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## UNITED STATES SENATE APPROVES “PREEMIE” BILL WITH UNANIMOUS VOTE

On August 1, 2006, the Prematurity Research Expansion and Education for Mothers who deliver Infants Early Act, or the “PREEMIE” bill, was approved by the United States Senate with no dissenting votes. On August 3, 2006, Senators Lamar Alexander (R-TN) and Chris Dodd (D-CT) held a press conference on Capitol Hill to announce the bill’s approval and to encourage their colleagues in the House of Representatives to act on the legislation before the end of this Congress. In addition to Senators Alexander and Dodd, Susan Boucher, a Mission Family mother of twins born at 28 weeks, and Dr. Marina L. Weiss, March of Dimes Senior Vice President for Public Policy and Government Affairs spoke at the press conference.

In a statement released at the press conference, Dr. Jennifer L. Howse, president of the March of Dimes, said, “Today, on behalf of 3 million active volunteers and 1400 staff of the March of Dimes working in every state, the District of Columbia and Puerto Rico, I commend the United State Senate for approving the “PREEMIE” bill. I particularly thank the bill sponsors, Senators Lamar Alexander (R-TN) and Christopher Dodd (D-CT), and Senator Mike Enzi (R-WY), Chairman of the Health, Education, Labor, and Pension Committee, for his leadership in bringing the bill to a vote in the Senate. I also thank the 40 additional Senate cosponsors for their endorsement of this measure that sets the stage for expanding federal support for much needed research into the causes of premature birth.”

Senator Alexander said, “On average, 214 babies are born prematurely each week in Tennessee. We simply do not know why half of these babies are born preterm and this legislation will help solve that mystery. It will also help us reduce the number of premature births and take better care of babies that do arrive too soon.”

Senator Dodd said, “Each year, more than 500,000 babies, 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.”

## Advocacy Update:

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Susan Boucher told the story of the birth of her twins, John and Eleanor. She spoke about how the twins, now 18 months old, spent nearly three months in a neonatal intensive care unit (NICU) and continue to experience health problems associated with their preterm birth. Ms. Boucher was also interviewed by a local television station about Senate approval of the “PREEMIE” bill.

Dr. Weiss said, “At the March of Dimes, we believe that in approving the “PREEMIE” Act by unanimous consent the Senate made a very strong statement about the need to address the serious and growing problem of preterm birth.”

All the speakers emphasized the need for the House of Representatives to quickly approve the “PREEMIE” Act in the House.



Speakers at the press conference announcing Senate approval of the “PREEMIE” bill. L to R: Senator Chris Dodd (D-CT), Susan Boucher, Dr. Marina Weiss, and Senator Lamar Alexander R-TN).

## **AMANDA MOLK JOINS OGA**

Amanda Molk joins the March of Dimes as Deputy Director of Federal Affairs after 2 years at the National Mental Health Association where she specialized in access issues, including Medicaid, the State Children's Health Insurance Program and private insurance coverage. Prior to her work with NMHA, for 3 years she worked as a legislative and press aide to Congresswoman Grace F. Napolitano of California. Amanda has a B.A. in government from Dartmouth College.



**Amanda Molk**

## **COLLEEN SONOSKY JOINS OGA**

Colleen A. Sonosky has joined the March of Dimes as Director of Public Policy Research after serving as Vice President for Policy at FirstFocus/America's Promise and Senior Director of Programs and Policy for the Children's Defense Fund. Since 1993, she has held various research and teaching positions in the Department of Health Policy at the George Washington University where she will remain on the faculty as Adjunct Assistant Professor. Colleen has a J.D. from the New England School of Law and a B.A. from Trinity College.



**Colleen Sonosky**

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## REGION REPORTS

### NORTH

Soon Illinois will soon join the small but growing number of states where every newborn is screened for all 29 conditions as recommended by the American College of Medical Genetics and supported by the March of Dimes.

