

March Winter of Dimes 2004



Advocacy Update

from the Office of Government Affairs

March of Dimes Calls for Increased Funding for Research on Prematurity

On November 16, at a press conference in Washington, D.C., Dr. Jennifer Howse, President of the March of Dimes, spoke about the high cost of prematurity. Dr. Howse reported that the national hospital bill for premature infants reached \$15.5 billion in 2002, up 12% from the previous year. These estimates were prepared by the March of Dimes Perinatal Data Center using data from the Agency for Healthcare Research and Quality. She also called on the federal government to increase funding for prematurity-related research.

Following Dr. Howse, Dr. Yvonne T. Maddox,

Deputy Director of the National Institute of Child Health and Human Development (NICHD), spoke about the impact of prematurity on the children who survive and their families.

Dr. Maddox also revealed that the study plan for the National Children's Study and request for proposals had been posted on the web that morning. The March of Dimes strongly supports the National Children's Study. Information about the study is available on the web at <http://nationalchildrensstudy.gov/>

Catherine Spong, M.D., Chief of the Pregnancy and Perinatology Branch at NICHD, spoke about NICHD's research studies on prematurity prevention, management, and treatment.



Dr. Howse speaking at the news conference.



Inside

- **New Census Data on Uninsured Women and Children (page 2)**
- **New Associate Director of Federal Affairs (page 3)**
- **Youth Volunteer Joins National Public Affairs Committee (page 3)**
- **Puerto Rico Birth Defects Surveillance Bill (page 3)**
- **March of Dimes Expands Newborn Screening Policy**

New Census Data on Uninsured Women and Children Released

The March of Dimes each year commissions the U.S. Census Bureau to prepare the most recent data nationally and by state on the health insurance status of women of childbearing age (15-44) and children under age 19.

HIGHLIGHTS OF NATIONAL DATA FOR 2003

Women of Childbearing Age (15-44):

- The number of uninsured women of childbearing age continued to rise in 2003, increasing by more than 470,000 to 12.6 million.
- One in five women of childbearing age was uninsured in 2003.

children (13%) were also more likely than whites to be uninsured.

- Among Hispanic children, Mexicans (24%) and Central/South Americans (22%) were uninsured at the highest rate, compared with 10% of Puerto Ricans and 16% for all other Hispanic children.

HIGHLIGHTS OF STATE DATA

- The rates of uninsured vary by state. For example, Texas (32.2%) and New Mexico (31.5%) had the highest average rates of uninsured for women of childbearing age over the 2001-2003 period, while at 10%,

— At 20.5%, the 2003 rate is both higher than it was in 2002 (19.6%), and greater than the 2003 rate for all Americans under age 65 (17.6%).

— These women accounted for 28% of all uninsured Americans.

- Hispanic women in this age group were more than 2.5 times as likely as non-Hispanic whites to be uninsured—39% compared with 15%. Native American (34%), African-American (23%) and Asian women (22%) were also more likely than whites to be uninsured.
- Among Hispanics, Mexican (44%) and Central/South American (39%) women were uninsured at the highest rates, compared with 17% of Puerto Ricans and 29% for all other Hispanic women.

Wisconsin and Minnesota had the lowest.

- For children under 19, Texas (21.6%) and Nevada (17.7%) had the highest rates, and Vermont (4.9%) and Rhode Island (5.3%) had the lowest.

Additional material on the Census Data, including a state by state chart, is available on the web at [http://www.modimes.org/files/](http://www.modimes.org/files/adv_MODCensus2004.pdf)

[adv_MODCensus2004.pdf](http://www.modimes.org/files/adv_MODCensus2004.pdf)

Source: U.S. Census Bureau, March 2004 Current Population Survey. Data prepared for the March of Dimes.

Children Under Age 19:

- In 2003, 9.1 million (11.8%) of the nation's 77.6 million children under 19 were uninsured—showing essentially no improvement from 2002.
- Medicaid and the State Children's Health Insurance Program remain critical sources of health insurance for children—covering nearly 26% of those under age 19 in 2003, up from 24% in 2002 according to the Census data. At the same time, the proportion of children covered by employer-based insurance declined from nearly 63% to 61%.
- Hispanic children were nearly three times as likely as non-Hispanic whites to be uninsured—22% compared with nearly 8%. Native American (19%), African-American (15%) and Asian

Federal Support for PAD

President George Bush and two U.S. Senators supported Prematurity Awareness Day.

