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ing programs through implementation of Title 26 of the “Children’s Health Act of 2000.” Among other things, Title 26 authorizes state use of federal funds to acquire innovative testing technologies.

Answer to May Data Book Question

Hospital charges are far higher for the sickest babies: \$274,000, on average, for the most severely ill, very low birthweight newborns in children’s hospitals in 2001 (the most recent information available).

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

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Medicaid Reform Update

Medicaid reform has been the subject of intense negotiations among governors in the last several months and the push for change is now moving to Capitol Hill. A bipartisan task force of ten governors (5 Democrats, 5 Republicans) in the National Governors Association (NGA) concluded their work on June 10 without reaching consensus.

In a letter to Department of Health and Human Services Secretary Thompson, the five Republican governors outlined a list of principles they believe the Secretary should consider during reform discussions. These principles include granting states more flexibility on the populations and benefits Medicaid

programs cover if states agree to cap federal financing for optional beneficiaries and services. The statement from Democratic governors on the task force also called for more state flexibility and for the Administration and Congress to federalize the full cost of care for elderly and disabled populations that are eligible for both Medicare and Medicaid—a policy change that would reduce state Medicaid spending by one-third.

Fourteen March of Dimes Chapters with governors on the NGA task force and the NGA Executive Committee sent letters to their governors in mid-May to express concerns about placing limits on federal contributions to Medicaid, a program that provides health insurance to nearly

40% of pregnant women and 23 million children.

Despite the inability of the NGA task force to reach agreement, Congress may still pursue Medicaid reform. The House Energy and Commerce Committee has appointed its own Medicaid reform task force, chaired by Rep. Heather Wilson (R-NM), and hearings are underway. The other members of the task force are Reps. Nathan Deal (R-GA), Ed Whitfield (R-KY), Mary Bono (R-CA), and Ernie Fletcher (R-KY). The New Mexico March of Dimes Chapter sent a letter to Rep. Wilson stressing the importance of Medicaid to women, infants and children. The U.S. Senate has not yet scheduled action on Medicaid reform.



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Newborn Screening Bill Introduced

On May 15, Senators Christopher Dodd (D-CT) and Mike DeWine (R-OH) reintroduced the “Newborn Screening Saves Lives Act,” (S. 1068). This bill authorizes grant programs to provide for education and outreach related to newborn screening and for coordinated follow-up care once a newborn has been identified as being in need of treatment.

In the words of the bill sponsors, “The Newborn Screening Saves Lives Act of 2003 seeks to address the shocking lack of information available to health care professionals and parents about newborn screening. Every parent should have the knowledge necessary to protect their child. The tragedy of a newborn’s death is only

compounded by the frustration of learning that the death was preventable.” — Senator Christopher Dodd (D-CT)

“The grant program established by our bill seeks to help states maintain and expand their newborn screening programs. Our legislation would be a good start toward ensuring that all newborns receive equal access to genetic tests and that their follow-up care, if needed, is available and coordinated. The importance of these screenings cannot be overstated. It can mean the difference between life and death for a newborn. And that, Mr. President, is something we must address.” — Senator Mike DeWine (R-OH)

The March of Dimes advocacy agenda seeks to eliminate disparities among states in newborn screening.

In a press statement released in conjunction with the introduction of S. 1068, Dr. Jennifer L. Howse, president of the March of Dimes, said “Parents are often unaware that, while nearly all babies born in the United States undergo newborn screening tests for genetic birth defects, the number and quality of these tests vary from state to state. The grants that will be made available through this bill will help educate parents about newborn screening.”

As part of its 2003 federal advocacy agenda, the March of Dimes is promoting congressional approval of S.1068 as well as a \$25 million appropriation to help strengthen state newborn screen-

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Vermont Establishes a Birth Defects Surveillance System

On May 21, Vermont Governor James Douglas (R) signed into law Act 32 authorizing the establishment of the Birth Information Network (BIN), the state’s first birth defects surveillance system. The purpose of the BIN is to identify newborns that have special medical needs which may respond to early intervention and treatment and to promote best practices to prevent adverse health outcomes in newborns. The state department of health has applied for start-up funding from the Centers for Disease Control and Prevention.

This two-year initiative, led by the March of Dimes Vermont Chapter, began in 2001 with a coalition of advocates committed to the establishment of a birth defects surveillance

system. The advocacy effort resulted in the 2001 enactment of a bill creating a task force to formally study the issue and make recommendations to the Vermont Legislature. March of Dimes Vermont Chapter State Director Sherry Wormser co-chaired the task force and was instrumental in transforming the task force recommendations into Senate Bill 139, introduced in March 2003. The Chapter worked closely with the Vermont Department of Health and the Regional Genetics Center as the bill moved through the legislative process. March of Dimes volunteers will continue to serve a critical role as members of the advisory committee responsible for overseeing implementation of the system.

From the March of Dimes Data Book for Policy Makers...

Newborn screening practices vary among the states. Which are the only two disorders for which newborns in all states are tested?

This fact-and more-is found in the 2003 Data Book.

Health Insurance Resource Guide

Karen Pollitz and Kevin Lucia of the Georgetown University Institute for Health Care Research and Policy prepared a *Health Insurance Resource Guide* for use by Chapters. The *Guide* is posted on *dimension*, the March of Dimes intranet system. The *Guide* provides March of Dimes staff an easy-to-use resource on health insurance public policy issues including: an introduction to the various types of health insurance coverage, regulation by the federal government and the states, and information developed specifically for the March of Dimes on state ma-

ternity and newborn coverage requirements for health insurance plans.

The *Guide* was developed as a public policy research project to provide Chapters a resource document useful in preparing March of Dimes State Public Affairs Plans and for researching issues involving state health insurance legislation and regulation. The format of the *Resource Guide* allows users to quickly find material by clicking on the relevant Table of Contents entry. Individual sections of the *Guide* can be printed and provided to staff and volunteers as needed.



March of Dimes President Dr. Jennifer L. Howse delivers remarks at the annual U.S. Coalition for the Eradication of Polio Capitol Hill Reception. The reception honored the 2003 Congressional Champions of Polio – Reps. Donna Christensen (D-VI), Donald Payne (D-NJ) and Joe Wilson (R-SC).

Georgia Chapter Works to Increase Tobacco Tax in State

On June 4, Georgia Governor Sonny Perdue (R) signed into law a bill that will increase the state’s tax on cigarettes from 12 cents to 37 cents per pack. The tax on cigars will also increase and a tax will be imposed on smokless tobacco for the first time. This is the first tobacco tax increase in 31 years. The change in law becomes effective July 1, 2003, the beginning of Georgia’s fiscal year.

March of Dimes volunteers and staff worked with other members of the Tobacco Prevention Alliance to draft bill language, a March of Dimes volunteer testified before the House Ways and Means Com-

mittee, and Chapter volunteers and staff participated in weekly meetings with the Governor’s staff to rally support for the bill.

Other members of the Tobacco Prevention Alliance include the American Cancer Society, the American Heart Association, the American Lung Association, Georgia Alliance for Community Hospitals, Georgia Hospital Association, and Emory Healthcare System.

Georgia’s constitution mandates that all state revenue go into the general fund. Therefore, the Chapter will now turn its attention to securing an appropriation for state health care and smok-

ing cessation programs.



The Office of Government Affairs (OGA) is proud to announce the birth of Joseph Foley Manero to Christina and Joe Manero. As many of you know, Christina is Public Affairs Communications Manager for OGA. Joseph was born on May 28, 2003, at 8:12 a.m. EDT. He weighed 7 lbs.-11 oz. and was 19 inches long.