



In This Issue

- "PREEMIE" Bill Sent to Full Senate
- HHS Appropriation Bill Passed by House Committee
- Carolyn Doyle Joins OGA
- Region Reports

SENATE HELP COMMITTEE APPROVES "PREEMIE" BILL WITH UNANIMOUS VOTE

On June 28, the Health, Education, Labor, and Pensions (HELP) Committee voted unanimously to approve and send the "PREEMIE" bill to the full Senate for its consideration. Committee Chairman Mike Enzi (R-WY) said he will ask for a vote on the bill before the end of July. This is a major step forward for PREEMIE. If passed by the Senate and House of Representatives, the bill will then be sent to the President for his signature. As a result of the efforts of volunteers and staff across the nation, the bill now has 40 cosponsors in the Senate and 74 cosponsors in the House.

The "PREEMIE" bill was introduced by Senators Lamar Alexander (R-TN) and Chris Dodd (D-CT). In a press release following committee approval, Senator Alexander said, "Premature infants are 14 times more likely to die in their first year than infants who are carried to term. Prematurity accounted for 19 percent of all childhood deaths in Tennessee in 2002 and, on average, 214 babies are born preterm in the state each week. We need to do all we can to help parents raise healthy children. This bill targets the earliest and most critical stages of a child's life and I'm very pleased the committee has approved it." In a separate release, Senator Dodd said, "More than 1,300 babies each day, and over 500,000 each year, including more than 4,100 in Connecticut, are born prematurely. Although we do know some risk factors associated with premature births, nearly half have no known cause. We need to ensure that both the education and research efforts associated with prematurity and low birth weight are reaching as many expectant mothers as possible."

As part of the March of Dimes grassroots advocacy campaign in support of this initiative, the Wyoming State Director Kim McJunkin, March of Dimes ambassador Kaden Gailey, and Kaden's parents Marc and Tonia met with Chairman Enzi in Casper to urge him to schedule the bill for committee action. In a press release issued on the day of the committee's vote, Chairman Enzi said, "By expanding, intensifying, and coordinating research into the causes and prevention of premature births, this bill will aim to reduce rates of premature delivery, promote evidence-based care for women and infants, and reduce infant mortality and disabilities caused by prematurity."

Immediately following the committee's approval of the bill, Senator Dodd joined Dr. Jennifer L. Howse, president of the March of Dimes, and Jenny Minton, author of [The Early Birds](#) on the Diane Rehm Show to discuss premature births and the

Advocacy Update

Editor: Joseph Luchok

Direct Questions or
Comments to:

March of Dimes Birth
Defects Foundation
Office of Government
Affairs
1146 19th Street N.W.
6th Floor
Washington D.C. 20036

Phone: (202) 659-1800
Fax: (202) 296-2964

Copyright © March of
Dimes

“PREEMIE” bill. The Diane Rehm Show is syndicated by National Public Radio and is broadcast on over 100 radio stations from coast to coast.



Senate Help Committee Considering “PREEMIE”

HIGHLIGHTS OF HOUSE LABOR-HHS APPROPRIATIONS BILL

The House Appropriations Committee approved their version of the fiscal year 2007 Labor, Health and Human Services (HHS) and Education Appropriations bill on June 13th. The legislation proposes \$141.9 billion in discretionary funding, a 0.6 percent increase over fiscal year 2006 levels. Specific funding recommendations include:

National Institutes of Health (NIH)

Level funding for NIH at \$28.3 billion. Nearly all the Institutes that compose NIH would experience small cuts in their funding in order to accommodate additional support for the ‘Roadmap Initiative’ managed by the NIH Director’s office. The ‘Roadmap Initiative’ is a management tool used to identify opportunities and gaps in biomedical research that no single institute at NIH could tackle alone but that the agency as a whole could address to accelerate progress in biomedical research.

The bill directs \$69 million for the continuation of the National Children’s Study. The National Children’s Study will examine the effects of environmental influences on the health and development of more than 100,000 children across the United States, following them from before birth until age 21. The first stage of the National Children’s Study will yield critical information for research on prematurity. This will enable scientists and clinicians to develop interventions, treatment, and preventive measures to help these families.

In addition, the Committee’s bill contains report language directing NIH to develop a strategic plan for prematurity research.

Centers for Disease Control and Prevention(CDC)

Under the Committee approved bill, the budget for CDC would be reduced by \$28 million below the fiscal year 2006 funding level.

