

March Winter 2005 of Dimes

Advocacy Update *from the Office of Government Affairs*



Dr. Jennifer L. Howse Meets with Senators Alexander and Dodd to Discuss Launch of a Grassroots Campaign to Build Support the “PREEMIE Bill”

On October 4, 2005 Dr. Jennifer L. Howse, President of the March of Dimes, met with Senators Lamar Alexander (R-TN) and Chris Dodd (D-CT), authors of the “Prematurity Research Expansion and Education for Mothers Who Deliver Infants Early” (PREEMIE) Bill (S 707; H.R. 2861).

Among points covered were the growing problem of prematurity, the March of Dimes Prematurity Campaign, and chapter prematurity summits. Dr. Howse emphasized the need for a stronger federal commitment to solving the prematurity



Dr. Jennifer L. Howse with Senator Lamar Alexander

crisis and the importance of the PREEMIE bill. She also sought advice from the Senators about what steps the March of Dimes could take to help move the PREEMIE bill to enactment. The

PREEMIE bill would increase federal support for research into the causes and strategies for prevention of prematurity. In addition, the bill would provide federal support for public and health professional education as well as health services related to prematurity. The PREEMIE bill was introduced by Senators Alexander and Dodd in the Senate and Representatives Fred Upton (R-MI) and Anna Eshoo (D-CA) in the House.

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Dr. Nancy Green Speaks About the National Children's Study

On September 29th, 2005, Dr. Nancy Green, Medical Director of the March of Dimes, spoke at a news conference sponsored by The National Institute of Child Health and Human Development (NICHD) announcing the vanguard sites for the National Children's Study.

The National Children's Study is designed to enroll and follow 100,000 children from birth to age 21 to help researchers obtain a better understanding of "how children's genes and environments interact to affect their health and development." Six vanguard sites were announced at the press conference but, when fully implemented, the plan calls for

data gathering and analysis at 105 sites across the country.

In her remarks before a large audience, Dr. Green said, "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 National Children's Study will generate information that will help reduce the incidence of serious birth defects."

Other speakers at the news conference included U.S. Surgeon General Dr. Richard H. Carmona, Dr. Dixie Snider, Chief Science Officer of the Centers for Disease Control, Dr. Duane Alexander, Director of NICHD, and Dr. William H. Farland, Chief Science Officer

of the Environmental Protection Agency.

More information about this important study is available on the internet at: <http://nationalchildrensstudy.gov/>



Dr. Nancy Green Speaking as U.S. Surgeon General Dr. Richard Carmona listens

New Hampshire Newborn Screening Bill Signed into Law

On July 28th, New Hampshire Governor John Lynch signed into law a bill calling for a number of steps to improve the state's newborn screening program. A newborn screening advisory committee will be created to help guide the department of health and human services in its deliberations over the addition of new screening tests. The bill also authorizes a fee increase for services provided through the program, with all revenue collected earmarked for the just established newborn screening fund. Currently New Hampshire offers screening for only six of the 29 conditions recommended by the March of Dimes. Chapter volunteers led

this advocacy effort through testimony and the use of key contacts to target communication with legislators and the Lynch administration.

The bill was sponsored by Senator Andre A. Martel (R) and Representatives James P. Pilloid (R), Mary Stuart Gile (D), and Maurice L. Pilotte (D).

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As a result of the meeting, the March of Dimes has begun a grassroots campaign through which volunteers and staff are being asked to contact members of congress to urge immediate action on the bill. By participating in this campaign you will help enact this important piece of legislation.

Background information for those wishing to participate in this important campaign can be found on the March of Dimes web site. The link http://www.marchofdimes.com/aboutus/855_17469.asp brings up a web page with a sample letter and instructions on contacting Members of the U.S. Senate and House of Representatives.

2005 databook for Policymakers Now Available

The March of Dimes Data Book for Policy Makers, 2005 will be released the first week of December. This Data Book replaces the 2003 edition, and provides ready-to-use talking points, charts and tables with national and state data. Topics covered include infant mortality, preterm and low birthweight births, incidence of birth defects, timing and adequacy of prenatal care, and insurance coverage. The Data Book promotes PeriStats as a complementary online resource, using the PeriStats logo to highlight where more detailed or more recent national, state and county data might be available through the web site.

According to reports from volunteers and staff in every region, the Data Book has proven useful to chapter advocacy efforts,

both in preparing testimony and other written materials, and in meetings with public officials, who are not always aware that the March of Dimes is an excellent source of maternal and child health data.

This edition provides additional information about state Medicaid programs, including enrollment and expenditures for women of childbearing age, smoking cessation policies, and enrollment processes.

As a service to Chapters, the Office of Government Affairs will send copies of the Data Book directly to members of the U.S. Congress, Governors, Health Commissioners, and State Legislators on health care and budget committees when post-election

mailing lists are available.

Copies are free to Chapters through the MOD Fulfillment Center, which is ready to accept orders (item number 50-1898-05). The book is available to the public for \$12 a copy and can be obtained by contacting the fulfillment center at (800) 367-6630.



New Survey Shows Importance of EPSDT to Infants and Children Enrolled in Medicaid

A new public policy research resource is available to help describe the importance of the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit for children enrolled in their state Medicaid plan.

The report provides an analysis of how Medicaid coverage available to children in each state would change if the EPSDT benefit requirement was eliminated and states applied the coverage policies in effect for adults. Findings show that absent EPSDT, all infants and children with disabling or chronic health conditions could face exclusions or restrictions in coverage for specialized

services, with especially severe limitations in some states.

The report examines 12 benefits of particular importance to infants and children with significant health needs, including birth defects and long term problems associated with preterm birth.

The report focuses on the following benefits: physician services, inpatient and outpatient hospital services; prescription drugs; physical, occupational, and speech therapy; home health services, and durable medical equipment and supplies. A detailed state by state table and summary memorandum are also included.

Prepared by Harriette Fox and Peggy McManus of the Maternal and Child Health Policy Research Center, the report can be found in the advocacy section of the March of Dimes website.

Advocacy Update Moving to Web Based Distribution

OGA mails about 700 copies of each issue of Advocacy Update at 37 cents per issue, or over \$1000 a year plus printing costs. We believe that these funds could be better spent in other mission related ways, therefore beginning in 2006, we plan to distribute the Advocacy Update primarily through the internet. Every issue will be placed on the March of Dimes web page where you will be able to view the text and print out a hard copy. In addition, you can sign up to be notified by email when new issues are posted. To be added to the e-mail list or if you cannot access the web and require a paper copy of Advocacy Update please

contact the Office of Government Affairs (OGA) via telephone or letter. Information on contacting OGA is on the right side of this page.

The *Advocacy Update* delivers legislative news about March of Dimes issues on a quarterly basis.

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