

# March of Dimes

September 2002

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



### U.S. Senate Hearing on Birth Defects Prevention

On July 26 Dr. Nancy Green, March of Dimes Medical Director, testified before the Senate Health, Education, Labor and Pensions Committee, Subcommittee on Children and Families. Chairman Christopher Dodd (D-Conn.) held the hearing entitled “Birth Defects: Strategies for Prevention and Ensuring Quality of Life” to assess current strategies for preventing birth defects and to determine what Congress can do to improve federal efforts to prevent birth defects and to assist those living with disabilities. Joining Dr. Green in testifying at the July 26 hearing were Dr. Jose Cordero, Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Cen-



Dr. Nancy Green, March of Dimes Medical Director

ters for Disease Control and Prevention (CDC); Fred Liguori, father of child with Spina Bifida; and Harold Pote, President of the Spina Bifida Foundation Board of Directors.

Dr. Green began her testimony by telling the Subcommittee that “The statistics on birth defects are very disturbing and illustrate a serious health problem facing our nation. Of the four million babies born each year in the United States, approximately 150,000, or 3-4% of all live births, have at least one serious birth defect.” She added that “The March of Dimes believes a two-pronged approach to prevention

and treatment of birth defects is required: research to identify causes and improve prevention tools, and access to health care so women and infants can benefit from existing medical knowledge.”

Dr. Green also provided the Subcommittee an overview of March of Dimes funded research on birth defects and she reaffirmed the Foundation’s strong support of federally funded research as well as programs that provide services to those living with birth defects. She reminded Subcommittee members that birth defects prevention activities of the CDC are authorized by the “Birth Defects Prevention Act of 1998,” and she noted the critical work of the

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## Public Affairs Chapter of the Year Recipients

Congratulations to the Greater Oregon and Indiana Chapters for winning the 2001 Chapter of the Year Awards in Public Affairs! These awards are given in recognition of outstanding achievement. Recipients have demonstrated the “best of the best” in Public Affairs, going beyond the criteria that determine eligibility for the President’s Team Award. To win, Chapters must meet all five Public Affairs Standards for Success and lead the advocacy effort in their state on at least two March of Dimes issue priorities.

### Oregon

In 2001, Greater Oregon Chapter volunteers and staff led the advocacy initiative to increase the number of newborn screening tests to 9 of the 10 core test recommended by the Foundation. Working in concert with Gov. John Kitzhaber (D) and key legislators, the Chapter testified at Committee hearings, met with key legislators and gathered support from other health organizations and advocates. Gov. Kitzhaber signed HB 2268 into law on July 7, 2001.

In addition to its work on newborn screening, the Chapter also led an advocacy effort to expand access to health coverage. Volunteers and staff joined state legislators to promote several bills to improve access to prenatal care for pregnant women. The Chapter began its work on this initiative prior to the legislative session by participating in Town Hall meetings and recruiting two legislators to introduce the bills. The Chapter also used its lobby day to educate legislators on the need for improving access to prenatal care.

Although legislation was not enacted in 2001, significant progress was made in raising the visibility of the issue, setting the stage for success in 2002.

### Indiana

Working with state legislators and health officials in 2001, the Indiana Chapter led the advocacy effort to improve the state’s current birth defects monitoring program by requiring reporting from hospitals and health care professionals. Volunteers and staff initially worked to gain endorsement of the proposal from the Department of Health then developed a legislative strategy. The Chapter built support for the bill by meeting with legislators and sending letters calling for immediate action. Volunteers also urged Gov. Frank O’Bannon (D) to lend his support to the proposal, the bill was signed on May 1, 2001.

Indiana volunteers and staff also led the advocacy effort to expand the state’s newborn screening program. Volunteers and staff worked with legislators to develop a bill to establish a task force with responsibility for developing recommendations on expanding the state’s newborn screening program to include all tests recommended by the March of Dimes. The Chapter was successful in securing an appointment to the task force for a March of Dimes representative. The task force recommended that additional tests be included on the state’s list, a recommendation that was later incorporated into a bill approved by the legislature and signed into law by Gov. O’Bannon on May 3, 2001.

### Senate Committee Approves Women’s Health Bill

On September 5 the Senate Health, Education, Labor and Pensions Committee approved a measure to create a series of new programs aimed at improving women’s health.

As approved, the bill would authorize more research and surveillance to improve pregnancy outcomes. The bill also authorizes Offices of Women’s Health in several agencies, centralized through HHS. In addition, the bill authorizes grants through the Maternal and Child Health Bureau (HRSA) to promote professional education and outreach about maternal oral health.

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NCBDDD. Dr. Green also discussed the work of the National Center for Health Statistics, National Institutes of Health, and the Health Resources and Services Administration in addressing birth defects.

