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## MISSION VOLUNTEER SPEAKS AT PRESS CONFERENCE AND TESTIFIES AT HEARING

Susan Boucher, a March of Dimes volunteer and mother of premature twins, recently spoke on behalf of the Foundation at two events on Capitol Hill.

On March 14, 2007, she represented the March of Dimes at a press conference in support of the “Children’s Health First Act” (S. 895/H.R. 1535) sponsored by Senator Hillary Rodham Clinton (D-NY) and Representative John Dingell (D-MI), Chairman of the House Energy and Commerce Committee. The March of Dimes helped develop the bill and enthusiastically supports this initiative. The bill proposes several steps to improve access to health coverage for pregnant women, infants and children, including allowing states to enroll income-eligible pregnant women in the State Children’s Health Insurance Program (SCHIP) and securing Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefits for all children enrolled in the new Medicaid “benchmark” benefit packages states are permitted to offer.

On March 29, 2007, Boucher also testified before the House Labor, Health and Human Services, and Education Appropriations Subcommittee on behalf of the Foundation. Her testimony highlighted March of Dimes’ fiscal year 2008 federal funding priorities and conveyed to Members of the Subcommittee the importance of increasing support for research related to preterm labor and delivery. A more comprehensive written statement was submitted for the hearing record and included detailed funding recommendations for the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA).

Ms. Boucher concluded by thanking the committee for providing full funding for the National Children’s Study in fiscal year 2007 and asking them to reaffirm their commitment by allocating \$111 million to the next phase of the study which begins in fiscal year 2008. Researchers project that within a year of enrolling the first study participants, important new data on pregnancy outcomes, premature birth in particular, will be available to researchers.

The March of Dimes will continue to work with Members of Congress to ensure that these important appropriations are made and the “Children’s Health First Act” is approved.

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**Senator Hillary Rodham Clinton meets Susan Boucher at Press Conference for “Children’s Health First Act”**



**Susan Boucher testifies before the House Labor, Health and Human Services, and Education Appropriations Subcommittee**

## UPDATES ON ISSUES OF INTEREST

The *March of Dimes 110<sup>th</sup> U.S. Congress Directory* is now available. This *Directory*, produced especially for the March of Dimes, contains biographical and contact information for U.S. Senators, Representatives, Cabinet Secretaries, Supreme Court Justices, State Governors, and more. Chapters and Divisions will be receiving their copy in the several weeks.

On March 21, 2007, Representatives Lucille Roybal-Allard (D-CA) and Mike Simpson (R-ID) introduced the “Newborn Screening Saves Lives Act” (H.R. 1634), the House companion to the bill introduced earlier this year by Senators Chris Dodd (D-CT) and Orrin Hatch (R-UT). The March issue of Advocacy Update contains a detailed article on this initiative.

<http://marchofdimes.com/MarchAdvocacyUpdate.pdf>

On March 23, 2007 the Senate voted 52-47 to approve a \$2.9 trillion fiscal year 2008 budget resolution that provides up to \$50 billion over five years for reauthorization and expansion of the State Children’s Health Insurance Program (SCHIP). Congressional budget resolutions are funding guides or “blueprints” that provide a fiscal framework for committees grappling with future year funding. Such resolutions are not laws and are not presented to the President for his signature.

In its original form, the resolution proposed a \$2.717 billion increase (5.2%) over fiscal year 2007 for most health programs. However, as a result of advocacy by the March of Dimes and other interested groups, an amendment offered by Senators Arlen Specter (R-PA) and Tom Harkin (D-IA) was unanimously approved and added an additional \$2.2 billion for health programs.

The House of Representatives approved its version of the budget resolution, creating a “reserve fund” of \$50 billion for SCHIP and allocating a \$2.148 billion increase (4.1%) over fiscal year 2007 for most health programs. The Senate and House approved versions of the resolution will now move to a conference committee where differences in the two proposals will be negotiated and a final compromise measure will be developed.

## REPORTS FROM THE REGIONS

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### NORTH

At their annual Lobby Day, Maine Chapter volunteers and staff met with over 50 legislators to gain support for a bill requiring health insurance coverage of medically necessary infant formula. The chapter was successful in securing four new co-sponsors for the bill. Medically necessary formula is used to feed newborns who require special diets, including babies with metabolic disorders detected through newborn screening. In 2003, of the 13,800 births in Maine, an estimated 277 babies suffered from medical conditions or allergies which require specialized infant formula. The Maine Chapter plans to testify in support of the bill at a public hearing in April.



