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NATIONAL CHILDREN'S STUDY RECEIVES FULL FUNDING FOR FIRST PHASE OF IMPLEMENTATION

On February 15th, President Bush signed a Joint Funding Resolution for FY 2007 that includes \$69 million for implementation of the next phase of the National Children's Study (NCS) for which the March of Dimes has advocated. The Funding Resolution was needed to keep the federal government operating because the 109th Congress adjourned before approving a budget for FY 2007.

As currently designed, the NCS would follow a representative sample of 100,000 pregnant women and their children from the prenatal period until the child reaches age 21, and would examine the impact of a broad range of environmental influences (physical, chemical, biological, and social) with the purpose of identifying the root causes of many childhood and adult diseases. Approximately one year after the full study is underway, researchers will begin a thorough review of data pertaining to premature birth and pregnancy outcomes and, using this data, will focus on an array of serious pediatric health problems. This landmark study holds the potential to dramatically enhance understanding of the causes of preterm birth, birth defects, and infant mortality as well as childhood onset of disease.

The \$69 million will allow institutions participating in the study to begin enrolling the first groups of subjects this year. Funding will also be used to recruit and hire staff, establish an information management system, conduct pilot studies and develop a request for proposals (RFP) for the next group of study sites.

MARCH OF DIMES VOLUNTEER TESTIFIES AT SCHIP HEARING

On February 14, 2007 the House Energy and Commerce Health Subcommittee held a hearing entitled, "Covering the Uninsured Through the Eyes of a Child," on reauthorization of the State Children's Health Insurance Program (SCHIP).

Kathy Pax Mingledorff, a March of Dimes Mission Volunteer from Springfield, Virginia, testified about the importance to her family of Medicaid and the Virginia SCHIP program (FAMIS). She spoke about her son Alex, who was born prematurely at 25 weeks and has suffered from serious health problems associated with his preterm birth. For his first two years, Alex was insured through Medicaid which covered medical bills exceeding \$800,000. In 2006, Kathy took a job where her income exceeded the eligibility level for Medicaid, but thanks to

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Virginia's FAMIS, a program that provides health insurance to children with family incomes above the Medicaid eligibility level, Alex did not lose his health coverage. Kathy and Alex are now privately insured for their health needs through the health plan of her husband's employer. As Kathy told Members of the Energy and Commerce Committee, "both Medicaid and SCHIP are important programs that should be protected and strengthened. These programs were key to accessing medical care at a time when Alex and I most needed help."

Also testifying were Susan Molina, a Community Leader with PICO in Denver, Co., Jeanne Lambrew, Associate Professor, Department of Health Policy at George Washington University, Chris L. Peterson, Specialist in Social Legislation, Domestic Social Policy Division, Congressional Research Service, Nina Owcharenko, Senior Policy Analyst, Center for Health Policy Studies, Heritage Foundation, and Dr. Jay E. Berkelhamer, President, American Academy of Pediatrics.



Kathy Pax Mingleorff with her children Alex and Lily and Representative Frank Pallone, Jr. (D-NJ), Chair of the Health Subcommittee

NEWBORN SCREENING SAVES LIVES ACT REINTRODUCED

On February 15, 2007 Senators Chris Dodd (D-CT) and Orrin Hatch (R-UT) reintroduced the Newborn Screening Saves Lives Act (S.634). The March of Dimes worked collaboratively with both Senators to develop the provisions of the bill.

Beginning in 1961 with its work on phenylketonuria (PKU), the March of Dimes Foundation has been at the forefront of building state newborn screening programs. In 2000 President Jennifer L. Howse and Dr. Michael Katz, Senior Vice President Research and Global Programs, co-authored a commentary, "The

Importance of Newborn Screening”, published in *Pediatrics*. In 2004 Dr. Howse served on the American College of Medical Genetics (ACMG) steering committee that developed the recommendation that every baby born in the United States be screened for a minimum of 29 treatable metabolic and functional disorders.

The Newborn Screening Saves Lives Act authorizes \$15 million in annual federal funding for use in educating parents and health professionals about newborn screening, and to improve access to follow-up care for infants when a condition or illness is detected.

S. 634 also calls for federal guidelines to establish a set of screens that should be available to all newborns and authorizes funding to help states expand and improve their programs. If enacted, the Newborn Screening Saves Lives Act would help states implement recommendations for program improvements that can mean the difference between a healthy life or a severe disability or even death for a newborn.

