

# March of Dimes

September 2003

## Advocacy Update *from the Office of Government Affairs*



### Senate Approves First Time Funding for the Newborn Screening Program

On September 10, the U.S. Senate approved an amendment offered by Senators Christopher Dodd (D-Conn.) and Mike DeWine (R-Ohio) to the Labor, Health and Human Services Appropriations bill. The amendment provides \$2 million in first time funding for the newborn screening (NBS) grants authorized under Title XXVI of the "Children's Health Act."

A joint letter from the March of Dimes and the American Academy of Pediatrics sent to all Senators urged support of the amendment which would provide funding that "... could be used for the purpose of enhancing, improving or expanding the ability of state and local public health agencies to provide screening, counseling or health care ser-

vices to newborns and children having, or at risk for, heritable disorders."

As part of the overall March of Dimes lobbying effort, nine Chapters contacted key Senators to urge their co-sponsorship of the amendment. Representatives from the Senate and House appropriations committees will soon begin a conference where the differences in the bills approved by the two chambers will be reconciled. The House bill does not include funding for Title XXVI. March of Dimes Office of Government Affairs staff will work closely with volunteers and staff from Chapters whose members serve on the Conference Committee to urge inclusion of the Senate provision in the final conference agreement.

### 2004 Public Affairs Issues & Advocacy Priorities Set

The March of Dimes Public Affairs Issues and Advocacy Priorities for 2004 were approved by the Board of Trustees on September 12. Chapters and the Office of Government Affairs in Washington, DC use this document to help set legislative and regulatory goals for the year. By establishing a short list of Foundation-wide advocacy priorities, the Foundation is better able to promote its legislative and regulatory agenda. Advancing Foundation-wide advocacy priorities helps Chapters qualify for the Public Affairs component of the President's Team Award.



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## **Public Affairs Issues and Year 2004 Advocacy Priorities**

The March of Dimes Public Affairs agenda focuses on public policies and programs that relate to the Foundation's mission and on issues that pertain to non-profit organizations. Public Affairs efforts are organized into the four general categories listed below (specific examples are listed for each category). A star in the left margin indicates that the issue is a Foundation-wide Chapter advocacy priority for the year 2004. Federal advocacy on any of the issues on this list will also require selective chapter participation.

### **I. ACCESS TO HEALTH CARE FOR WOMEN OF CHILDBEARING AGE, INFANTS, AND CHILDREN**

- ★ Federal and state initiatives to expand newborn screening and treatment.
- ★ Federal and state policies regarding Medicaid, SCHIP and other publicly-supported coverage and subsidies to improve enrollment and access to health care.
- Standards of care for mothers and children enrolled in health plans.
- Standards to protect patient privacy and prohibit genetic discrimination.
- Federal and state initiatives to improve maternal and child health care.
- Initiatives to improve the health of preterm and low birthweight infants and children living with birth defects.

### **II. RESEARCH TO PREVENT BIRTH DEFECTS AND INFANT MORTALITY**

- ★ Birth defects surveillance, research and prevention programs at the state, federal, and international levels.
- Research funded by the National Institutes of Health, the Centers for Disease Control and Prevention and other Federal agencies to increase knowledge relating to the prevention of birth defects, prematurity and infant mortality.

### **III. PREVENTION AND TREATMENT PROGRAMS TO IMPROVE MATERNAL, INFANT, AND CHILD HEALTH**

- ★ Smoking prevention and cessation programs affecting women of childbearing age and children.
- Substance abuse prevention and treatment for pregnant women and their infants.
- Programs to improve prematurity risk detection and prevent preterm births.
- Food and nutrition education programs such as WIC - Supplemental Food Program for Women, Infants and Children.
- Preconception programs and services including increased use of folic acid.
- Programs to reduce racial and ethnic disparities in health care.
- Programs to immunize infants and children, research to develop new vaccines, and efforts to eradicate polio worldwide.
- Programs to reduce exposure to environmental and reproductive hazards that are associated with birth defects.

### **IV. INSTITUTIONAL CONCERNS FOR NONPROFIT ORGANIZATIONS**

- Federal and state laws and regulations related to non-profit organizations.
- Postal reform and rate changes.
- Tax treatment of charitable contributions.

## New Kaiser Reports on Impact of State Fiscal Crisis on Health Programs

In recent months, the Kaiser Commission on Medicaid and the Uninsured has issued several reports describing the fiscal pressures facing states and their effect on Medicaid, SCHIP and other health programs.

