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Direct Questions or
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March of Dimes
Foundation

DR. EDWIN TREVATHAN SELECTED AS NEW DIRECTOR OF NCBDDD

Edwin Trevathan, M.D., M.P.H. has been selected as new director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention. Dr. Trevathan is expected to begin this assignment on July 23, 2007. He is currently a professor of neurology and pediatrics and director of the Division of Pediatric and Developmental Neurology at the St. Louis School of Medicine of Washington University. Dr. Trevathan is also the Neurologist-in-Chief at St. Louis Children's Hospital. Dr. Trevathan has worked at Boston Children's Hospital and served as an Epidemic Intelligence Service (EIS) Officer in birth defects and developmental disabilities at CDC. Dr. Trevathan received his M.D. and M.P.H. at Emory University.

In 2000, the March of Dimes led the advocacy effort that resulted in the creation of the Center, and the Foundation's President, Dr. Jennifer L. Howse, served on the committee that developed the short list of candidates from which Dr. Trevathan was selected to be its second Director.

UPDATES ON ISSUES OF INTEREST

The U.S. Congress has begun the appropriations process for fiscal year 2008. During the coming weeks, the House and Senate Labor, Health and Human Services and Education (LHHS) Appropriations Subcommittees will draft and consider a bill that includes funding for the National Institutes of Health, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the Agency for Healthcare Research and Quality and scores of other federal agencies. Throughout the appropriations process, the Foundation will be advocating to increase funding for several high priority projects and programs, including: the National Children's Study; newborn screening; and birth defects. In addition, the March of Dimes is seeking support for provisions of the PREEMIE Act approved by Congress and signed by the President late last year. (See story below).

Members of Congress Request Funding for Implementation of the Preemie Act

In December of 2006, the President signed the PREEMIE Act into law (PL109-450). Enactment of this measure was a victory for the March of Dimes and sets the stage for a significant step forward in expanding federally supported

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prematurity related research and education. However, the PREEMIE Act was an authorizing bill and funding must be obtained separately to implement many of its provisions. The March of Dimes is working closely with Senators Christopher Dodd (D-CT) and Lamar Alexander (R-TN), Senate sponsors of the PREEMIE Act, to obtain the necessary appropriations. As part of that strategy, a letter signed by 25 Senators has been sent to members of the Appropriations Subcommittee with jurisdiction over health programs. In the House of Representatives, Representatives Anna Eshoo (D-CA) and Fred Upton (R-MI), House sponsors of the PREEMIE Act, have also contacted members of the Appropriations Subcommittee with a separate request for funding.

The strong bipartisan support for the PREEMIE Act demonstrated in both chambers of Congress is important to obtaining the necessary funding. Volunteers and staff in Chapters worked collaboratively with the Office of Government Affairs to secure the support of key Senators.

National Children's Study

The study is being funded by several federal agencies, and will be conducted under the direction of the National Institutes of Health. On the NIH website, the National Children's Study is described as "one of the richest information resources available for answering questions related to children's health and development and will form the basis of child health guidance, interventions, and policy for generations to come." The longitudinal study is designed to follow a representative sample of 100,000 children from the time their mother's become pregnant until they reach age 21. The study will focus on the impacts of a broad range of environmental influences (physical, chemical, biological and social) with the intent of identifying root causes of many childhood conditions and diseases, including preterm birth, asthma, obesity, heart disease, injury, and diabetes.

Together with the American Academy of Pediatrics, the March of Dimes initiated a letter to the Chairmen and Ranking Members of the House and Senate Appropriations Subcommittees recommending that \$110.9 million be allocated to the NCS for fiscal year 2008. The letter was co-signed by more than 50 organizations representing a broad spectrum of interests in children's health.

Newborn Screening

The March of Dimes is working with Senators Christopher Dodd (D-CT) and Orrin Hatch (R-UT) to obtain \$3 million in new federal funding for support of state newborn screening programs and activities. If approved, the additional funding could be used by states to purchase new technologies, provide education and materials to health professionals, and support follow-up treatment. Fourteen Senators co-signed a letter which has been sent to Chairman Harkin (D-IA) and Ranking Member Specter (R-PA) of the Senate LHHS Appropriations Subcommittee.

REGION REPORTS

NORTH

On April 12, Dr. Chris Hayes, Ohio Chapter Family Teams Chair, testified before the House Finance Health and Human Services (HHS) Subcommittee. Dr. Hayes's comments addressed two March of Dimes advocacy priorities: expansion of Medicaid eligibility for pregnant women to 200% of the Federal Poverty Level (\$41,300 for a family of 4 in 2007) and funding for the "Connection for Children with Special Needs" birth defects surveillance system.

