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## Advocacy Update

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Direct Questions or

## **"PREEMIE" BILL GRASSROOTS CAMPAIGN UPDATE**

Since October 2005, when the grassroots campaign to engage volunteers and staff began, an additional 34 Senators and 54 Representatives have signed on as cosponsors of the "PREEMIE" bill. This brings the total number of bill sponsors to 37 in the Senate and 65 in the House.

Postcards signed by WalkAmerica participants from across the nation have begun to arrive and will be delivered to the offices of Senate and House members. In addition, op-eds are being submitted to major newspapers, with placements having already appeared in the Orlando Sentinel, Corpus Christi Caller-Times, Cincinnati Enquirer, Grand Forks Herald, Minot Daily News, Tampa Tribune, Fort Myers News, Syracuse Post-Standard, Fort Lauderdale Sun-Sentinel, Vero Beach Press-Journal, Tallahassee Democrat, the Buffalo News, and 4 Scripps Treasure Coast Newspapers along Florida's south coast.

Much has been done but enactment of the bill requires continued efforts by volunteers and staff in every state.

## **MARCH OF DIMES WORKING TO SAVE NATIONAL CHILDREN'S STUDY**

The President's budget proposal for Fiscal Year 2007 omitted funding for the National Children's Study (NCS) and directed the lead agency – the National Institute for Child Health and Human Development – to cease activities related to the study by the end of the current fiscal year. In order to continue enrollment of participants and collection of data, Congress must act. The March of Dimes is working on a bipartisan basis with several members of the Senate and House to arrange staff briefings on the importance and content of the study. The March of Dimes also initiated a letter to members of the Appropriations Committees that was signed by more than 60 supporting organizations concerned with children's health issues.

As currently designed, the NCS would follow a representative sample of 100,000 pregnant women and their children from the prenatal period until the children reach 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 (projected to be 2010) researchers will begin a thorough review of data pertaining to premature birth and

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pregnancy outcomes and, using this data, will focus on an array of serious pediatric health problems.

## **SENATORS DODD AND DeWINE INTRODUCE BILL TO IMPROVE NEWBORN SCREENING KNOWLEDGE BASE**

On April 27, 2006, Senators Christopher Dodd (D-CT) and Mike DeWine (R-OH), introduced the “Newborn Screening Saves Lives Act,” a bill that would create a federal grant program to educate health care professionals and the public about the technology and benefits of newborn screening. OGA worked with Senator Dodd’s staff on the language of the bill. A companion bill is expected to be introduced in the House of Representatives shortly.

More specifically, the bill:

- Authorizes \$15 million in 2007 (and such sums as may be necessary in 2008-2011) for grants to:
  - Educate and train health care professionals and state laboratory personnel in newborn screening and relevant new technologies;
  - Educate and inform parents, families, and patient advocacy and support groups about newborn screening; and
  - Establish a coordinated system of follow-up care for newborns and their families after screening and diagnosis.
- Provides for grants to states to expand and improve newborn screening programs so that states are encouraged to screen for the full panel of disorders recommended by the Advisory Committee on Heritable Disorders in Newborns and Children;
- Reauthorizes and expands the role of the Advisory Committee to include revising and updating the panel of recommended screens and advising the U.S. Secretary of Health and Human Services (HHS) on other steps to improve newborn screening programs, including new treatments and technologies;
- Requires the Centers for Disease Control and Prevention (CDC) to ensure that laboratories involved in newborn screening meet quality standards for accuracy of results; and
- Establishes a system for collection and analysis of data gleaned from newborn screening programs, to help researchers develop a better understanding of the disorders detected, and how they might be better detected, prevented, treated, and cured.

Quoted in Senator Dodd’s press release, Dr. Jennifer L. Howse, president of the March of Dimes said, “The March of Dimes strongly supports the Newborn Screening Saves Lives Act. We are deeply grateful for Senator Dodd’s and Senator DeWine’s leadership to improve newborn screening programs across the country.”

Along with Senator Lamar Alexander (R-TN), Senator Dodd is also the author of Senate Bill 707, the “Prematurity Research Expansion and Education for Mothers who deliver Infants Early Act” (the “PREEMIE Act”).

