal care is preventative and can actually save states money by avoiding more serious complications of birth," said Hayward. "It's very important that prenatal care begins early in a woman's pregnancy to assure a healthy outcome for both the child and mom."

For the 2004 fiscal year, Michigan has been allotted approximately \$89 million and Rhode Island about \$7 million in SCHIP funding. Together, the states plan to provide prenatal care to nearly 6,000 pregnant women and their unborn children within the first year.

For more information on the State Children's Health Insurance Program (SCHIP) call the Centers for Medicare & Medicaid Services at 877-267-2323 or go to <http://cms.hhs.gov/schip>

Mothers Beginning Prenatal Care in the First Trimester (All Births) by Race/Ethnicity, 2001



Source: Maternal Child Health Bureau, *Women's Health USA 2003*

# Not Just the “Baby Blues”

## *Postpartum Depression*

Kauthar B. Umar, M.A.

Just days after Melanie Stokes gave birth to her first child, her behavior changed dramatically. The normally cheerful 41-year-old was engulfed in a sense of hopelessness that caused her family great concern.

Five months later, after being hospitalized three times, misdiagnosed, and improperly medicated, Stokes finally took her own life. Only after her death did doctors carefully review Stokes’ medical files and determine that she was suffering from postpartum psychosis.

“When Melanie told me that she felt that she was going to have to die, I told her that no way in this world was she going to die, because I wouldn’t let her die,” Stokes’ mother, Carol Blocker, said. “See, at that time I did not know anything about postpartum psychosis. I didn’t know what could happen.”

While postpartum blues, depression and psychosis affect women from all races, ethnic and economic groups, African American women face additional challenges, preventing proper diagnosis and adequate treatment. As a result, thousands of women may live in fear of harming themselves or their babies, with little understanding and no available outlet for help.

According to the National Women’s Health Information Center, 70 percent of new mothers experience symptoms of postpartum blues, which begin three to five days after delivery, can last up to three weeks and appear in short sporadic spurts. Postpartum depression, which persists more than two weeks, is seen in eight to 15 percent of new mothers.

Sufferers are often unable to deal with daily life and family stress and can neglect their babies. The most severe of the disorders, postpartum psychosis, affects one to two new mothers out of every thousand. The condition can cause a new mother to experience hallucinations or delusions, and can lead to suicide, homicide, or infanticide, killing an infant or child.

Although women with a history of depression are more likely to suffer from postpartum psychiatric disorders, factors that can contribute to their onset include “depressive symptoms during pregnancy, unstable marital or other significant relationships, stressful life events, low income, low educational attainment and not breastfeeding,” according to a 2001 study published in the “American Journal of Psychiatry.”

Dr. Nada Stotland, head of the American Psychiatric Association’s (APA) public affairs committee, said that low-income African American women suffer from many of these stressors.

### African Americans and Mental Illness

The number of African American women affected by postpartum psychiatric disorders is unclear, since many tend to conceal symptoms of mental illness, maintains Linda Clark Amankwaa, an assistant professor of nursing at Virginia Commonwealth University.

In a study of postpartum depression among African American women published in the spring 2003 volume of the “Journal of Cultural Diversity,” Amankwaa found that “depression was something that would not be disclosed readily among African American people [or] outsiders because of the stigma attached to it and the negative consequences.”

Besides their distrust of the health care system, Amankwaa says that African American women have shied away from mental health treatment out of fear that their children might be taken away from them. They also fear a depression diagnosis may affect their health insurance and employment.

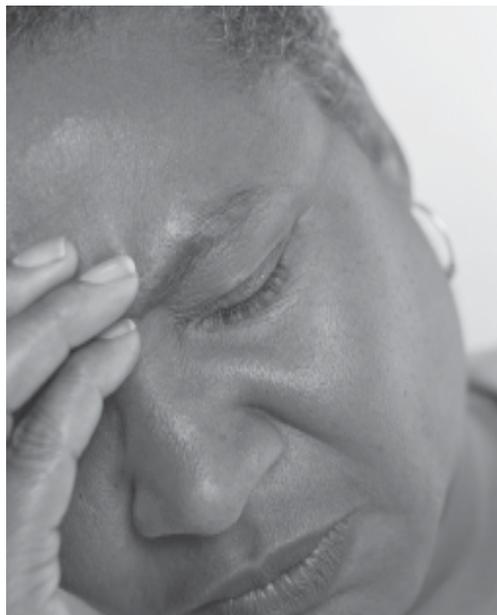
What’s more, African American women are slow to admit depressive symptoms for cultural reasons.

“It is a cultural belief that depression is symbolic of weakness, not a disease,” Amankwaa wrote. “For African Americans, depression means that you are crazy and ‘crazy’ in African culture is an insult of the greatest magnitude.”

Moreover, postpartum psychiatric disorder sufferers often delay treatment because they don’t understand why they are not happy after giving birth. With family and friends welcoming the new baby and expecting the mother to be happy, APA’s Stotland says women tend to suppress their true feelings because they are embarrassed.

### Barriers to Treatment

Though most women who suffer from postpartum depression or psychosis don’t kill themselves or their babies, Stotland says they still need to be screened and receive emergency medical treatment if warranted.



*Postpartum continued on 15*

# Breaking Cultural Barriers

## *Cervical Cancer in Asian American and Pacific Islander Women*

Kauthar B. Umar, M.A.

The thought of having a Pap smear conjures up uncomfortable feelings for millions of women throughout the United States. But for the Asian American and Pacific Islander (AAPI) community, and Vietnamese Americans in particular, this pelvic exam, which screens for cervical cancer, is seen as not only invasive but unnecessary.

And that's a big problem, according to Dr. Si Van Nguyen, a pathologist and secretary of the Vietnam Medical Association of the USA. By neglecting this exam, thousands of women unknowingly remain at risk for cervical cancer.

"Awareness of cervical cancer is not high among Vietnamese women," Van Nguyen said. "Add that to the reluctance of getting a Pap smear and the problem becomes clear. The overwhelming majority of women diagnosed today with cervical cancer have either not had regular Pap smears or they have not followed up after having an abnormal smear."

According to JHPIEGO Corporation, a nonprofit health advocacy organization affiliated with Johns Hopkins University, 99.7 percent of all cervical cancers are directly linked to previous infection with one or more cancer-inducing strains of the human papilloma virus (HPV), the most common sexually transmitted disease in the United States.

