

March of Dimes

June 2002

Advocacy Update *from the Office of Government Affairs*



Senate Holds Hearing on Newborn Screening

On June 14, the Senate Health, Education, Labor and Pensions Committee, Subcommittee on Children and Families held a hearing on newborn screening. At the hearing, subcommittee members inquired about new legislative authority that may be needed to improve awareness of the need for newborn screening. In particular, subcommittee chairman Senator Christopher Dodd (D-Conn.) asked about expanding state programs and improving information sharing among state programs.

Jill Wood, March of Dimes volunteer with the National Capital Area



Chapter, testified before the subcommittee (see photos below). Mrs. Wood shared with the subcommittee the tragic story of her daughter, Hayley, and the importance of newborn screening. Hayley died unexpectedly in her sleep on her first night home, three days after a healthy hospital delivery. After many tests, most at the Woods' expense, it was revealed that Hayley died of a metabolic birth defect, CPT-II.

The Woods learned that in their home state of Virginia newborns were tested for only 8 diseases. They began working with the March of Dimes to expand Virginia's newborn screening program. (Jill Wood's testimony can be

found on March of Dimes website at www.marchofdimes.com)

The March of Dimes submitted a formal statement to the Subcommittee expressing the Foundation's concern over the disparities among state programs and the March of Dimes recommendation that all babies receive the same core set of tests. While this committee is not responsible for appropriating funds, the March of Dimes statement noted the Foundation's recommendation to Congress that \$25 million be appro



Continued on page 2



Inside

- Petition Supporting Proposed Charitable Contribution Tax Incentive (page 2)
- Foundation Comments on Proposed Federal Regulation (page 2)
- Vermont Takes First Step in Expanding BDS Program (page 2)
- News You Can Use (page 3)
- First Step Achieved in Expanding Florida's Newborn Screening Prog. (page 3)
- Zerhouni Confirmed as Director of NIH (page 3)
- You Can Help the Foundation Save on Mailing (page 4)

Petition Supporting Proposed Charitable Contribution Tax Incentives

At selected WalkAmerica sites throughout the country, March of Dimes volunteers collected signatures to urge the Senate Finance Committee to approve tax incentives for charitable contributions. Due to the hard work of participating chapters, more than 5,100 signatures were collected.

Following the receipt of the petitions, the Senate Finance Committee reported out the following incentives strongly supported by the March of Dimes:

- A deduction for tax payers who file the short form of up to \$250 for single filers (\$500 for joint) for charitable contributions; and
- A provision allowing individuals age 59 1/2 to rollover

their IRA to create a life income gift. At age 70 1/2, donors can give their IRA directly to charities without incurring income tax on the gift.

The cover letter that accompanied the petitions delivered to members of the Senate Finance Committee said “these provisions would benefit the March of Dimes and other charities that rely on small donations, by creating incentives for current donors and encouraging others to become donors.”

This bill is awaiting vote by the full Senate. If it passes the Senate, it will then go to conference where final provisions will be negotiated with the House version of the bill passed July 19, 2001.

Continued from page 1

priated for 2003 to implement the newborn screening program authorized in Title XXVI of the “Children’s Health Act of 2000.” In addition to the testimony, the March of Dimes issued a press release commending Senators Christopher Dodd (D-Conn.) and Mike DeWine (R-Ohio) for their leadership in raising the visibility of this important issue. (March of Dimes testimony and press release can be found in the public affairs section of the Foundation’s website at www.marchofdimes.com)

The March of Dimes is working in Washington to increase federal support for newborn screening. In addition to the testimony at the above mentioned Senate hearing, the Foundation has testified before the House Appro

Continued on page 3

Foundation Comments on Proposed Federal Regulation

In a January 31 announcement, Health and Human Services Secretary Tommy Thompson stated his intent to use administrative authority to revise the definition of child under SCHIP.

The March of Dimes submitted formal comments on the proposal that emphasizes the importance of health services related to the needs of pregnant women. The comments can be found in the public affairs section of the Foundation’s website at www.marchofdimes.com.

Vermont Takes First Step in Expanding BDS Program

On May 2, Gov. Howard Dean (D) signed into law HB 636, a bill that establishes a birth information council to advise the General Assembly on issues relating to birth defects surveillance (BDS) in Vermont.

After an unsuccessful attempt to expand the state’s BDS program through non-legislative means, the Chapter met with state elected officials in December to plan a legislative strategy. The Chapter’s well timed early January lobby day provided an opportunity for the newly formed Public Affairs Committee and staff to meet with legislators to promote the issue. In February, following lobby day, State Rep. Tom Koch (R), the chair of the state House Health and Welfare Com-

mittee introduced a bill.

The Chapter continued to advocate for the approval of this legislation by testifying before the state Health and Welfare Committee and negotiating on changes needed to obtain the required number of votes. A special feature of the final bill is that it calls for council members to be appointed by the state health commissioner in consultation with the March of Dimes.