Within the next few weeks, Representatives Lucille Roybal-Allard (D-CA) and Mike Simpson (R-ID) are expected to introduce a companion bill in the House of Representatives.

REPORTS FROM the REGIONS

NORTH

On February 15, Michigan Chapter volunteers visited the state Capitol and recruited 35 legislators for the Michigan Prematurity Caucus. The March of Dimes created the bipartisan Caucus to gain support for prematurity-related policy issues, including access to health coverage for pregnant women, infants and children, smoking cessation services for pregnant women, and reduction of exposure to secondhand smoke. Two House Members and two Senators agreed to serve as co-chairs of the Prematurity Caucus.

The Minnesota Chapter is leading an advocacy initiative to secure \$1.5 million in state funding for the Birth Defects Information System (BDIS). At their January 30th Lobby Day, March of Dimes volunteers met with legislators to discuss birth defects surveillance and secure support for increased funding. Two legislators agreed to add their names as bill sponsors and five agreed to cosponsor a proposed appropriations bill.

The Puerto Rico Chapter’s Walk America Kick Off was the venue for Dr. José Cordero, March of Dimes Trustee, to talk with corporate leaders about the Foundation’s mission priorities. This year, the Chapter is advocating for expansion of the number of treatable conditions for which newborns are screened.



Dr. José Cordero Addresses Corporate Leaders

SOUTH

On February 7th, volunteers and staff with the Virginia Chapter met with Members of the General Assembly during the Chapter's annual Lobby Day. Participants advocated for raising the income eligibility level for the state's Family Access to Medical Insurance Security program (FAMIS), which currently provides health coverage for pregnant women with incomes below 166% of the federal poverty level (\$34,279 for a family of 4). Additionally, volunteers and staff called upon Members to impose a state-wide smoking ban which would benefit women of childbearing age, infants and children across the Commonwealth.



Staff members Pat Irvin and Betty Loudermilk meet with Delegate Lacy Putney, Vice Chair of the House Appropriations Committee, to advocate for increasing eligibility in FAMIS

On February 7th, the South Carolina Chapter held its annual Legislative Breakfast at the state Capitol complex. March of Dimes volunteers advocated on behalf of several Chapter Public Affairs issue priorities including: 1) expanding the state panel to include screening for hearing deficiencies which, if approved, would benefit approximately 56,000 babies annually; 2) raising the tax on cigarettes by \$.93/pack to fund health coverage initiatives which would benefit women of childbearing age, infants and children; and 3) banning smoking in the workplace and in public spaces statewide. Over 70 legislators and 40 volunteers discussed the Chapter's advocacy priorities over breakfast.

WEST

On February 6, 2007, the Washington Chapter held its Day at the Capitol. Forty volunteers and staff held over 60 meetings with legislators. One of the Chapter's advocacy priorities was support for a bill to help pay for treatment and follow-up services for infants and children born with disorders detected through newborn screening. Volunteers secured a Senate bill sponsor, the Chair of the Senate Ways and Means Committee, as well as several co-sponsors. Additional legislators made commitments to write to the state's Department of Health to urge expansion of the panel of treatable conditions for which newborns are screened. Volunteers also urged legislators to support a bill to increase health care coverage for infants and children with family incomes below 250% of the federal poverty level (\$51,625 for a family of 4).



Volunteer Kerry Hooks meets with Representative Springer to discuss newborn screening follow-up, health care access, and family planning issues.

On February 12, 2007, the Montana Chapter held a Day at the Capitol. Chapter staff and volunteers braved the snow to advocate for passage of a bill to

expand newborn screening to include 29 treatable disorders, as recommended by the American College of Medical Genetics and endorsed by March of Dimes and the American Academy of Pediatrics. Participants met with Members of the Senate where the legislation was pending, as well as with Members of the House Human Services Committee who will soon hear the bill. Less than a week after the Chapter's Day at the Capitol, the Montana Senate approved the legislation by a vote of 49-1.



The March of Dimes banner adorns the second floor of the Capitol rotunda for the Montana Chapter's Day at the Capitol on February 12th. .



Montana volunteers Courtney, Tyler and Hannah Stovall; Director of Program Services Debbie Donovan; and State Director Lori Simon gather before heading out to meet with legislators to advocate for expanded newborn screening.