The organization says that 10 percent of women infected with HPV will develop dysplasia—pre-cancerous changes in cervical tissue that can be treated if detected early. But since cancer symptoms don't appear for as long as 10 or 20 years after HPV infection, the most effective way to prevent cervical cancer is an annual pelvic exam, including a Pap smear.

Indeed, since its introduction in 1941, the Pap smear has reduced U.S. deaths from cervical cancer by 70 percent, according to the National Library of Medicine (NLM). Despite the positive strides, though, 15,000 women in the United States are still diagnosed with the cancer annually, and a disproportionate percentage are AAPIs.

Rates are so high because AAPI women have the lowest rates of preventive screening, according to Karen Lim, executive director of the National Asian Women's Health Organization (NAWHO). For Vietnamese women, who have cervical cancer rates five times higher than the general U.S. population, the problem is particularly acute.

"In general, you discover dysplasia first so it won't turn into cancer. For Vietnamese women, who don't get regular Paps, they miss that stage," said Van Nguyen. "The problem is primarily cultural; we don't talk about disease in our community. It's bad luck. It's bad karma."

Among Asian Americans, who are approximately 70 percent foreign-born, language and cultural barriers limit their knowledge about cervical cancer and reproductive health, according to Van Nguyen. Experiences with poor health systems in their native countries also make immigrant women even more unlikely to visit a doctor.

### Change in the Making

In order to reach AAPI women directly, Van Nguyen approached the National Cancer Institute (NCI) and the Vietnamese Community Health Promotion Project at the University of California, San Francisco, to help develop a brochure specifically targeting Vietnamese women.

The brochure "Cervical Cancer Screening: What Vietnamese Women Should Know," is now available. Written in Vietnamese, the brochure informs women of their risk for cervical cancer and highlights the need for women to get regular Pap smears in order to detect early abnormalities in the cervix. Van Nguyen says that the brochure uses non-scientific language, simple diagrams, and familiar images to explain what a Pap smear is, how often it should be done, and what to do if the results show abnormalities.

And since Vietnamese patients are uncomfortable discussing their concerns about the Pap smear procedure and reproductive health in general, Van Nguyen says the brochure provides the information so the doctor doesn't have to.

Since January 2001, NCI has distributed more than 64,000 copies of the 18-page brochure to physician's offices and at community events throughout the United States and abroad.

But Van Nguyen said that they are working to publicize their message beyond the waiting room walls.

"We're trying to reach a population that is not in the habit of going to the doctor," said Van Nguyen. "We've put an advertisement for

### Cervical Cancer ABC's

- ① Cancer of the cervix is a disease in which cancer cells are found in the tissues of the cervix—the opening of the uterus, or womb, that connects the uterus to the vagina (the birth canal).
- ② Before cancer cells are found on the cervix, the tissues of the cervix go through changes in which abnormal cells begin to appear (a condition called dysplasia).
- ③ Screening is designed to detect abnormal cells before they turn into cancer, and spread more deeply into the cervix and to surrounding areas.

Source: National Women's Health Information Center • <http://www.4woman.gov> ♦

the brochure in major Vietnamese journals. We would love to see it in the Vietnamese popular media, Vietnamese magazines, radio and television.”

“The Pap only costs ten dollars,” he added. “For a small amount of cost, we can save a lot of lives.” In an effort to address cervical cancer in the greater AAPI population, NAWHO launched a program called *Communicating Across Boundaries: A Cultural Competency Training on Breast and Cervical Cancers in Asian American Women*, which aims to train health care professionals to understand sexual behaviors and attitudes in culturally diverse AAPI communities.

“We don’t just clump all Asians in one group,” Lim said. “Through our training, we address each specific culture and show the similarities and differences between groups.”

From there, Lim says, the training instructs healthcare providers in ways to successfully communicate with their AAPI patients about cervical cancer.” Specifically, we teach providers how to break the ice

without insulting culture,” she said.

“We help providers to break down barriers and reach the women before cervical cancer becomes a problem.”

Lim says that health care providers continue to use the program in 26 states. After follow-ups and evaluations with trainers, NAWHO discovered an increase in knowledge among participating health care providers and a willingness to train others in culturally competent cervical and breast cancer prevention techniques for AAPIs.

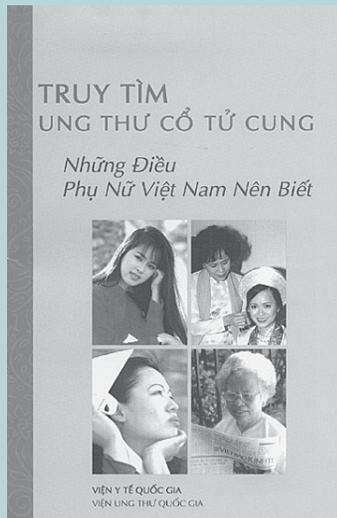
That, Lim said, bodes well for the future. “In the future, we’ll start seeing an increase in Paps and referrals for Paps, but that will take some time,” she said. “Right now we’re just working to help providers identify and analyze the problems.” Lim said the next step will include educating the public on these issues and in turn reaching more patients.

*For more information on Communicating Across Boundaries: A Cultural Competency Training on Breast and Cervical Cancers in Asian American Women and NAWHO’s cervical cancer program go to <http://www.nawho.org>* ♦

## Asian Americans and Cancer

- ♦ Cancer is the leading cause of death for female Asian Americans.
- ♦ Cervical cancer is a significant health problem in Korean American women.
- ♦ Forty-eight percent of Filipino and 41 percent of Korean women receive Pap smear tests within the recommended time.
- ♦ A significant number of Korean Americans have never heard of the Pap smear test.
- ♦ Southeast Asian women have higher invasive cervical cancer incidence rates and lower Pap testing frequencies than most other ethnic groups in the United States.
- ♦ According to some studies, a large number of Vietnamese women cannot correctly explain what a Pap test is used for.
- ♦ The most commonly occurring cancer in Vietnamese females in the United States is cervical cancer.
- ♦ Cervical cancer incidence rates are five times higher among Vietnamese American women than White women.

