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PREEMIE BILL UPDATE



convenes in January, 2007.

Congress is scheduled to return for a “lame-duck” session on November 13, giving the U.S. House of Representatives the opportunity to approve the “PREEMIE” Act. Although the “PREEMIE” Act was passed by the Senate earlier this year, the House has not yet voted on the bill. If “PREEMIE” is not approved by House Members during the “lame-duck” session, sponsors will have to start over when the next Congress

There is still time to contact your U.S. Representative to let them know that action on this bill should be completed this year. Visit marchofdimes.com/advocacy for information on how to contact your Representative.



Dr. Jennifer L. Howse, President of the March of Dimes, speaks about the PREEMIE Bill at a Congressional Briefing on Capitol Hill, October, 2006. The briefing, sponsored by Senator Lamar Alexander (R-TN), Senator Chris Dodd (D-CT), Representative Fred Upton (R-MI), Representative Anna Eshoo (D-CA), the Institute of Medicine and the March of Dimes, was titled “Preterm Birth: Causes, Consequences, and Prevention.”

MARCH OF DIMES SUPPORTS NATIONAL CHILDREN'S STUDY

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On October 30, 2006 a letter recommending funding for the National Children's Study was sent to the Chairmen and Ranking Members of the Senate and House Appropriations Subcommittees on Labor, HHS, and Related Agencies. The March of Dimes initiated the letter and was one of 108 signatory organizations.

The National Children's Study is designed to support groundbreaking research to increase understanding of the role of family genetics and the environment on childhood development. The study will follow 100,000 children for 21 years, beginning with the pregnancies of their mothers.

The first stage of the National Children's Study is expected to yield critical data for use in research on prematurity. The information generated by the study will enable scientists and clinicians to develop interventions, treatment, and preventive measures to help these families.

In addition, the National Children's Study will generate information that could help reduce the incidence of serious birth defects. Birth defects are a leading cause of death in the first year of life, and can cause physical and mental disabilities that last a lifetime. In 2004, 120,000 babies were born with one or more significant birth defects. The cause of up to 70 percent of birth defects is unknown.

REGION REPORTS

NORTH

In Ohio, March of Dimes volunteers celebrated a newborn screening victory when the Department of Health recently added two disorders – cystic fibrosis (CF) and carnitine update deficiency (CUD) – to its panel of required newborn screens. The additions took effect on August 30 and, as a result, infants born in Ohio will be screened for 28 of the 29 conditions recommended by the American College of Medical Genetics and endorsed by the March of Dimes. Chapter volunteers promoted the initiative through testimony and letters and will continue to advocate for expansion of the screening panel to include the 29th disorder, Tyrosinemia type (TYR I).

The First Lady of Maine, Karen Baldacci, is serving in her fourth year as Honorary Chair of the Chapter's Prematurity Campaign. As Campaign Chair, she has taken a particular interest in the Premie Project 1372, a unique effort to increase awareness of the 1,372 babies born preterm in Maine in 2005. Stitchers sew premie outfits that are donated to NICU's. The outfits will be displayed during the "Moment of Hope" which Mrs. Baldacci will host on November 14th, National Prematurity Awareness Day. In addition to her volunteer efforts on behalf of the Maine Chapter, Mrs. Baldacci recently recruited five of her fellow

National Governor's Association First Spouses to work with their state March of Dimes chapters in support of the Prematurity Campaign.



Maine First Lady Karen Baldacci (left) thanks Preemie Project 1372 stitchers and surveys some of the outfits received so far this year.

Earlier this year, Governor John Baldacci signed a law authorizing legislation to initiate a Maternal Infant Mortality and Resiliency Review. The review is intended to help identify strategies for improving outcomes for pregnant and postpartum women and infants. March of Dimes advocates worked with the Governor and his staff to provide technical expertise and support for the legislation.

SOUTH

The South Carolina Chapter recently secured administrative approval to add Tyrosinemia to the panel of conditions for which newborns are screened at birth. Led by neonatologist and Public Affairs volunteer Dr. Robert Newell and lead Public Affairs staff Holly Hayes, the Chapter advocated for this addition through the Advisory Panel for Metabolic Screening of the South Carolina Department of Health and Environmental Control. As a result of the Chapter's leadership on this issue, over 50,000 babies will be screened every year for this deadly inherited disease. South Carolina now screens for 28 of the 29 recommended "core" conditions endorsed by the American College of Medical Genetics and the March of Dimes. The Chapter has made the addition of the last "core" condition, newborn hearing screening, a top Public Affairs priority for 2007.

The Virginia and National Capital Area Chapters successfully advocated for an increase in the eligibility threshold and funding for pregnant women in the state's Family Access to Medical Insurance Security program (FAMIS MOMS). This program provides health coverage for pregnant women. The threshold will increase from 150% (\$30,000) of the Federal Poverty Level (FPL) for a family of four to 166% of FPL (\$33,200) for a family of four. Chapter volunteers and staff successfully advocated for the expansion during Lobby Day 2006 at the Virginia State Capitol.



WEST

On October 18, 2006, by a vote of 13-2, the Houston City Council approved expanding a city ordinance to prohibit smoking in all enclosed workspaces, including bars. The expanded ban will take effect in September of 2007. Certain exemptions, including smoking in outdoor patios and tobacco bars will continue to be allowed. The Houston Division of the Texas Chapter worked for several years to prohibit smoking in public places. Volunteers and staff testified at meetings and sent letters to City Council members urging approval of an expanded smoking ordinance. The expanded ordinance has the potential to reduce exposure to second-hand smoke for pregnant women and children.