On July 14, Dr. Eric E. Whitaker, Director of the Illinois Department of Public Health, announced that the state is moving forward with plans to require screening all newborns for Cystic Fibrosis, the only metabolic screen absent from the panel required by state law. Dr. Whitaker made the announcement at a press event jointly sponsored by the March of Dimes and the Illinois Department of Health at Children's Memorial Hospital in Chicago.

State Representative David Miller (D-Calumet City) and the March of Dimes Chapter, working together, convinced the Department of Public Affairs to add Cystic Fibrosis to the panel. In addition to the screening expansion, the Department of Public Health will initiate other changes to the Administrative Rules governing newborn screening, including raising the current newborn screening fee to cover any additional costs of equipment and staff.

The Vermont Chapter led two tobacco-related initiatives recently signed into law by Governor James Douglas. Through the Chapter's advocacy efforts, the FY2007 Vermont Tobacco Control Program's budget includes \$75,000 for provider education on smoking cessation provided through the Vermont Department of Health. According to state health officials, 20% of pregnant women in Vermont smoke during pregnancy, compared to 12.2% nationwide. Both the March of Dimes and the Department of Health believe the provider education program is a positive step toward reducing the number of women who smoke while pregnant.

In addition, Chapter advocacy efforts achieved a 61 cent increase in the cigarette excise tax, raising the tax on a pack of cigarettes to \$1.80. Revenue from the increased tax will be used to finance health care coverage for state Medicaid



**Kathryn and Dave Karwowski with son Alex, age three; Dr. Adrienne Prestridge, Attending Physician for Pulmonary and Critical Care at Children's Hospital; Dr. Eric E. Whitaker, Director, Illinois Department of Public Health; and Gail Wilson, State Director, March of Dimes Illinois Chapter. Alex Karwowski was diagnosed with Cystic Fibrosis at 18 months of age. The Karwowski family serves as March of Dimes spokespersons on the topic of newborn screening.**

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## WEST

In California, Governor Schwarzenegger signed into law a budget bill that includes \$8.5 million to implement newborn screening for Cystic Fibrosis and Biotinidase deficiency. The March of Dimes led the advocacy effort to secure the necessary funding as newborn screening has been a major element of the Chapter's 2006 legislative agenda.

During the recently concluded special legislative session, the Oklahoma Chapter was successful in its effort to secure \$622,806 in state funds to improve prenatal coverage for women with high risk pregnancies who rely on Medicaid for their health insurance. When the federal match is joined to the state appropriation, the result is \$1,951,306 for a number of program improvements including expanded access to ultrasound and non-stress test benefits.

As Congress continues its work on the federal PREEMIE bill, Chapters in the West have focused their efforts on securing additional cosponsors. Congresswoman Heather Wilson (R-NM) participated in Walk and agreed to lend her name to the bill as a result of interaction with Chapter volunteers and staff.

Utilizing key volunteer contacts as well as influential elected state officials, the Texas Chapter persuaded Congressman Michael Burgess (R-TX) and Congresswoman Kay Granger (R-TX) to cosponsor the PREEMIE bill.

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## SOUTH

South Carolina is celebrating a significant advocacy accomplishment. As part of its Lobby Day, the Chapter held a breakfast at the State Capitol that was attended by many legislators and staff. Volunteers met with their legislators and made the critical – and successful – “ask” for an appropriation to fund the South Carolina Birth Defects Surveillance and Prevention program. As a result, after 9 years and more than \$2 million in March of Dimes grants, volunteers and staff have convinced Governor Mark Sanford and Members of the state Legislature to provide public funding for the system. In 2007, more than \$608,000 in recurring state funds will be available to operate the system, and an additional \$244,000 will be applied to upgrading the program’s data collection capacity. Because the state has assumed responsibility for on-going funding of the system, the Chapter will be able to support other urgently needed programs aimed at improving the health of South Carolina’s women, infants and children.