Source: Intercultural Cancer Council—Asian Americans & Cancer • <http://iccnetwork.org/cancerfacts/cfs3.htm> ♦



To order Cervical Cancer Screening: What Vietnamese Women Should Know, call the National Cancer Institute at 800-422-6237 or go to <http://www3.cancer.gov/hpb/vietnamese/cervical/> ♦

## Screening

A Healthy People 2010 goal is to increase the percent of women ever receiving Pap tests to 97 percent. In 2000, the following reported ever receiving a Pap test (age adjusted, aged 18 years and over):

- 95 percent • American Indian or Alaska Native only
- 95 percent • Black or African American only, not Hispanic/Latino
- 95 percent • White only, not Hispanic/Latino
- 87 percent • Hispanic/Latino
- 77 percent • Asian only

A Healthy People 2010 goal is to increase the percent of women having received a Pap test within the past 3 years to 90 percent. In 2000, the following reported receiving a Pap test, within the past three years (age adjusted, aged 18 years and over):

- 84 percent • Black or African American only, not Hispanic/Latino
- 83 percent • White only, not Hispanic/Latino
- 77 percent • Hispanic/Latino
- 76 percent • American Indian or Alaska Native only
- 66 percent • Asian only

Source: Healthy People 2010 • <http://wonder.cdc.gov/DATA2010> ♦

# Promoting Positive Behavior

## *Abstinence Education Programs Reach Minority Youth*

Kauthar B. Umar, M.A.

Eighteen-year-old Ruth Adams is proud to be a part of a growing trend among America's teens. "I used to think that being a virgin was kind of stupid," Adams said. "But abstaining from sex is great: you feel like you're on top of the world, that you know you are worth waiting for."

Adams is among the young leaders who are reaching out to minority communities and schools across the country in an attempt to boost self-esteem and lower teen pregnancy rates. Despite raging hormones and peer pressure, their message, sexual abstinence, is catching on, and the messengers are often the teens themselves.

According to the Centers for Disease Control and Prevention, the teen birth rate has declined slowly but steadily from 1991 to 2002—dropping 28 percent since 1990. The largest decline was for African American women, with African American teens, ages 15 to 19, falling 42 percent. Hispanic teen birth rates also declined 20 percent between the same periods.

Despite these declines, however, about 850,000 teens become pregnant each year, of which, eight in ten are unintended. The rates of both Hispanics and African Americans remain higher than for other groups, with Hispanic teens now having the highest teenage birth rates.

As a result, various initiatives have been developed to reduce behavior leading to unintended pregnancies among at-risk youth, nationwide.

President Bush's Fiscal Year 2005 budget would increase funding for abstinence education programs to more than \$270 million. In his State of the Union address, the President directed HHS to develop research-based standards for model abstinence education curricula, and called for a review of Federal programming for youth addressing teen pregnancy prevention, family planning, and STD and HIV/AIDS prevention to ensure that the Federal government is sending the right messages to teens. He also announced a public education campaign designed to help parents communicate with their children about the health risks associated with early sexual activity.

"Abstinence from sexual activity is the only 100 percent effective way to prevent pregnancy and sexually transmitted diseases," said Department of Health and Human Services (HHS) Secretary Tommy Thompson in a statement last year. "Education supporting an abstinence-until-marriage message is a positive development in our nation's efforts to help adolescents avoid behaviors that could jeopardize their futures."

To successfully reach youth, the administration has focused on ways to filter the pregnancy prevention and abstinence message into the nation's school system. While opinions vary on the type of sexuality education schools should offer, 91 percent of parents want schools to teach that "adolescents should be expected to abstain from sexual activity during high school years," according to the January 24, 2004 published poll results conducted by Zogby International.

In response, HHS funds more than 700 abstinence education programs nationwide. Along with abstinence-until-marriage messages, many include educational and cultural enrichments and teach about healthy friendships and marital relationships.

"Abstinence education is more than telling teens not to have sex. It is teaching young people how to set goals, make healthy decisions and build healthy relationships. Young people who are equipped with these skills generally make the healthiest decisions about sex," said Dr. Alma Golden, Deputy Assistant Secretary for Population Affairs.

One such program is ReCapturing the Vision International (RTV), which has reached more than 5,500 at-risk teens and pre-teens in southern Florida within the past eight years.

RTV targets African American, Haitian and Hispanic sixth through twelfth graders through a three-tier approach focusing on school, home and community. Offered as an elective course throughout the academic year, RTV's Vessels of Honor curriculum addresses the underlying reasons for risk-taking and teaches kids the skills they need to make tough choices. Students are taught about character, image, marriage, wedding planning, goal setting and how to value their virginity as they transition into adulthood.

According to founder and CEO Jacqueline Del Rosario, RTV does not just teach teens to say no to sex, but teaches them to value themselves and embrace their future.

"ReCapturing the Vision has become that one voice that tells kids that they do not need to have sex, nor do they have to," said Rosario in testimony before the House Subcommittee on Health last year.

In an attempt to take abstinence education outside of the classroom and into the community, RTV also partners with corporations, community organizations and state agencies to host concerts, conferences, rallies, training workshops and after-school programs.

Adams, who was named Ms. RTV in 2002 for progress in community service and academics, attended the "teen empowerment" workshops last year.

"They talked about how you can prepare for your future," she said. "They talked about parents and how you have to talk to them in

*"Abstinence from sexual activity is the only 100 percent effective way to prevent pregnancy and sexually transmitted diseases..."*

Secretary Tommy Thompson  
Department of Health and Human Services (HHS)

order for them to know how to help you. They also encouraged you to abstain from sex for a better future.”

Though encouraging teens to value their future is no easy feat, programs that introduce abstinence as the best form of pregnancy prevention and a tool to gain more opportunities have been quite successful.

Within the past year alone, the Pima Youth Partnership (PYP) founded in 1990, has introduced similar abstinence strategies to over 2000 rural youth in Pima County, Arizona. Home to 21 American Indian tribes, Arizona is currently tied for second in the country for the highest rate of births among 15- to 19-year-olds, according to the Arizona Coalition on Adolescent Pregnancy and Parenting.

In an effort to reduce the birth numbers, PYP educators visit health, science and social studies classes throughout the county to teach delay and resistance skills, and discuss the impact media, peers and parents have on teens and sex. Using the “Why Am I Tempted” (W.A.I.T.) training curricula, sixth through 12th graders discuss HIV/AIDS, refusal skills, marriage and parenting. The fourth and fifth grade curriculum, “Managing Pressures before Marriage,” discusses values and teaches decision-making.