In July, the Commission released an especially useful report in this series that is entitled *Preserving Recent Progress for Health Coverage of Children and Parents: New Tensions Emerge*. The July report includes information on recent state changes to health programs such as narrowing eligibility and tightening the scope of coverage for low-income parents and children. The full report can be found at the Kaiser web site [kff.org/content/2003/4125/4125.pdf](http://kff.org/content/2003/4125/4125.pdf). Note that after

the survey was fielded in early 2003, states continued to take budgetary steps to reduce program expenditures.

In a second report, the Commission's third annual 50 state survey on budgets and Medicaid was released at the end of September. The survey catalogues FY 2003 changes in Medicaid eligibility and benefits. In addition, findings reveal that many states have approved Medicaid cost containment measures for FY 2004 that could affect coverage for women, infants and children. Specifically, the report indicates that:

- 18 states plan to reduce or restrict eligibility;

- 20 states plan to reduce benefits; and,
- 21 states plan to increase beneficiary cost-sharing requirements.

The data in the full report should be helpful in monitoring state budget plans and in comparing plans across states.

For more information visit the Commission's web site [kff.org/content/2003/20030922/](http://kff.org/content/2003/20030922/).

Public Affairs Conference  
Washington, DC  
October 14-16, 2003

## Missouri Chapter Works to Save SCHIP from Fiscal Shortfall

In a year when the state is experiencing a budget shortfall of \$800 million, volunteers from the Greater Missouri Chapter lobbied Gov. Bob Holden (D) and state legislators to protect funding for the State Children's Health Insurance Program (SCHIP).

Chapter volunteers and staff led a coalition effort to counter proposals in the House of Representatives to repeal the SCHIP program. The House appropriations committee approved the proposal, but an aggressive advocacy strategy blocked repeal of the program.

The coalition included representatives from the Kansas City and St. Louis mayors' offices, State and Regional Chambers of Commerce and Growth Associations, the Regional

Health Commission, several major hospitals and more than 14 state and regional children's advocacy groups.

An unusually large class of first year legislators—90 in the House and 12 in the Senate—forced advocates to spend much of their time educating Members about the importance of SCHIP to the health of infants and children across Missouri. Coalition representatives interacted with Senators and House Members through personal meetings, letters and telephone calls. In addition, advocates used the media to draw attention to the significant loss of health coverage that would occur if up to 80,000 children were denied access to SCHIP. The coalition framed its case for support of SCHIP by describing the program in the context of the state's overall

economic situation, demonstrating that SCHIP helped spur job growth and revenue for the state.

Gov. Holden vetoed the first budget approved by the legislature that contained a \$5 million cut in the \$26 million state contribution to the SCHIP budget. Having been given another opportunity to lobby the legislature on behalf of the program, the coalition mobilized to delete the \$5 million cut from the final budget and thereby preserved full coverage for pregnant women and children. Chapter volunteers and staff and other members of the coalition will soon meet with the governor, health department representatives and members of key legislative committees to begin work on the 2004 budget.

## Texas Chapter Succeeds on Two Foundation-wide Advocacy Priorities

The Texas Department of Health recommended elimination of state funding for the birth defects registry, beginning in 2004. Mobilizing to sideline this proposal, Chapter volunteers and staff led the successful advocacy effort to restore \$2.8 million in funding to the Texas Birth Defects Registry (\$1.4 million for each year of the biennium).

Chapter volunteers and staff were also successful in lobbying for legislation to strengthen the registry and for a bill that authorizes the Texas Department of Transportation to produce a March of Dimes license plate. Revenue generated from the sale of the license plates will go toward support of the registry.

The March of Dimes secured bill sponsors, gave testimony to the

health committees in both the Senate and House, and used the Chapter's Capital Day and calls from the state-wide advocacy network to win passage of these measures. Gov. Rick Perry (R) signed both bills into law within days of their approval.

Texas volunteers and staff also worked with key legislators to protect the SCHIP program from budget cuts, which would have forced reductions in eligibility for the program. In addition, the Chapter joined a coalition effort that was successful in defeating a proposal to allow the sale of health insurance policies that would have limited direct access to OB/Gyns, eliminated coverage for infant hearing screening, as well as PKU formula, immunization, and surgery for craniofacial abnormalities.

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

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