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Advocacy Update

Editor: Joseph Luchok

Direct Questions or

PUBLIC POLICY ADVISORY COUNCIL MEETS

The March of Dimes Public Policy Advisory Council, which provides guidance on the Foundation's public policy research and advocacy activities, met on May 12th, 2006, in Washington, D.C. The Council is co-chaired by Dr. Bruce Vladeck, March of Dimes Trustee and member of the National Public Affairs Committee, and Janet Shikles, Health Policy Consultant. The Council includes individuals with public policy expertise who offer a variety of perspectives, including public policy research, health care delivery, and advocacy. Several Council members have held elective office or served as presidential or gubernatorial appointees.

Guest speaker Lisa Simpson, MD, BCh, MPH, FAAP, who is the All Children's Hospital Guild Endowed Chair in Child Health Policy at the University of South Florida, and the National Director for Child Health Policy for the National Initiative for Children's Healthcare Quality, provided an overview on quality and performance measures for perinatal care.

Dr. Simpson suggested that the March of Dimes continue to support national action on health information technology, demonstration programs and other specific initiatives on quality improvement, and continue to work with the U.S. Centers for Medicare and Medicaid Services on developing perinatal quality of care tools for use by state Medicaid programs.

The Council discussed the need to encourage greater public and private sector support for improvements in the quality of pediatric care, by demonstrating the long-run economic and social benefits of keeping pregnant women, infants, and children healthy.

The Council noted that the lack of written federal guidance to the states on implementing the new Medicaid benefit flexibility requires vigilance in monitoring state activities. The March of Dimes was encouraged to continue its constructive participation in state Medicaid reform.

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REPRESENTATIVE LUCILLE ROYBAL-ALLARD INTRODUCES NEWBORN SCREENING BILL

On May 16, 2006, Representative Lucille Roybal-Allard (D-CA) and Representative Mike Simpson (R-ID) introduced the “Newborn Screening Saves Lives Act” (H.R. 5397) which, if enacted into law, would create a federal grant program to support educating health professionals and the public about the technology and benefits of newborn screening. The March of Dimes worked closely with Representatives Roybal-Allard and Simpson and Senate sponsors Christopher Dodd (D-CT) and Mike DeWine (R-OH) to craft the initiative. A more detailed description of the bill can be found in the May issue of Advocacy Update at http://www.marchofdimes.com/files/Advocacy_Update_May.pdf

“PREEMIE” BILL GRASSROOTS CAMPAIGN UPDATE

Since the grassroots campaign began in October, 2005, an additional 36 Senators and 60 Representatives have signed on as cosponsors of the “PREEMIE” bill, bringing the total number of bill sponsors to 39 in the Senate and 71 in the House.

Chapters have been very effective in generating congressional support for the “PREEMIE” bill. Twelve Members of Congress participated in WalkAmerica activities and over 47,000 postcards were signed by walkers from nearly every state, which will be delivered to Congressional Offices. Op-eds and letters to the editor calling for enactment of the “PREEMIE” bill have appeared in more than 20 newspapers. The grassroots campaign has generated strong support for the bill, but continuing effort is needed from volunteers and staff to ensure it is enacted into law.



Left to right: Morgan Walthall, State Director of Public Affairs, Representative Michael McCaul (R-TX), and Paula Ransom, State Director at WalkAmerica, Austin, Texas.

Jo Merrill Retiring After 22 Years With The March of Dimes

Jo Merrill, Director of Public Policy and Government Affairs, has announced her retirement effective the end of June, 2006, after 22 years with the March of Dimes National Office of Government Affairs. Jo joined the March of Dimes in 1984 after 10 years working for several members of Congress. At the beginning of her affiliation with the March of Dimes she focused on state based advocacy, working closely with the Chapters and Regional offices. In 1996 she moved to her current position where she oversees a staff of two who lobby federal agencies and Congress on behalf of the Foundation.

Jo has been a key staff member in gaining enactment of a number of bills important to the March of Dimes. Among the measures on which Jo has worked are creation of the State Children's Health Insurance Program (SCHIP); approval of the Birth Defects Prevention Act of 1998, which authorized a comprehensive birth defects surveillance, research and prevention program at the Centers for Disease Control (CDC); development and implementation of the Children's Health Act of 2000, which established the National Center on Birth Defects and Developmental Disabilities at CDC, expanded the National Folic Acid Education Campaign, and authorized a Federal newborn screening program; and reauthorization of the National Center on Birth Defects and Developmental Disabilities in 2003.

Jo's colleagues at OGA and the many March of Dimes volunteers and staff with whom she has collaborated wish her well and look forward to working with her in her new capacity as a Public Affairs volunteer when she and her husband David get settled in their new home.

Emil Wigode Promoted To Director, Federal Affairs

Emil Wigode has been promoted from Deputy Director to Director of Federal Affairs, for the March of Dimes. In this position, he will lead the federal lobbying team responsible for promoting the Foundation's federal policy agenda with both executive branch agencies and in Congress.

Emil joined the March of Dimes Office of Government Affairs staff in March of 2000 after several years as assistant manager of Legislative and Regulatory Affairs for the Flexible Packaging Association. Emil also worked as an analyst for LEGI-SLATE, Inc, a subsidiary of the Washington Post Company, and as a government affairs assistant for the American Psychiatric Association. He began his career in Washington as an aide to Senator Robert Smith of New Hampshire.