“In ‘Managing Pressures before Marriage,’ kids are asked to identify three ways to delay having sex, two reasons why it’s important to delay, and then they practice those skills,” said Dr. Luan E. Wagner, the executive director of PYP. “By the end of the

classes, kids talk about what they’ve learned. They remember and are better informed.”

A condensed version of the PYP program is incorporated each summer into the Tohono O’odham three-week cultural camp, Truck of Love (TOL). For the past eight years TOL has enrolled 60 youth annually for life skills and peer leadership development training. The abstinence curricula is incorporated into education about O’odham legends, cultural rights and traditional O’odham language, cooking and art.

According to Wagner, using culturally appropriate messages has proved to be the most effective way to teach abstinence.

“In one of the tribes, our definition of family really bothered the kids, so we adapted family and marriage to mean what it does in their tribe,” Wagner said.

In the Tohono O’odham culture, a man and a woman can create a family without what western society considers a formal ceremony, stated Wagner. By discussing the definition of family and how it relates to their tribe, Wagner said the children concluded that it is most important to be faithful.

“We have to recognize cultural differences and variety, and so does Congress, if we want to get this right.”

*For more information on ReCapturing the Vision, call 305-232-6003 or go to <http://www.recapturingthevision.org>* ◆

*For more information on the Pima Youth Partnership, call 520-744-9595 or go to <http://www.pyp.com>* ◆

## “What Do Parents Want Taught in Sex Education Programs?”

This recently released, nationally representative poll of parents with children under age 18 conducted by Zogby International in December 2003, shows that parents strongly support abstinence education. Some additional findings include:

- ❖ Seventy-nine percent of parents want teens to be taught to delay sexual activity until they are married or for an adult relationship leading to marriage.
- ❖ Ninety-one percent of parents want teens to be taught that sex should be linked to love, intimacy, and commitment and that these qualities are most likely to occur in marriage.
- ❖ Sixty-eight percent of parents want schools to teach teens that “individuals, who are not sexually active until marriage, have the best chances of marital stability and happiness.”
- ❖ Ninety-six percent of parents want teens to be taught that abstinence is best.

## One-Stop Shopping for Federal Grants

**Grants.gov**, formerly known as the E-Grants Initiative, was launched in December 2003 as simple, unified “storefront” for all customers of Federal grants to electronically find, apply for, and manage grants. In addition to simplifying the grant application process, Grants.gov also creates avenues for consolidation and best practices within each grant-making agency.

One of the 24 Federal cross-agency E-Government initiatives focused on improving access to services via the Internet, Grants.gov encompasses over 900 grant programs offered by the 26 Federal grant-making agencies. It streamlines the process of awarding over \$350 billion annually to state and local governments, academia, not-for-profits and other organizations.

Key benefits include:

- ◆ A single source for finding grant opportunities.
- ◆ A standardized manner of locating and learning more about funding opportunities.
- ◆ A single, secure and reliable source for applying for Federal grants online.
- ◆ A simplified grant application process with reduction of paperwork.
- ◆ A unified interface for all agencies to announce their grant opportunities.

*For more information on finding, applying for, and managing Federal grants, go to <http://www.grants.gov>* ◆

# Remembering the Boys

## *The Male Role in Pregnancy Prevention*

Kauthar B. Umar, M.A.

The U.S. Department of Health and Human Services (HHS) has implemented abstinence education programs such as the Adolescent Family Life program, the Adolescent Male Family Planning initiative and the Partners for Fragile Families demonstration program to encourage boys to postpone fatherhood until they are emotionally and financially capable of supporting children.

But teaching boys about abstinence can be difficult, according to Kim Dettmer, manager of special projects at the Lao Family Community of Minnesota.

"It's difficult working with boys, trying to get them to believe that they actually have a choice not to have sex," she said. "There are many social pressures, not just the media, that tell young men it's okay to have sex."

Now in its sixth year, it's Kev Xaiv: Making Choices program teaches 11- to 14-year-old boys and girls from Laotian Hmong refugee families how to make informed decisions through role-playing. Each week, the youth discuss cultural enrichment and steps to break the cycle of teen pregnancy and interrupted schooling. Traditionally, Dettmer said, Laotian youth are not supposed to have sex until after marriage, so cultural learning is an important part of the program. In Hmong culture, however, there isn't a word for "no," so the program teaches a variety of alternate refusal skills.

Though tailoring the abstinence message to reach various cultures has proven difficult, programs are taking on the challenge and providing additional opportunities for underserved youth.

For example, the Decision for Life (DLF) program of the Baptist Child and Family Services in San Antonio, Texas, is tailored to teach predominately Mexican American youth and successfully reaches young males.

"What's that saying, 'Only men can teach boys to be men?'" said Christina Diaz, the program director. "We have two teams and each team has a male and female team leader. Boys really look up to our male staff and they see a positive, healthy male/female working relationship. The males treat the female staff with respect and our boys learn how to respect women."

Now in its fifth year, DFL works annually with 60 -70 bilingual

youth on a variety of abstinence curricula, like Families United to Prevent Teen Pregnancy. In an attempt to eliminate the belief that boys don't have to abstain from sex but girls must, both sexes participate in sports and recreation, cultural enrichment, leadership and character development. With each activity, youth receive the message that waiting to have sex will allow them to reach their goals.

Setting goals is the secret to Jonathan Marin's success. The recipient of DFL's 2003 Student of the Year award, Marin, 16, feels abstinence is a sure way to get what he wants in life.

"After high school, I would like to go to college," said Marin. "I don't want to have to worry about being a dad or having kids, or anything like that."

"It's hard for guys, it's not easy," added 17-year-old Elson Sandoval, DFL's Student of the Year for 2002. "For me, I'm not ready to have a kid because I'm way too young, but some guys they say they don't care whether they have a kid or not."

"Once they find out the news, that they're having a kid, they don't know what to do," Marin chimed in. "They struggle a lot, and they start saying they should have waited to have sex."

Exposure to new and different experiences and community service is a huge factor in teen pregnancy prevention says Diaz, because it helps teens feel more vested in their community and gives them something to strive for.