President Bush issued a greeting to those gathered on Freedom Plaza in Washington, D.C. His greeting applauded the March of Dimes "for providing a forum to raise awareness about premature births....."

Senator Richard Lugar (R-IN), who with his wife Char is a long-time March of Dimes volunteer, issued a statement that was printed in the November 16 Congressional Record.

Senator Larry Craig (R-ID) also issued a statement that was printed in the November 16 Congressional Record.

Lynsey Morris New Associate Director of Federal Affairs

Lynsey Morris has joined the Office of Government Affairs as the Associate Director of Federal Affairs. Among the issues she will be handling are access to health care coverage, medical malpractice, disparities, and genetic discrimination.

Ms. Morris previously worked as the Government Relations Manager for the American Association of University Women and as a Legislative Fellow in the office of Representative Louise Slaughter (D-NY). While working for Representative Slaughter, she served as Staff Director of the Congressional Caucus for Women's Issues. She earned her B.A. from Berry College in Rome, Georgia, has

an M.A. in political science from the University of Oklahoma, where she is currently a doctoral candidate in political science.



Jacob Landry Joins National Public Affairs Committee

March of Dimes National Youth Council member, Jacob Landry, a sophomore at Louisiana State University, has joined the Foundation's National Public Affairs Committee.

Jake began volunteering for the March of Dimes in high school as a member of Future Business Leaders of America (FBLA). He served as the 2000-2001 FBLA National Treasurer and helped lead FBLA in raising more than \$500,000 for the March of Dimes. He played a leadership role in both the 2001 Florida Youth WalkAmerica conference and the 2001 Volunteer Leadership Conference held in Washington, D.C.

Puerto Rico Governor Signs Birth Defects Surveillance Bill Into Law

On September 16, 2004, in the midst of widespread destruction caused by Hurricane Jeanne just the day before, Puerto Rico's Governor Sila M. Calderon signed the Birth Defects Surveillance bill into law. The bill authorizes the birth defects surveillance system that, until now, has operated on a voluntary basis. For three years the March of Dimes chapter worked closely with the Puerto Rico Department of Health to secure legislative authority and administrative support for the program.

Key to the legislative victory was the chapter's strong working relationship with the governor's office. Puerto Rico's First Lady Maria Elena

Gonzalez Calderon, who also serves as honorary WalkAmerica Chair, helped secure the necessary legislative support for the initiative. Another critical element was

the involvement of March of Dimes Trustee Brent Minor. In May of 2004, Mr. Minor led a series of meetings with key Puerto Rico officials at which the importance of establishing the system by law was discussed.



(l-r) former Chapter Chair Tony Ceglia; Regional Director of Public Affairs Amy Richardson; Director of Program Services Lorel Crespo; Brent Minor; First Lady Maria Elena Gonzalez Calderon; Executive Director Alma Seda; Public Affairs Chair Ana Bravo.

On September 22, 2004, the March of Dimes expanded its newborn screening policy. The policy change was a reaction to a report that the Health Resources and Services Administration (HRSA) commissioned the American College of Medical Genetics (ACMG) to produce. HRSA asked members of the Advisory Committee on Heritable Disorders and Genetic Diseases, to review the report. The committee, of which Dr. Howse is a member, reviewed the report and recommended its approval by the Secretary of HHS.

The previous March of Dimes' policy had recommended states screen for

10 disorders. The new policy urges every state to screen every newborn for at least 30 disorders and to report on an additional 25 conditions that can be detected in the course of screening for the list of 30.

The HHS Advisory Committee on Heritable Disorders and Genetic Diseases was created in 2002 as a result of legislation developed and promoted by the March of Dimes.

A list of the tests recommended by the March of Dimes can be found on the internet web at http://www.modimes.org/aboutus/298_834.asp

The *Advocacy Update* delivers legislative news about March of Dimes issues on a quarterly basis.

Editor:
Joseph A. Luchok

If you have questions or comments about the *Advocacy Update*, contact:

**March of Dimes
Birth Defects Foundation
Office of Government Affairs
1146 19th Street, N.W.
6th Floor
Washington, D.C. 20036
Telephone: (202) 659-1800
Fax: (202) 296-2964**

copyright © March of Dimes



Office of Government Affairs
1146 19th Street, N.W., 6th
Floor
Washington, D.C. 20036