

March of Dimes

May 2003

Advocacy Update *from the Office of Government Affairs*



Dr. Howse Testifies before House Appropriations Subcommittee

On May 8, Dr. Jennifer L. Howse, president of the March of Dimes, testified before the House Appropriations Subcommittee on Labor, Health and Human Services, and Education. Dr. Howse encouraged subcommittee members to increase funding for federal programs consistent with the Foundation's mission. She highlighted areas where, by providing adequate funding, Congress could take significant and affordable steps to improve the health of mothers, infants and children.

Dr. Howse described the

Foundation's Prematurity Campaign and called on members of the Subcommittee to join the March of Dimes effort to increase funds devoted to prematurity-related research. Specifically, she asked that the Subcommittee support additional research through the National Institute for Child Health and Human Development (NICHD). An increase of \$50 million over the next five years would enable NICHD to ex-



pand the number of grants awarded through the collaborative networks for Maternal-Fetal Medicine Units

and Neonatal Research.

In addition, Dr. Howse urged Subcommittee Members to continue building the budget of the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. This year, the March of Dimes is calling for a total NCBDDD budget of \$125 million with new funding targeted to three high priority programs: (1) cooperative agreements with states to create and improve birth defects surveillance systems; (2) the ten regional Centers on Birth Defects Research and Prevention

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Report on Progress of State Birth Defects Surveillance Programs

On April 29, the Trust for America's Health released a report on the progress of state birth defects surveillance programs entitled *Birth Defects Tracking and Prevention One Year Later: One Step Forward*. This month marks the one-year anniversary of the release of the last report card that rated state birth defects surveillance systems.

For March of Dimes Chapters—especially those leading a birth defects surveillance initiative—the report should be useful in working with governors and state legislators to protect programs from budget cuts, authorize new programs and/or secure ap-

propriations.

In compiling its report, the Trust found that 43 states and territories have improved their birth defects surveillance systems over the past year. However, even with the improvements, there is considerable concern among state officials that budget cuts to public health programs could put these improvements at risk.

“State surveillance programs are the linchpin for finding the causes of birth defects,” said Dr. Jennifer L. Howse, president of the March of Dimes, in a March of Dimes press statement issued concurrent with the report. Dr. Howse went on to say that “While it may be tempting to

cut funding for birth defects surveillance and research as a short-term budget balancing strategy, cutting these budget items today will undermine critical efforts to prevent health and financial tragedies of tomorrow.”

The complete report is available at <http://healthyamericans.org/state/birthdefects/files/2003bdreportupdate.pdf>. You will need Adobe Acrobat Reader to view this report. The March of Dimes press statement is available at www.marchofdimes.com.

US General Accounting Office Releases Newborn Screening Report

In March 2003 the United States General Accounting Office (GAO) issued a report entitled *Newborn Screening: Characteristics of State Programs*. Prepared at the request of Senators Chris Dodd (D-Conn.) and Mike DeWine (R-Ohio), the report includes information on criteria considered in selecting disorders to include in state screening programs, efforts being made by states to educate parents and providers about newborn screening programs, state-



by-state screening program expenditures, and funding sources used by states to support these programs. To collect this information, GAO surveyed newborn screening programs in all 50 states and the District of Columbia. Also included is information on efforts by the Department of Health and Human Services and states to evaluate the quality of newborn screening programs as well as a summation of state law and regulations pertaining to parental consent for newborn screening, and

confidentiality of information obtained through newborn screening.

Chapters should find the report very helpful as they lead initiatives to expand and improve state NBS programs. Note that the report acknowledges March of Dimes newborn screening activities, including Chapter representation on state NBS advisory committees.

The complete GAO report is available at <http://www.gao.gov/new.items/d03449.pdf>. You will need Adobe Acrobat Reader in order to view this report.

Covering the Uninsured Week

The Robert Wood Johnson Foundation (RWJF) and its partner organizations declared the week of March 10-16, 2003, *Covering the Uninsured Week*. The March of Dimes was a national supporter of the initiative with several Chapters participating in activities carried out at the state level.

Throughout the week, a series of national and local activities were held as part of a larger campaign designed to sensitize the public and opinion leaders to the difficulties faced by the more than 41 million Americans who lack health insurance. Increasing access to health coverage for women of childbear-

ing age (especially those who are pregnant) and children is a Foundation-wide advocacy priority for the March of Dimes.

RWJF is currently tallying the final results of the week but information available at press time indicates that 879 events were held across the country with 160 national and 700 local organizations participating.

For more information about the initiative visit their web site at www.covertheuninsuredweek.com.

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

Hospital charges are far higher for the sickest babies: On average, what is the hospital charge for the most severely ill, very low birthweight newborns in children's hospitals in 2001?

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

Iowa Succeeds on Two Foundation-wide Advocacy Priorities

On May 1, Iowa Gov. Tom Vilsack (D) signed into law a bill mandating universal infant hearing screening and a second bill funding an expansion of the state birth defects surveillance (BDS) program. Iowa Chapter volunteers and staff led the advocacy effort associated with both bills.

The Chapter's involvement began in December 2002, when volunteers and staff reviewed a proposed bill to make universal newborn hearing screening mandatory in the state. The Chapter then secured a Senate sponsor for the bill and began lobbying Members of the House and Senate to

obtain broad-based support as the legislation moved to a vote.

Simultaneously, the Chapter



worked to secure funding for the state Birth Defects Surveillance program by increasing the birth

certificate fee from \$10 to \$15 in 2003, and to \$20 in 2004. Again the Chapter obtained sponsors for the bill and lobbied state House and Senate committee Members as well as state health department staff. On April 10, the bill passed the House on a vote of 78-20. House sponsors and a March of Dimes key contact in the Senate were instrumental in obtaining quick approval in the Senate where the vote was unanimous.

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where cutting edge research is underway; and, (3) folic acid education.

Dr. Howse also told Subcommittee Members that “one of the great advances in preventive medicine has been the introduction of newborn screening.” She recommended that \$25 million be appropriated to begin funding the newborn screening program created two years ago as part of the “Children’s Health Act.”

The full text of Dr. Howse’s testimony is posted on the March of Dimes web site at www.marchofdimes.com.

Answer to April’s Data Book Questions

In 2000, Medicaid covered about 50% of hospital stays for preterm and low birthweight infants and covered about 40% of infant and child hospital stays due to birth defects.

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

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May 2003**



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