"Exposure to local events like college football games has provided these kids with goals," Diaz said. "Most have not been off of their 10-block area, so we take them out and teach them about making the right choices."

"I tell them, 'all that's out there could be yours,'" she said.

For more information on the Kev Xaiv: Making Choices Program, call 651-221-0069 or go to <http://www.laofamily.org/programs/family.htm> ♦

For more information on the Decision for Life program call 210-212-5518 or e-mail [decisions4life@aol.com](mailto:decisions4life@aol.com) ♦

### Office of Population Affairs Factsheets

#### Teen Talk (Volume 1): Many Teens Are Saying No

[http://opa.osophs.dhhs.gov/pubs/teentalk\\_vol1\\_sayno.pdf](http://opa.osophs.dhhs.gov/pubs/teentalk_vol1_sayno.pdf)

#### Teen Talk (Volume 1): Many Teens Are Saying No (Spanish)

[http://opa.osophs.dhhs.gov/pubs/teentalk\\_spanish\\_vol1\\_sayno.pdf](http://opa.osophs.dhhs.gov/pubs/teentalk_spanish_vol1_sayno.pdf)

#### What You Should Know About Abstinence

[http://opa.osophs.dhhs.gov/pubs/whatknow\\_abstinence.pdf](http://opa.osophs.dhhs.gov/pubs/whatknow_abstinence.pdf)

#### What You Should Know About Abstinence (Spanish)

[http://opa.osophs.dhhs.gov/pubs/whatknow\\_spanish\\_abstinence.pdf](http://opa.osophs.dhhs.gov/pubs/whatknow_spanish_abstinence.pdf)

But even African American women who go through the screening often suffer due to lack of treatment, according to Stotland.

For many low-income African American women, treatment, even in public clinics, is difficult to access.

“What if it’s February in Chicago?” Stotland said. “You have a newborn baby and a toddler and you live on the 10th floor of a housing project. How do you get to a mental health clinic, in the snow, with two babies? You don’t. You have to wait.” Stotland argued that if a mother cannot access a clinic for mental health treatment, health care providers often just assume she did not comply with treatment recommendations.

Moreover, often those patients receiving treatment do not receive culturally sensitive care, Stotland said. For example, mental health care providers are often unaware or disregard the connection that African Americans have to religion and spirituality as a path to healing. According to Stotland, historically, African Americans turn to the church for spiritual healing before seeking contemporary medical treatment—especially when it pertains to mental illness.

As a start, Stotland has met with various clergy throughout Chicago to make sure these issues are being discussed from the pulpit. By acknowledging the role that the Black church plays in the African American community and creating discussions with the pastors, Stotland hopes to eventually reach the women who are suffering.

“We’ve been educating the clergy so that we are all on the same page,” Stotland said. “People need to understand this disease. Society needs to understand it.”

Amankwaa agrees that the society needs to be educated. She points out that there are protocols for providing health care for babies for a full year after birth, but no care for the mother beyond one postpartum check up. She recommends that specific programs be developed to address the health and welfare of the family during this postpartum period, and that new mothers, like new babies, receive care during the first year after giving birth. This, she believes, will help women get into treatment early before they become a threat to themselves or their babies.

*For more information, contact the National Women’s Health Information Center at 800-994-WOMAN (1-800-994-9662) or go to <http://www.4woman.gov/>* ◆

*For more information, contact the National Mental Health Association at <http://www.nmha.org/children/ppd.pdf>* ◆

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The Office of Minority Health Resource Center is a nationwide service of the U.S. Department of Health and Human Services.

## Upcoming Health Observances

### March is ...

#### **National Kidney Month**

Contact the National Kidney Foundation at 800-622-9010 or go to <http://www.kidney.org> for more information.

#### **National Colorectal Cancer Awareness Month**

Contact the Cancer Research and Prevention Foundation at 800-227-2732 or go to <http://www.preventcancer.org/colorectal> for more information.

#### **National Nutrition Month**

Contact the American Dietetic Association at 800-877-1600 x4853 or go to <http://www.eatright.org/> for more information.

### April 18 - 24 is...

#### **National Minority Cancer Awareness Week**

Contact the National Cancer Institute at 301-402-5557 or go to <http://www.cancer.gov> for more information.

### April 18 - 24 is...

#### **National Volunteer Week**

Contact the Volunteer Centers National Network at the Points of Light Foundation at 202-729-8168 or go to <http://www.pointsoflight.org/nvw/nvw.cfm> for more information.

### April 24 - 25 is...

#### **2004 WalkAmerica**

Contact the March of Dimes Birth Defects Foundation at 800-525-WALK or go to <http://www.walkamerica.org> for more information.

### May is...

#### **Mental Health Month**

Contact the National Mental Health Association at 800-969-6642 or go to <http://www.nmha.org> for more information.

#### **National Teen Pregnancy Prevention Month**

Contact the Advocates for Youth at 202-347-5700 or go to <http://www.advocatesforyouth.org> for more information.

# New Hope on the Horizon

## Screening for Sickle Cell Disease

Kauthar B. Umar, M.A.

When Andrew Chase suffered a stroke four years ago, his family was devastated. It wasn't the severity of the stroke or the grueling rehabilitation that left them stunned, it was his age. Andrew was just three years old. But for this particular toddler, such complications were not completely unexpected.

Like more than 72,000 Americans of predominately African and Mediterranean decent, Andrew was born with sickle cell disease (SCD), a type of genetic blood disorder. The March of Dimes reports that 10 percent of children living with SCD suffer a stroke and can experience damage to blood vessels in the brain. By the time Andrew was five years old, he underwent bilateral brain surgery and today, at seven years old, he receives a blood transfusion every month.

"When you have a child with sickle cell and you see him in pain, it's the absolute worst feeling in the world," said Andrew's mother, Syreeta Chase. "The hardest thing is looking your child in the eye and knowing that you can't do anything."

But now, thanks to federal dollars and advancing medical technology, there's new hope for families affected by SCD.

The Sickle Cell Disease Association of America reports that 1,000 babies are born with SCD each year, making it one of the most prevalent genetic disorders in the United States. Largely found in the minority community, sickle cell disease occurs in about one in every 600 African American births and one in every 1,000-1,400 Hispanic American births, according to the National Institutes of Health (NIH).