Over 250 people heard Dr. Hayes share his personal story about the loss of his 16-month old son Ben to complications of premature birth in 2003. In Ben's memory, the Hayes family created Ben's Team, one of top 25 March of Dimes Family Teams in the country in 2006, which raised over \$15,000 in WalkAmerica. Immediately following the hearing, Dr. Hayes invited the Committee Chairman, Jimmy Stewart of Athens, Ohio, to join Ben's Team in the Athens County WalkAmerica.



Dr. Chris Hayes, Ohio March of Dimes Board Member and State Family Teams Chair.

Iowa Lobby Day

More than 70 volunteers and staff participated in the Iowa Chapter's annual March of Dimes Day at the Capitol. House Speaker Pat Murphy (D-Dubuque) addressed the group and voiced support for the Foundation's efforts. Following Speaker Murphy's remarks, Chapter volunteers and staff met with other elected officials to advocate for two issues: a tobacco tax increase of one dollar to support smoking cessation programs and an insurance mandate to cover treatment of Phenylketonuria (PKU) and other metabolic disorders identified through newborn screening.



Iowa House Speaker Pat Murphy spoke with March of Dimes advocates at the Chapter's annual lobby day.

SOUTH

West Virginia Governor Joe Manchin recently signed a bill to expand and fund the state's newborn screening program to include all 29 "core" conditions recommended by the American College of Medical Genetics and endorsed by the March of Dimes. The Chapter led a comprehensive advocacy campaign to secure the expansion of this vital public health program which will provide screening for an estimated 21,000 infants each year. \$460,000 in start-up funding was appropriated and implementation will take place in two phases, with required testing for all of the core conditions to occur no later than July 1, 2008.

The Tennessee Chapter recently held its lobby day in Nashville where Chapter representatives urged legislators to add screening for hearing deficiencies and cystic fibrosis to the state's newborn screening panel. Additionally, participants asked legislators to support a state-wide smoking ban and an increase in the cigarette tax. Advocates also heard from several members of Governor Phil Bredesen's administration regarding maternal and child health policy. Speakers included the Director of the Office of Coordinated Children's Care, the Commissioner of Health, the Assistant Director of TN CoverKids, the Director of the Bureau of TennCare, and the Senior Advisor to the Governor for Policy and Legislation.



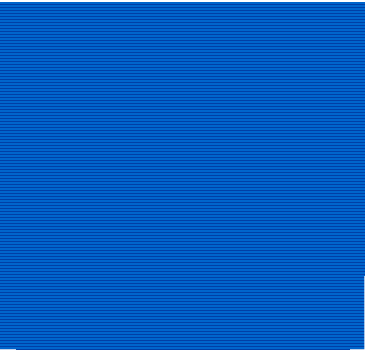
During the Tennessee Chapter's Lobby Day activities, youth volunteer Alexandra Wallace discusses public affairs priorities with State Representative Richard Floyd. Apple pie slices distributed to legislators and passersby can be seen behind Alexandra.

WEST

The Idaho Legislature has overturned Governor C.L. "Butch" Otter's veto of a bill, allowing the measure to become law. The bill removes bowling alleys from the list of sites exempt from compliance with the Clean Indoor Air Act, meaning that smoking will no longer be permitted in bowling alleys. The March of Dimes Chapter has been involved with this issue for many years and advocated successfully for the underlying ban and to overturn the Governor's veto.

Utah's budget bill for the coming year was recently signed into law by Governor John Huntsman, Jr. Included in the budget is \$360,000 in recurring funds and an additional \$173,000 in onetime funding for the state's Birth Defects Network (UBDN). The March of Dimes worked for more than two years to achieve this important victory, which it secured by activating 'key contacts' and its advocacy network, meeting with representatives of the Governor's office, collaborating with health department officials, engaging the support of appropriations committee members, testifying at numerous hearings, and holding a legislative event.

In Washington state, Governor Christine Gregoire recently signed into law a bill increasing access to health coverage for infants and children. The legislation combines funding from the state's Children's Health Insurance Program (CHIP), Medicaid, and Children's Health Plan and provides coverage for all children with family incomes below 250% of the Federal Poverty Level (FPL) (\$51,625 for a family of 4 in 2007). In addition, the bill establishes a new cost-sharing program



that provides access to subsidized coverage for children with family incomes between 250-300 percent of FPL (up to \$61,950 for a family of 4 in 2007). The bill was a priority for the Chapter at its lobby day this year.