Emil has an undergraduate degree from George Mason University in International Studies and has done graduate work in legislative affairs at the George Washington University Graduate School of Political Management.

REGION REPORTS

NORTH

Minnesota Chapter Advocacy Protects Newborn Screening and Immunizations

All Minnesota infants will continue to receive comprehensive newborn screening thanks to March of Dimes advocacy that defeated a proposal to replace automatic screening of infants with a system requiring parents to request screening for their babies. Minnesota requires that every newborn be screened for 52 disorders including all 28 metabolic conditions recommended by the American College of Medical Genetics and the March of Dimes.

The Minnesota Chapter also worked successfully to defeat a bill that would have narrowed the number of vaccines available to Minnesota residents by banning the use of vaccines containing even a trace of Thimerosal. Public Affairs volunteers worked closely with members of the House and Senate Health Committees to protect access to immunizations for all Minnesotans.

New York NICU Family Support Project Launched

The New York Chapter's Neonatal Intensive Care Unit (NICU) Family Support Project launch at Stony Brook University Hospital attracted elected officials as well as key volunteers. This project offers comfort and support to families of premature and other critically ill infants in the NICU. It is one of 28 operated by the March of Dimes across the country, only the second in New York State, and is supported by the Foundation in partnership with the Bank of America.



(left to right) State Senator John J. Flanagan (R-Suffolk Co); March of Dimes President Dr. Jennifer L. Howse; Long Island Division Board Chair Jeffrey Ravetz; Long Island Division Executive Director Annette Kosar; and Suffolk County Legislator Vivian Viloría-Fisher. Senator Flanagan and Legislator Viloría-Fisher helped the Chapter secure multi-year funding for the Stony Brook project through a combination of county and state resources.

SOUTH

National Capital Area Chapter Visits Capitol Hill

On May 10th, 2006, March of Dimes volunteers and staff representing the National Capital Area Chapter traveled to Capitol Hill to visit members of the Virginia Congressional Delegation. Participants lobbied for passage of the “PREEMIE” bill in visits to Senators John Warner (R-VA) and George Allen (R-VA) and Representatives Tom Davis (R-VA) and Frank Wolf (R-VA). As a result of their efforts Representative Davis signed on as a cosponsor the “PREEMIE” bill and other members are reviewing the information left behind by the group.



Pictured in the front row from right to left are: Shannon Gilbert, Executive Director of the National Capital Area Chapter; Dona Dei, Lead Public Affairs Staff; and volunteer Malou Gemeniano-Salud, holding preemie Matthew Salud. Back row from right to left: Rob Davis, District of Columbia Division Director; and volunteers Nicole Vagnerini, Greg Discenza with daughter Becky on his shoulders, Deb Discenza (Editor in Chief, *Preemie Magazine*) Susan Boucher with preemie twins, John and Eleanor Ferry, and Brooke Fowler with preemie Evan.

WEST

Alaska Newborns Now Screened for Hearing Impairment

On May 25th, 2006, Governor Frank H. Murkowski signed legislation requiring all newborns in the state to be screened for hearing impairment.

March of Dimes National Ambassador Participates in Oklahoma Lobby Day

The March of Dimes National Ambassador Family visited the Oklahoma Chapter on April 20 to participate in a wide variety of activities and events, including the Chapter's Lobby Day at the Capitol. The Ostolaza Family participated in a prematurity awareness proclamation signing with Governor Brad Henry, was introduced on the House and Senate Floors, and spoke at the March of Dimes-sponsored Women's Legislative Caucus Luncheon. The Chapter advocated for Medicaid funding to cover additional services for women with high-risk pregnancies, as well as passage of legislation establishing a March of Dimes specialty license plate with proceeds from sales benefiting the Foundation.



Alexa Ostolaza and Governor Brad Henry talk for a few minutes while he signs a special prematurity awareness proclamation for March of Dimes and the family.



Representative Gus Blackwell and Ostolaza family take a moment after having made remarks on the House Floor.

Minors in Colorado Allowed to Access Prenatal Care

On April 22 legislation that allows minors to access prenatal care without

parental consent became law in Colorado. March of Dimes volunteers and staff had advocated for passage of the bill, submitted testimony, activated the Chapter's Advocacy Network, and discussed the issue with Members during Lobby Day.

California Lobby Day Focuses on Newborn Screening and Children's Health Coverage

Ninety-two volunteers and staff from the California Chapter participated in Lobby Day on May 10 visiting all 120 legislators' offices. The Chapter advocated for passage of legislation to require all newborns be screened for hearing impairment, funding to implement newborn screening for Biotinidase Deficiency and Cystic Fibrosis, and legislation to allow for 12 months continuous eligibility for children enrolled in various health programs who sign-up via the state's Gateway program. The Gateway program links children to enrollment in state health services at hospitals and doctor offices. Parents can now apply for these services through a computer in any doctor office or hospital. Speakers during the training portion of the day included Assembly Member Dave Jones, sponsor of the newborn hearing screening legislation, Jim Brune, Interim CEO of the Deaf Counseling, Advocacy, and Resource Agency, Dr. Richard Powers, Medical Director of the NICU at Good Samaritan Hospital, and Licia King, mother of twins who screened positive for hearing loss at birth and received cochlear implants.



Left to right: Dani Montague, State Director, Assembly Member Dave Jones (receiving March of Dimes award for "2006 Legislative Champion"), and Gail Margolis, State Public Affairs Committee Chair