Three common types of sickle cell disease in the United States are hemoglobin SS, better known as sickle cell anemia, hemoglobin SC disease and hemoglobin sickle beta-thalassemia.

The disease is caused by a mutation in one of the two genes that determines the structure of hemoglobin, a critical molecule found in red blood cells that transports oxygen from the lungs to other parts of the body. In patients with this disease, abnormal hemoglobin molecules stick to one another and form long, rod-like structures.

Under a microscope, these abnormal cells may look like the C-shaped farm tool called a sickle. Sickle cells tend to become trapped and destroyed in small blood vessels, the spleen, liver and other organs. The result is a shortage of red blood cells, or anemia.

While Andrew suffers from the most severe complications from SCD, the effects of the disease vary greatly from one person to the next. Sufferers can develop chronic severe anemia, infections and periodic episodes of pain.

To improve services for infants with sickle cell and their families,

the Health Resources and Services Administration (HRSA) awarded \$3.6 million in October 2003 to projects that link comprehensive sickle cell treatment centers, state newborn screening programs and health care professionals to broad community-based organizations. The 17 two-year grants are funded under HRSA's SCD and Newborn Screening Program through its Maternal and Child Health Bureau. For families affected by the disease, new preventive opportunities, advanced treatment and better outreach can save lives.

Chase admits that access to outreach and education would have helped a great deal—approximately 2 million Americans carry the sickle cell trait and 1 in 12 African Americans have the trait.

Like many parents, she was uneducated about and ill-prepared for the reality of SCD. She was unaware that Andrew's father was a carrier of sickle cell disease and it wasn't until her pregnancy with Andrew that she discovered that she also had the sickle cell trait (see next page).

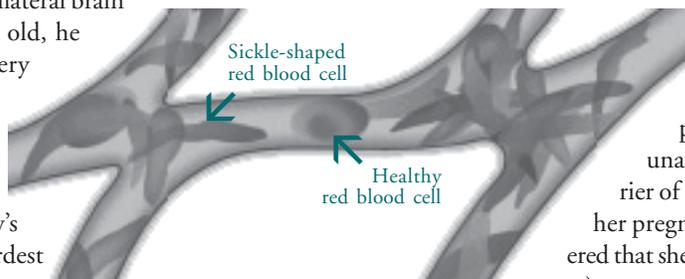
Today, Barbara Harrison, a certified genetics counselor from the Center for Sickle Cell Disease at Howard University Hospital, says that genetic testing has changed the face of SCD and other genetic diseases.

Couples who are planning to have a baby can get carrier testing at medical centers and sickle cell treatment facilities throughout the country. A blood test called the hemoglobin electrophoresis, performed on both partners, is the most complete test for sickle cell trait and related conditions.

"If they find out that both have the trait, then they need to know their options, and there are many," said Harrison. "The first thing the couple should do is to appreciate the 25 percent chance that the offspring will not have SCD, instead of focusing on the 75 percent chance that they could. It's quite possible for a couple to have kids that do not have the disease."

With the proper genetic testing, a couple with the trait can also undergo specific procedures to ensure that their baby will be free from SCD. In vitro fertilization and pre-implantation genetic diagnosis involve harvesting several eggs and sperm. After allowing the cells to grow for a number of days, genetic testing can be completed on the group of cells. Those cells that do not carry the disease or the trait are isolated and then implanted back into the mother. The process is expensive though, and doesn't work all the time, Harrison warned.

Once the baby is conceived, there are two main options for prenatal diagnosis, according to Harrison. Chorionic villus sampling, CVS, which has a one percent chance of miscarriage, is performed



between the 10th and 12th weeks of pregnancy. A sample of the placenta is removed to allow doctors to test DNA and determine if the fetus has SCD. Amniocentesis, which involves sampling the amniotic fluid, is done after 15 weeks and has a 0.5 percent risk of miscarriage.

“One sure thing is that you don’t have to unknowingly have a child with SCD in this day and age,” said Harrison.

Over the years, as this disease has become a legitimate national health concern, postnatal testing has become routine. Today, nearly every state in the U.S., as well as the District of Columbia, Puerto Rico and the Virgin Islands, performs hemoglobin screenings on all newborns, regardless of race, to test for SCD. Children are usually diagnosed within their first few months, allowing for proper treatment to begin.

NIH recommends that patients with sickle cell disease seek consistent treatment in order to manage the symptoms and limit the frequency of medical crises. Supplementation with folic acid, an essential element in producing cells, is recommended because of the rapid red blood cell turnover. Such treatment, in combination with newborn screening programs, parent education and penicillin prophylaxis to prevent infection, has aided in a drastic reduction in mortality rates in recent years.

Currently, researchers are studying a number of new drug treatments to possibly reduce the severity and frequency of complications of

the disease. These include treatment with an antifungal drug called clotrimazole, which may help prevent red blood cells from sickling. Hydroxyurea—approved in 1998 by the Food and Drug Administration for use in treating patients over the age of 18 with SCD—has improved the survival rate of some of the most severe patients, according to NIH. About 100 children with sickle cell disease have been cured through a bone marrow transplant, using donated bone marrow from an immunologically matched sibling. However, this approach carries a high risk—about 10 percent of children have died as a result of the transplant.

For all of the advanced research and new treatments, though, Andrew’s mother still thinks there is work to be done to educate the public about the disease.

“I think about Andrew and I want people to know about this disease,” she said. “I want them to be sensitive. I want them to be knowledgeable.”

