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Advocacy Update

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Direct Questions or
Comments to:

2007 NEWBORN SCREENING REPORT CARD RELEASED

On July 11, the March of Dimes released its 2007 state Newborn Screening Report Card. The report card was made public by Dr. Jennifer L. Howse, president of the March of Dimes, on the CBS Morning Show.

Among findings in the 2007 Report Card are:

- 1) Thirteen states and the District of Columbia screen for the 29 core and treatable conditions recommended by the American College of Genetics and endorsed by the March of Dimes and the American Academy of Pediatrics.
- 2) Nearly 90% of all infants born in the United States live in states that require screening for at least 21 of the core conditions. Only 38% were born in states requiring screening for at least 21 core conditions in 2005.
- 3) 6.1% of infants are born in states that that require screening for 10 to 20 of the core conditions and 6.2% are born in states that require screening for less than 10 of the core conditions.

The Report Card and related material can be found at:

http://marchofdimes.com/aboutus/22663_25778.asp

MARCH OF DIMES PARTICIPATES IN PRESS CONFERENCE ON SCHIP

On Wednesday, July 25, the March of Dimes was one of 29 organizations that joined together for a press conference calling for the reauthorization of the State Children's Health Insurance Program (SCHIP). Dr. Marina L. Weiss, senior vice president, public policy and government affairs of the March of Dimes, spoke at the event, which was held in the U.S. Capitol building.

Dr. Weiss said, "The CHIP package approved by the Senate Finance Committee is a very strong first step toward reauthorization. Several March of Dimes priorities are included: protecting coverage for all currently enrolled children, enabling states to add millions of uninsured children to the program, giving states the authority they need to cover uninsured pregnant women and launching a much needed pediatric quality initiative. All of us at the Foundation look forward to working with members of the House and Senate to send the strongest possible bipartisan reauthorization bill to the President for his signature."

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Other speakers at the event were Sr. Carol Keehan, D.C., President and CEO, Catholic Health Association; Robert Zarr, MD, representing the American Academy of Pediatrics; John Sweeney, President, AFL-CIO; Charles Kolb, President of the Committee for Economic Development, representing the Better Health Care Together Coalition; Dennis Rivera, Chair, SEIU Healthcare, and Chair, Partnership for Quality Care; Charles N. Kahn III, President, Federation of American Hospitals; and Kathleen Stoll, Director, Health Policy, Families USA.

The SCHIP reauthorization bills were approved by the House on August 1 and the Senate on August 2. Because the two bills have several differences, the next step will be a conference committee in September to reconcile the differences in the bills.



Dr. Marina L. Weiss speaks at SCHIP press conference as representatives of 28 organizations stand behind her.

REGION REPORTS

NORTH

Minnesota Governor Tim Pawlenty signed into law the Universal Newborn and Infant Hearing Screening Act which establishes a mandatory hearing screening and reporting system for newborns and a follow-up intervention program for newborns diagnosed with a hearing loss. The Act authorizes a birth certificate fee increase to cover the costs of the expanded screening, and it establishes a Newborn Hearing Screening Advisory Committee. The Minnesota Chapter played a leadership role in this initiative through the State Newborn Screening Advisory Committee, which make recommendations to the Commissioner of Health. Additionally, chapter volunteers and staff testified in support of the bill at Senate and House committee hearings and featured the issue at their lobby day earlier this

session.

The Maine Chapter led the initiative to require the state's audiologists to report on newborn hearing screening follow-up to the Maine Center for Disease Control. Chapter volunteers submitted public testimony and wrote letters in support of the initiative. Each year about 400 Maine babies are identified with possible hearing loss, and 40-50 are identified with a significant loss. Hearing loss is one of the most common and treatable infant health problems. Undetected, the condition will impede speech, language, and cognitive development. Reporting will allow the Maine Center for Disease Control to better track outcomes and assist families in locating and accessing support and resources for their newborn



Providence, Rhode Island, WalkAmerica: State Director of Program Services Dawn Cardeiro speaks with U.S. Representative Patrick J. Kennedy (D-RI) about the need to reauthorize the State Children's Health Insurance Program (SCHIP).

SOUTH

The Tennessee Chapter achieved three major victories for pregnant women and children in the area of smoking cessation. The Tennessee General Assembly passed legislation to increase the state's cigarette tax by \$.42, bringing the total tax to \$.62. Lawmakers also approved a state-wide smoking ban for most indoor places, including restaurants. Additionally, Governor Phil Bredesen's approved budget includes \$10 million for smoking cessation initiatives. Chapter volunteers advocated for each of these initiatives through their lobby day activities in Nashville, face-to-face meetings and telephone conversations with legislators, and by reacting to advocacy alerts distributed by Chapter staff. These legislative wins are even more of an accomplishment when you consider that Tennessee's number one legal cash crop is tobacco.

WEST

On May 15, 2007, ninety-four volunteers and staff converged on the California Capitol for the Chapter's annual lobby day. Volunteers visited with legislators to advocate for coverage of medical foods for children born with a disorder detected through newborn screening and for legislation dealing with preconception care for high-risk populations. One of the day's events included a birthday party for Zachary Black, one of the subjects of the 2004 *Wall Street Journal* article that focused national media attention on the disparity in newborn screening across states.



California Chapter State Director, Dani Montague, helps kick off singing “Happy Birthday” to Zachary Black, subject of the 2005 Wall Street Journal article on disparities in newborn screening programs as he celebrates his 4th birthday at the Capitol during the chapter’s lobby day.



Ninety-four staff and volunteers participate in the training session during the California Chapters' Day at the Capitol. Following lunch, volunteers visited 120 legislators' offices to advocate for insurance coverage of medical foods and preconception care legislation.

On April 18, 2007, the Oklahoma Chapter hosted the March of Dimes National Ambassador Family at their annual lobby day. The Chapter partnered with the Alpha Phi Alpha fraternity and had a prematurity awareness proclamation signing with a Judge of the Oklahoma Supreme Court. The Chapter then hosted a luncheon for the Women's Legislative Caucus. Seventeen of the 23 members of the Caucus and the Lt. Governor attended. Zeke Taylor, the March of Dimes national ambassador, was recognized in the Senate Gallery and on the House Floor, where he got a standing ovation. Volunteers then visited legislators' offices and asked for support of a Senate bill which would increase the income eligibility threshold for Oklahoma's State Children's Health Insurance Program.

The recently passed Montana state budget includes \$290,000 to fund follow-up and treatment for children born with a disorder detected by newborn screening. Earlier this year, the Montana Chapter led the effort to expand newborn screening to the 29 disorders recommended by the American College of Medical Genetics and endorsed by the March of Dimes and American Academy of Pediatrics. The Chapter also advocated for funding for follow-up and treatment.