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## REGION REPORTS

### NORTH

#### **Newborn Screening Press Event with U.S. Senator Christopher Dodd**

On April 12, 2006, United States Senator Christopher Dodd (D-CT) and the Connecticut Chapter participated in a press event at Stamford Hospital to raise awareness about the issue of newborn screening and, specifically, about the “Newborn Screening Saves Lives Act.” The Chapter’s Ambassador Family, Thomas and Pamela Sweeney, told their personal story about 7-year old son Jonathan who was not screened at birth for LCHAD ( long-chain hydroxyaci-CoA dehydrogenase deficiency), a rare metabolic disorder from which he nearly died. Connecticut now screens for 28 of the 29 conditions recommended by the March of Dimes.



**(l-r) Ambassador Father Thomas Sweeney; Senator Christopher Dodd; Ambassador Mother Pamela Sweeney; March of Dimes State Director Julie Fronckowiak; and Michael Botelho, March of Dimes State Public Affairs Committee Chair**

## **Michigan Governor Signs Newborn Screening Authorization Bill**

March of Dimes representatives and other health advocates met with Michigan Governor Jennifer Granholm March 29, 2006, to discuss her maternal and child health agenda. The event provided the March of Dimes an opportunity to thank the Governor for signing a bill that creates a Newborn Screening Quality Assurance Advisory Committee, which will be responsible for review of the list of conditions for which newborns are screened and for recommending additions or deletions. This is an important step in expanding the state's newborn screening program. Michigan currently tests all newborns for 11 conditions.



(l-r) Julie Greichunos, Kalamazoo Division Director; Gail Martin, State Director of Program Services; Michigan Governor Jennifer Granholm; and Kara Brennan, Associate State Director of Program Services

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## **SOUTH**

### **Georgia Governor Signs Bill To Provide Funding for Newborn Screening Expansion**

On April 27, 2006, the Georgia Chapter participated in a bill signing by Governor Sonny Perdue. The bill establishes a \$40 fee for newborn screening with the revenues dedicated to expanding the state program. Georgia currently screens newborns for 12 metabolic disorders but with new funding the program will be expanded to include screening for 28 of the 29 core conditions recommended by the March of Dimes.



**Pictured are: Georgia Governor Sonny Perdue (center) and Mrs. Mary Perdue, families that have been affected by newborn metabolic disorders, Dr. Paul Fernhoff, Chapter Board Member and Chair of the Program Services Committee (front row, 3<sup>rd</sup> from left), representatives from the Chapter Public Affairs Committee and Board, State Director Brian Ziegler, representatives from the Georgia Department of Human Resources, the Division of Public Health, the Centers for Disease Control and Prevention (CDC), Emory University School of Medicine Department of Genetics, the Georgia State Laboratory**

### **Maryland Governor Signs Bill To Require Distribution of Folic Acid Supplements**

On May 2, 2006, Governor Robert Ehrlich signed legislation requiring the Department of Health and Mental Hygiene to distribute folic acid supplements to women of childbearing age with family incomes at or below \$37,000 (185 % of the Federal Poverty Level for a family of four in 2006).

The Chapter advocated for enactment of this bill by providing testimony before the House Health and Government Operations Committee of the General Assembly, sending letters from Chapter volunteers and staff, and making legislative visits on lobby day at the Capitol in Annapolis. Chapter volunteer Dr. Lee Woods led the effort with support from Interim State Director Pyda Sterling, Director of Program Services Anne Eder, and Chapter Public Affairs Consultant John Stierhoff.

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## **WEST**

### **Washington Increases Funding to Provide Health Services to Uninsured Children**

Washington Chapter volunteers and staff secured \$10.9 million in state funding to support health coverage for an estimated 12,890 uninsured children. Funding begins July 2006. Chapter volunteers and staff met with legislators on lobby day, activated the March of Dimes Advocacy Network, and joined other stakeholders to advance this important initiative.

### **Alaska Newborn Screening Legislation Moves to Senate**

After obtaining House approval of newborn hearing screening legislation in 2005, the Alaska Chapter has set its sights on Senate passage of the legislation in 2006. To bolster that effort the Chapter had a letter to the editor published in the Anchorage Daily News.

### **California Legislature Health Committees Tour NICU**

In California, Senate Health Committee members participated in a March of Dimes sponsored NICU tour on March 22, 2006. The tour was covered by the local television network affiliates for ABC, CBS and NBC and was given airtime on the largest AM talk radio station in the media market. After hearing of the event's success, members of the Assembly Health Committee contacted the Chapter to arrange for a similar tour.