*For more information, contact the Sickle Cell Disease Association of America at 800-421-8453 or go to <http://www.sicklecelldisease.org>* ♦

*For more information on the Sickle Cell Disease and Newborn Screening Program at HRSA, go to <http://mcbb.hrsa.gov/grants/default.htm#sickle>* ♦

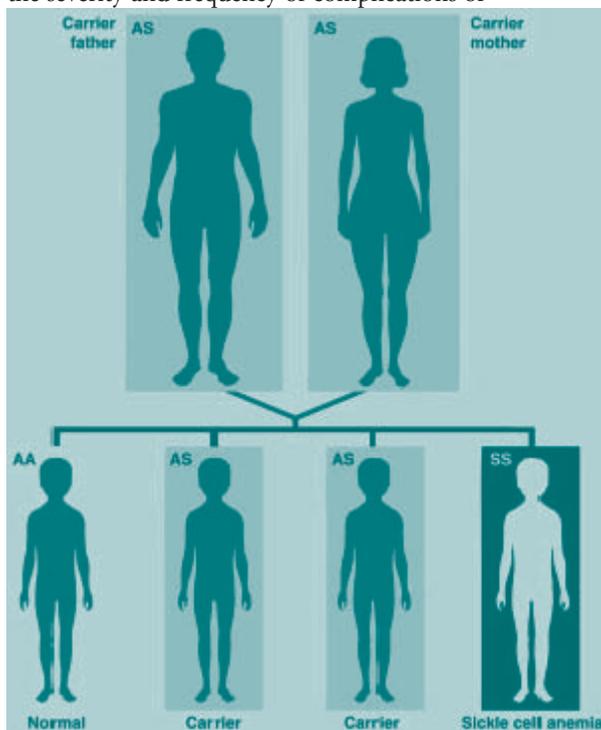
*For more information, contact the National Heart, Lung, and Blood Institute at 301-592-8573 or go to <http://www.nhlbi.nih.gov/health/public/blood/index.htm>* ♦

## Signs and Symptoms

The signs and symptoms of sickle cell anemia are different in each person. Some people have mild symptoms. Others have very severe symptoms and are often hospitalized for treatment. The most common symptoms or signs include, but are not limited to:

- ♦ Anemia
- ♦ Pain when sickle-shaped red blood cells block the flow of blood to an organ
- ♦ Fatigue (feeling very tired)
- ♦ Paleness
- ♦ Yellowing of the skin and eyes (jaundice)
- ♦ Shortness of breath
- ♦ Swelling in hands and feet
- ♦ Eye problems
- ♦ Infections
- ♦ Pneumonia and influenza
- ♦ Hepatitis
- ♦ Delayed growth and puberty
- ♦ Sores (ulcers) on the legs.
- ♦ Stroke
- ♦ Gallstones

Source: National Heart, Lung, and Blood Institute



## Trait vs. Disease

When two people with sickle cell trait have a baby, there is a:

- ❖ One in four chance (25 percent) the baby will inherit two sickle cell genes and have the disease.
- ❖ One in four chance (25 percent) the baby will inherit two normal genes and not have the disease or trait.
- ❖ Two in four chance (50 percent) the baby will inherit one normal gene and one sickle cell gene. The baby will not have the disease, but will have sickle cell trait like the parents.

*For more information, visit the National Institutes of Health Diseases and Conditions Index at [http://dci.nhlbi.nih.gov/Diseases/Sca/SCA\\_Causes.html](http://dci.nhlbi.nih.gov/Diseases/Sca/SCA_Causes.html)* ♦

Information and charts/National Heart, Lung, and Blood Institute

# Dr. Day 2003 Wrap-Up

More than 500 organizations, along with leaders from the Department of Health and Human Services (HHS), elected officials and celebrities across the nation participated in the 2003, “Take A Loved One to the Doctor Day” on September 16th. Events were carried out in more than 150 communities, in all 50 states, the District of Columbia and Puerto Rico. HHS Regional Directors and staff teamed with state and local partners and planned Dr. Day activities in all 10 regions.

This year’s campaign expanded beyond the African American community to include all racial and ethnic minority groups, with a particular emphasis on Hispanic/Latino Americans. Radio Unica, one of the leading Spanish-language national radio networks with significant reach into Hispanic communities, was a new partner this year and provided support through on-air messages and 12 regional health fairs throughout the fall. Here’s a sample of some of the participants in Doctor Day 2003—go to <http://www.omhrc.gov> for a complete list.

## Atlanta, GA

Decatur Medical Center • Morehouse School of Medicine • Oakhurst Medical Center • West End Medical Center

## Baltimore, MD

Arte Flamenco • Baltimore Times Foundation • John Hopkins Hospital • Maryland State Department of Health and Mental Hygiene • Native American Ensemble • The Choir Boys • Times Community Services, Inc. • University of Maryland Medical Systems • University of Maryland, School of Medicine • WERQ-FM 92.3 • WWIN-FM 95.9

## Boston, MA

Boston Black Women’s Health Institute • Boston Public Health Van for Brothers • Boston Red Sox • Dimock Community Health Center • Hype Park Women’s Health Center • Rhode Island Department of Health • South Central Connecticut Agency on Aging • Whittier Street Health Center

## Chicago, IL

Cermak Hospital • Cook County Jail • St. Xavier University

## Dallas, TX

Martin Luther King Clinic • Los Barrios Unidos Community Center

## Davenport, IA

Community Health Care, Inc. • YMCA

## Denver, CO

Adventist Community Services’ Mobile Medical Van • Colorado Coalition for the Homeless • Denver Women’s Health Unit

## Detroit, MI

AIM HI Project • Dexter/Elmhurst and Franklin Wright Settlement, Inc. Community Centers • Henry Ford Health System

## Fort Worth, TX

Harris Methodist Hospital

## Hampton, VA

Hampton University School of Nursing

## Harlingen, TX

Su Clinica Familiar

## Indianapolis, IN

Martin Luther King Service Center

## Kansas City, MO

Cabot Westside Health Center • Seton Center Family & Health Services • Swope Community Enterprise Services

## Los Angeles, CA

South Central Family Health Center • Wilshire Grace Church

## Marion County, IN

HealthNet Community Health Centers • Indiana Commission on African-American Males • Indiana OMH • Marion County Health Department • Minority Health Coalition of Marion County • Raphael Health

## Milwaukee, WI

Central City Cyberschool • Lapham Park • United Community Center

## Philadelphia, PA

Asian Refuse Tobacco Day at Temple University • Body Challenge Fitness Center • Chinese Health Information Center • Fairmount Primary Care Center • Haddington Multi-Service Center • St. Agnes Medical Center • Women’s Institute for Family Health

## Pittsburgh, PA

Center for Minority Health at the University of Pittsburgh • Gateway Health Plan • Pittsburgh Medical Center

## Seattle, WA

Center for Multicultural Health • First AME Child & Family Center • Public Health Departments of Seattle & King County • Sea Mar Community Health Centers • Seattle Nutrition Action Consortium

## St. Louis, MO

People’s Health Centers

## Tallahassee, FL

Florida Agency for Health Care Administration • Florida Department of Health

## Union City, NJ

Save Latin America

## Virginia Beach, VA

Making a Difference Foundation

## Washington, DC

DC Department of Health • Shiloh Baptist Church - Family Life Center Foundation



HHS Photos

l. to r.—Blood pressure screening in Baltimore; healthy cooking in Seattle; Mayor James A. Garner, President, United States Conference of Mayors; Surgeon General Richard Carmona; Kevin Miller, Sr. Vice President, ABC Radio; Baltimore Mayor Martin O’Malley; glucose testing in Seattle.