Funding for the National Center on Birth Defects and Developmental Disabilities (NCBDDD) would be cut by \$7 million-- \$134,000 from the Birth defects and Developmental Disabilities Division; \$6.2 million from the Human Development and Disability Division and \$660,000 from the Heritable Disorders Division.

Despite the budgetary picture described above, the report accompanying the Committee bill includes language affirming continued Congressional support for birth defects surveillance, research and prevention, and for federal support of folic acid education.

Health Resources and Services Administration(HRSA)

The Committee recommends a funding increase of \$524 million above fiscal year 2006 for HRSA. The majority of this increase would be directed to support Community Health Centers.

Newborn screening activities as part of Special Projects of Regional and National Significance (within the Title V Maternal and Child Health Block Grant) would be increased by \$1 million for a total of \$3 million. Included in the Committee Chairman's 'Manager's Amendment' is a directive to the Secretary of the Department of Health and Human Services (HHS) which calls for adoption or rejection (with rationale) within 180 days of recommendations made by the HHS Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children.

CAROLYN DOYLE JOINS OGA

Carolyn Doyle has joined the Office of Government Affairs as the Associate Director of Federal Affairs.

Ms. Doyle previously worked as the Senior Federal Affairs Representative for the MWW Group and as a Legislative Aide in the office of Senator Arlen Specter (R-PA). She earned her B.A. from Villanova University in Villanova, PA.



Carolyn Doyle

REGION REPORTS

NORTH

On June 1, Iowa Governor Tom Vilsack signed into law two bills supported by the Iowa March of Dimes Chapter. The first restores \$40,000 in state funding for the Iowa Congenital and Inherited Disorders Registry (ICIDR), the state's birth defects surveillance program.

The second authorizes \$40,000 in funding from the "Healthy Iowans Tobacco Trust" for treatment of Phenylketonuria (PKU), a condition that can be detected at birth through newborn screening. The Iowa March of Dimes Chapter lead the advocacy effort and secured \$160,000 for PKU treatment during the 2005 legislative session, bringing total state funding for PKU treatment to \$200,000.



At the Iowa March of Dimes Lobby Day, volunteer Jim Brown, left, spoke with Representative Ralph Watts (R) about the high cost of foods and formula for children with PKU. Jim and his wife Donna attended lobby day to speak with legislators about the need for insurance coverage for all Iowans with PKU. The Browns have four children, ages 10-17 years, diagnosed with PKU at birth. They estimate their family's annual expenditure for special formula and foods at about \$20,000.



Vermont Governor Jim Douglas (R) at WalkAmerica in Montpelier, Vermont

WEST

Several Chapters in the Western Region achieved legislative victories by obtaining approval of key bills that address March of Dimes advocacy priorities. In Oklahoma the Governor signed into law a measure authorizing production of March of Dimes license plates with the proceeds from sale of the plates benefiting the Foundation.

In Kansas Chapter secured the establishment of a newborn screening advisory

committee that will make recommendations to the Kansas Legislature in preparation for the 2007 session.

Advocacy by Utah Chapter volunteers and staff resulted in reinstatement of a year of funding for the Utah Birth Defects Network. Future year funding will be a chapter advocacy priority for 2007.

A bill increasing eligibility from 185% top 200% of the federal poverty level (a little more than \$33,000 for a family of 3) for pregnant women under the State Children's Health Insurance Program (SCHIP) was recently signed into law in Colorado. (Colorado currently has a waiver that authorizes SCHIP to cover pregnant women.)

Legislation establishing a family planning task force, with the March of Dimes named as a member, passed in Hawaii. The Chapter also secured \$100,000 in state funding to support a Fetal Alcohol Spectrum Disorder Coordinator position at the health department.

As a result of aggressive advocacy by chapter volunteers and staff, the Texas Department of State Health Services agreed to phase-in screening for Biotinidase deficiency when the state implements its newborn screening expansion later this year.

Western Region Chapters supported the grassroots activities related to securing co-sponsorship of the federal PREEMIE Act by collecting more than 10,500 postcards region-wide during WalkAmerica. In addition, six members of Congress attended various WalkAmerica events in Hawaii, Nebraska, New Mexico, Texas, and Washington. Furthermore, the Montana, North Dakota, Texas, and Washington Chapters placed the PREEMIE Act op-ed article in seven newspapers.