March of Dimes volunteer Kate Hession and daughter Bryanna, 14 months, told legislators their personal story at Maine's Lobby Day. Bryanna is one of approximately 2% of babies born in the United States with potentially life threatening food allergies and other metabolic disorders, which require medically prescribed formula to sustain their lives. Bryanna is wearing a t-shirt supporting the bill.



At Maine's Lobby Day, State Representative Jeffrey Gifford met with March of Dimes State Director of Program Services Sharon Schulberger (left), State Public Affairs Committee Chair Amy Carlisle (back) and volunteer Kate Hession (right) to discuss proposed legislation requiring insurance coverage of medically necessary formula. Representative Gifford signed on as a bill co-sponsor.

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## SOUTH

On February 21, 2007, the Greater Missouri Chapter held its Lobby Day at the Capitol in Jefferson City. March of Dimes volunteers and staff advocated on behalf of mothers and babies, requesting that legislators keep \$1 million in the state budget for smoking cessation programs. Additionally, participants thanked legislators for their support of expanded newborn screening, which will benefit the approximately 77,000 babies born in the state each year. Missouri currently requires screening for 27 of 29 treatable conditions, with screening for biotinidase and cystic fibrosis approved but not yet implemented.



**Leaders of the Missouri Chapter of the March of Dimes hand Gov. Matt Blunt a check symbolizing the March of Dimes \$4.179 million investment in 2007 for programs that help fight premature birth in Missouri. From left: Board members Mike Brady, Anne Heine, Gov. Blunt, Board members Joan Berkman, Sylvia Jura, Mary McEntire, Sarah Schmidt, John Spesia, Public Affairs Chair Joe Pierle, Board members Marybeth Placke, Joan Barry, and State Director Deborah Kersting.**

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## WEST

By adding cystic fibrosis to its newborn screening panel earlier this year, Alaska became the 12<sup>th</sup> state to require screening for all 29 treatable disorders as recommended by the American College of Medical Genetics (ACMG) and endorsed by March of Dimes and the American Academy of Pediatrics. The March of Dimes is represented on the state's newborn screening advisory committee which recommended the addition.

On March 6, 2007, the Oregon Chapter hosted its Day at the Capitol. Volunteers and staff advocated for passage of a Senate bill to create a state birth defects surveillance program. The Chapter secured the bill sponsors, assisted in drafting the legislation, and is leading the advocacy effort on this important initiative. 53 of the 90 members of the Oregon Legislature are co-sponsors of the bill.



**Senator Laurie Monnes Anderson, chair of the Senate Health Policy and Public Affairs Committee and bill sponsor, speaks about the importance of birth defect surveillance programs during the Oregon Chapter's lobby day.**

On March 13, 2007, more than 200 Texas Chapter volunteers and staff converged on the state Capitol to advocate on key issues affecting newborns and children. Volunteers met with legislators and staff members to ask for support of funding sufficient to implement newborn screening for cystic fibrosis, and to maintain the statewide birth defects registry. In addition, volunteers discussed policy changes needed to expand enrollment in the State Children's Health Insurance Program, including restoration of 12 months continuous eligibility and elimination of the 90 day waiting period before coverage begins.



**During the morning training session, Senator Royce West speaks to March of Dimes volunteers concerning issues before the Texas Legislature.**



**More than 200 volunteers gather for a training session prior to meetings with legislators and staff regarding newborn screening for cystic fibrosis, birth defects surveillance and children's health insurance.**

On March 13, 2007, the Arizona Chapter hosted their Legislative Luncheon. Among attendees were 84 legislators; legislative staff; Governor's office staff; Chapter Board, public affairs, and program volunteers; and Mission Families. Volunteers advocated for passage of a Senate bill which would increase the

income eligibility threshold for pregnant women enrolling in Medicaid to 185% of the Federal Poverty Level (\$38,202 for a family of four), funding for folic acid programs, and a change in the birth defects surveillance law that would allow the state to link families who have a child born with a birth defect with available services. Several legislators made commitments to move the bills forward this session.



**Arizona State Senator Barbara Leff, lead sponsor for Senate Bill 1361, and Representative Bob Stump, lead sponsor for House Bill 2156, visit with Mission Family Suzanne Young and her daughter, Catherine, during the March of Dimes legislative luncheon on the Capitol grounds on March 13, 2007.**