# Resources

## African American Breast Feeding Alliance

940 Madison Ave.  
Baltimore, MD 21201  
877-532-8535  
<http://www.aabaonline.org>

## The American Academy of Pediatrics

141 Northwest Point Blvd.  
Elk Grove Village, IL 60007  
847-434-4000  
<http://www.aap.org>

## Chinatown Public Health Clinic

1490 Mason St.  
San Francisco, CA 94133  
415-705-8500

## La Leche League International

1400 N. Meacham Rd.  
Schaumburg, IL 60173  
800-525-3243  
<http://www.lalecheleague.org>

## Lao Family Community of Minnesota

320 University Ave.  
St. Paul, MN 55103  
651-221-0069  
<http://www.laofamily.org>

## Michigan Children's Health Insurance Program (MI Child)

P. O. Box 30412  
Lansing, MI 48909  
888-988-6300  
<http://www.michigan.gov/mdch>

## National Organization for Fetal Alcohol Syndrome

900 17th Street, NW  
Suite 910  
Washington, DC 20006  
202 785 4585  
<http://www.nofas.org>

## Office on Women's Health

200 Independence Ave., SW  
Room 730 B  
Washington, DC 20201  
202-690-7650  
<http://www.4woman.gov/owh/>

## Phoenix Indian Medical Center

Diabetes Center of Excellence  
4212 North 16th St.  
Phoenix, AZ 85016  
606-263-1200  
<http://www.ihs.gov>

## Pima Youth Partnership

4239 West Ina Rd.  
Suite 101  
Tucson, AZ 85741  
520-744-9595  
<http://www.pypp.com>

## ReCapturing the Vision

9950 Hibiscus St.  
Miami FL 33157  
305-232-6003  
<http://www.recapturingthevision.org>

## Rhode Island's Rite Care Program

RI Department of Human Services  
Center for Child and Family Health  
600 New London Ave., 2nd Floor  
Cranston, RI 02920  
401-462-5300  
<http://www.dhs.state.ri.us>

## Sexuality Information and Education Council of the United States (SIECUS)

130 West 42nd St.  
Suite 350  
New York, NY 10036  
212-819-9770  
<http://www.siecus.org>

## State Children's Health Insurance Program

Center for Medicare & Medicaid Services  
7500 Security Blvd.  
Baltimore, MD 21244-1850  
877-267-2323  
<http://cms.hhs.gov/schip/>

## Breastfeeding Materials

The **LaLeche League** offers breastfeeding information in Chinese, Czech, Dutch, Flemish, French, German, Hebrew, Hungarian, Italian, Japanese, Luxembourgish, Portuguese, Serbian, Slovenian and Spanish, as well as a many articles containing breastfeeding information in Chinese, Russian, Spanish and Italian.

*For more information, contact LaLeche League at 800-525-3243 or go to <http://www.lalecheleague.org>* ♦

The **National Women's Health Information Center (NWHIC)** has a new Breastfeeding Helpline which operates in both English and Spanish. NWHIC also has free breastfeeding information packets. Call 800-994-WOMAN (9662) or follow the links below to download the packets.

**Chinese**—<http://www.4woman.gov/Breastfeeding/bf-chinese.pdf>

**English**—<http://www.4woman.gov/Breastfeeding/Breastfeeding.pdf>

**Spanish**—<http://www.4woman.gov/Breastfeeding/Spanish/sp-breastfeeding.pdf>

## New Survey on Virginity Available

**SexSmarts**, an on-going public information partnership between *seventeen* magazine and the Kaiser Family Foundation, found that more than 90 percent of 15-17 year olds surveyed in 2003 agree that being a virgin in high school is a good decision and teens who decide to abstain from sex are supported in their decision. Other findings include:

- ❖ Teens overwhelmingly value virginity;
- ❖ Nearly 80 percent agreed that they were waiting to have sex when they are married or in a committed relationship;
- ❖ More than 90 percent noted that abstaining from sexual activity in high school results in having respect for yourself and enjoying the respect of your family; and
- ❖ Most adolescents surveyed agreed that sexual activity is most appropriate among people who are married or in a committed relationship, or among people aged 18 and older.

*For more information, go to <http://www.kff.org/entpartnerships/3368-index.cfm>* ♦

**DEPARTMENT OF HEALTH & HUMAN SERVICES**

Office of Public Health and Science  
Office of Minority Health Resource Center  
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Washington DC 20013-7337

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## Conferences

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### April 4-7, 2004

**22nd Annual National Indian Child Welfare Association:**  
*"Protecting Our Children" National American Indian Conference on  
Child Abuse and Neglect*  
Marriott Tech Center Hotel, Denver, CO  
Contact: Kim Just  
503-222-4044 ext.113  
<http://www.nicwa.org>

### April 16, 2004

**Third Annual Asian Americans and Health Conference**  
*Reducing Cultural and Communication Barriers in Health Care  
for Asian Americans*  
New York, NY  
Contact: Asian American Network for Cancer Awareness, Research  
and Training  
212-305-9079  
<http://www.aancart.org/PDFs/NY%20Conf%204.03.pdf>

### April 29-30, 2004

**2nd National Steps to a Healthier US Summit**  
Baltimore Marriott Waterfront Hotel, Baltimore, MD  
Contact: U.S. Department of Health and Human Services  
202-260-3601  
<http://www.healthierus.gov/steps/summit.html>

### May 20-22, 2004

**H. Lee Moffitt Cancer Center 4th Biennial Conference**  
*Cancer, Culture and Literacy: Innovative Approaches for Advancing  
Effective Cancer Communications and Research*  
Sheraton Sand Key Resort, Clearwater Beach, FL  
Contact: Chrystyna Pospolyta  
813-745-1775  
<http://www.moffitt.usf.edu/promotions/ccl>