The council is charged with the task of reviewing the need for a comprehensive, integrated and confidential birth information system to collect data on infants and children up to six years of age.

Using PeriStats to Strengthen Advocacy Activities

The PeriStats interactive data website is a key resource for March of Dimes public affairs activities. Since its unveiling in the fall, program volunteers and staff have become familiar with using this site to obtain the data needed to support March of Dimes initiatives. PeriStats is an interactive website which provides free, easy to access national, state and county-specific data, including customized graphs and tables on a wide range of perinatal outcomes: preterm births, prenatal care, infant mortality, health insurance coverage and much more.

How does PeriStats support advocacy activities?

- Data strengthens our arguments.

Compare the following two statements: “Too many babies in our

state are born premature.” versus “Too many babies in our state are born premature. Almost 13% of all births —nearly 9,200 babies in 2000 —were born preterm, a rate higher than 42 other states.” Clearly, the data helps make a more persuasive case.

- Providing up to date information to decision-makers reinforces March of Dimes relationships and credibility with policy makers.

If you have examples about how your chapter used PeriStats to support your advocacy efforts, please share them with your Regional Director of Public Affairs and the Office of Government Affairs. PeriStats is available at www.marchofdimes.com/peristats.

Zerhouni Confirmed as Director of NIH

On May 2, 2002, the Senate approved the nomination of Elias Zerhouni, MD to be director of the National Institutes of Health (NIH). When he was announced as President Bush’s nominee, Dr. Zerhouni was the Executive Vice Dean of The Johns Hopkins University School of Medicine, Chairman of the Russell H. Morgan Department of Radiology and Radiological Science at Johns Hopkins and Professor of Radiology and Biomedical Engineering. He has also served as Vice Dean for Research at The Johns Hopkins University School of Medicine. Dr. Zerhouni’s appointment ends a two-year leadership vacancy at NIH.

First Step Achieved in Expanding Florida’s Newborn Screening Program

In Florida, the Chapter’s 2002 advocacy priorities include establishing a task force to determine how the state should expand its newborn screening program. Florida currently screens for five metabolic disorders plus hearing.

The Florida Public Affairs Committee (PAC) worked with State Representative Eleanor Sobel and State Senator Debbie Wasserman-Schultz to develop legislation to establish a newborn screening task force to study the issue and develop recommendations. The task force members include a March of Dimes representative. Volunteers and staff built support for the legislation through the use of their

chapter advocacy network. The Florida PAC chair and co-chair testified before the relevant committees in the House and Senate.

The bill passed the state legislature in mid-March and Gov. Jeb Bush (R) signed it into law on April 22.

The Infant Screening Task Force held its first meeting on May 13. The task force is to submit a final report of its review and recommended plan by the fall of 2002.

Continued from page 2

priations Subcommittee on Labor, Health and Human Services, and Education and has submitted written testimony to the Senate Appropriations Subcommittee urging Members to fund Title XXVI of the “Children’s Health Act of 2000” at \$25 million in 2003. If approved, funding would be directed to support work with states to implement the heritable disorders (newborn screening) program authorized in Title XXVI. This program is designed to strengthen states’ newborn screening programs; to improve states’ ability to develop, evaluate, and acquire innovative testing technologies; and to establish and improve programs to provide screening, counseling, testing and special services for newborns and children at risk for heritable disorders.

You Can Help the Foundation Save on Mailing: Receive the Electronic Version of the *Advocacy Update*

Whether we volunteer in public affairs or through service on a chapter board, we all work in our own ways to help the Foundation fulfill its mission which includes raising needed funds. You can help in a new way by agreeing to receive the *Advocacy Update* via email or accessing it through the March of Dimes website at www.marchofdimes.com.

To receive the newsletter electronically, please contact Christina Manero. She can be reached by email at cmanero@marchofdimes.com or by telephone at 202-261-7582. Please include in your message your name, email address and

your telephone number in case there is a question about your request. Let us know whether you will access the newsletter on the March of Dimes website or would like to receive it via email. Thank you for helping further our mission by electing to receive the newsletter electronically—a cost-effective way of keeping up with the Foundation's advocacy related activities. A hard copy version of the newsletter will continue to be mailed to any subscriber who does not choose to receive it electronically.

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

Editor:
Christina F. Manero

If you have questions or comments about the *Advocacy Update*, contact:

**March of Dimes
Birth Defects Foundation
Office of Government Affairs
1146 19th Street, N.W.
6th Floor
Washington, D.C. 20036
Telephone: (202) 659-1800
Fax: (202) 296-2964**

copyright © March of Dimes
June 2002



Office of Government Affairs
1146 19th Street, N.W., 6th Floor
Washington, D.C. 20036