Dr. Green’s testimony highlighted the success of the National Folic Acid Campaign and its impact on preventing neural tube defects. The campaign success was also addressed during Dr. Cordero’s testimony when he announced new findings that between 1995-1999 the prevalence of neural tube defects declined by 31%.

The full text of Dr. Green’s testimony can be found in the Public Affairs section of the March of Dimes website, [www.marchofdimes.com](http://www.marchofdimes.com).

## State Budget Tightening Likely to Target Medicaid

In 2003 most states are projected to be facing challenging budget environments. Working under tight budget conditions, many governors and state legislators can be expected to consider proposals to reduce current and future Medicaid expenditures. As March of Dimes volunteers and staff work to protect Medicaid coverage for women, infants and children in this budget environment, the following resources may be useful.

### What States Might be Planning

A new issue brief—"State Budgets Under Stress: How are States Planning to Reduce the Growth in Medicaid Costs?"—is available at The Henry J. Kaiser Family Foundation website [www.kff.org](http://www.kff.org). In an effort to

identify how states are reducing growth in Medicaid expenditures, the Kaiser Commission on Medicaid and the Uninsured sponsored a survey of all 50 states and the District of Columbia. Vern Smith, Principal of Health Management Associates, led the survey. Mr. Smith is a former Michigan Medicaid Commissioner and member of the March of Dimes Public Policy Advisory Council.

### State Medicaid Data

March of Dimes PeriStats provides information to help volunteers and staff advocate to protect and improve Medicaid services for women and children. Nationally, pregnant women, children, and other nondisabled, nonelderly adults and

children make up 72% of those covered by Medicaid, but account for only about 26% of the program's overall cost. Information on these percentages is available by state on PeriStats, and was recently updated to include 1999 data. As state officials debate cuts in Medicaid spending, it is important to point out that expenditures on behalf of women and children are a relatively small fraction of total program expenditures. While PeriStats includes the most recent national set of Medicaid data, more recent information on program enrollment and expenditures may be available in some states. March of Dimes PeriStats website is <http://www.marchofdimes.com/peristats>.

## Team Effort in Advocating for the CARE Act

The unified effort of the Chapters and Office of Government Affairs (OGA) to generate support for "The Charity Aid, Recovery and Empowerment Act" (CARE Act) continued during the August congressional recess. OGA worked with the bill's sponsors and the White House to identify Senators key to Senate approval of the bill. March of Dimes Chapters in Louisiana, Minnesota, Mississippi, Montana, South Dakota, and Texas were asked to submit letters to the editor urging Senator(s) in their state to support the legislation. All six Chapters did and to date, letters have appeared in *The Dallas Morning News* (Texas), *The Advocate* (La.), the *Bastrop Daily Enterprise* (La.), *The News-Star* (La.), the *Daily Advertiser*

(La.), the *Hattiesburg American* (Miss.), the *Bolivar Commercial* (Miss.) and the *Delta Democrat-Times* (Miss.).

The letters made the point that congressional approval of the CARE Act will help charities weather financial pressures associated with the current soft economy and will promote increased contributions over the longer term. The letters went on to say that the legislation addresses "two important issues: 1) it provides incentives to increase charitable contributions and 2) offers greater equity for all taxpayers by recognizing donations made by the 86 million Americans who — every April 15 — file the short form."

OGA requests to select Chapters

for help in contacting key Senators began in the spring with petitions at WalkAmerica sites (For more on the petitions, see the June issue of *Advocacy Update*). Following receipt of the petitions, members of the Senate Finance Committee favorably reported the bill. As the bill moved toward action by the full Senate, OGA requested Chapters in states where Senator(s) remained undecided on the issue to contact their Senator(s) to obtain a commitment of support. The Pennsylvania, Vermont, North Dakota, and Maine Chapters confirmed their Senator(s) position on the bill.

Continuing the momentum of the Senate Finance Committee action, Dr.

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Jennifer L. Howse, President of the March of Dimes, joined Senators Lieberman and Santorum-the bill authors-and other leaders of national charitable organizations at a press conference in the U.S. Capitol. Each speaker urged the Senate to approve the CARE Act and described how the legislation will help support the work of America's charities. (For more on the press conference, see the July issue of *Advocacy Update*.)

If enacted, a charitable deduction for non-itemizers has been projected to increase annual donations by up to \$14 billion and to expand the number of donors by nearly 12 million.

## October *Advocacy Update*

Look for the Public Affairs Issues & 2003 Foundation-wide Advocacy Priorities approved by the Board of Trustees. Chapters and OGA use this document to develop 2003 public affairs plans.

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**

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