

March Fall of Dimes 2004



Advocacy Update

from the Office of Government Affairs

Dr. Jennifer Howse Keynotes and March of Dimes Receives Award At 2nd “NCBDDD” Conference

On July 26, 2004, Dr. Jennifer Howse, President of the March of Dimes, delivered the keynote speech at the opening session of the National Center on Birth Defects and Developmental Disabilities



Dr. Howse speaking at the NCBDDD Conference

(NCBDDD) Conference in Washington, D.C. Dr. Howse spoke about the importance of partnership between public and private organizations. She pointed out that successfully dealing with birth defects can only occur through strong



George Jesien, Dr. Cordero and Anna Eleanor Roosevelt

leadership in an atmosphere of mutual trust where all parties recognize mutual goals.

Later in the conference, the March of Dimes received the first “Champion of NCBDDD 2004 Award”. The award is given to recognize individuals or organizations that have played a “major role in the creation and/or advancement of the NCBDDD.” Awardees are chosen by The External Partners Group, a coalition of 150 organizations that work together to promote the mission of the NCBDDD.

The March of Dimes was the first organization to call for creation of a center devoted to research on the prevention and

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treatment of birth defects. The Foundation joined with Senator Christopher “Kit” Bond (R-MO) to develop a legislative proposal and to build congressional support for the idea. The award credited the March of Dimes for its role in creating the NCBDDD, one of only 7 research centers that make up the Centers for Disease Control and Prevention. Senator Bond also received a “Champion of NCBDDD” award in recognition of his legislative efforts.

On introducing Anna Eleanor Roosevelt, March of Dimes Trustee and Chair of the national Public Affairs committee, George Jesien, chair of the External Partners group, said, “Many organizations and individuals played an important

role in the establishment of the center, but it was the March of Dimes that provided the leadership, the rallying point, the nexus for action to get the legislation passed that would mark the beginning point of the history of the national center.”

As she accepted the award on behalf of the March of Dimes, Ms. Roosevelt said, “I’d like to thank the External partners group for this honor and recognition.

“In three short years, the Center has elevated the stature and visibility of understanding the causes, occurrence, and consequences of birth defects, developmental disabilities, and heritable blood disorders-not only within CDC, but with the general public as well.”

2005 Public Affairs Issues and Advocacy Priorities Set

The March of Dimes Public Affairs Issues and Advocacy Priorities for 2003 is included on page 3. The Public Affairs policy issues and advocacy priorities were developed under the guidance of the National Public Affairs Committee of the Board of Trustees. By identifying Foundation-wide advocacy priorities the March of Dimes is better able to speak with one voice about the Foundation’s legislative and regulatory agenda.

Chapters and the Office of Government Affairs use this document to help set advocacy objectives. Work to advance Foundation-wide advocacy priorities helps Chapters qualify for the Public Affairs component of the President’s Team Award.

March of Dimes Comments on Senate Finance Committee Proposals to Reform Tax Exempt Organizations

On June 22, the Senate Committee on Finance held a hearing on charitable governance reforms. As a follow-up to the hearing, on July 22nd Sen. Chuck Grassley (R-IA), chairman of the Committee, and ranking member Sen. Max Baucus (D-MT), convened a roundtable to discuss a bipartisan draft “white paper” of proposed reforms developed by committee staff. The March of Dimes has submitted comments on the draft “white paper”.

In its formal comments, the Foundation raised several

concerns. Among them is the proposal to require reapplication to the Internal Revenue Service for tax-exempt status every 5 years. Currently an organization receives permanent tax-exempt status subject to IRS review of the form filed annually by tax exempt organizations, often referred to as ‘Form 990’. The March of Dimes is concerned that having to reapply every 5 years would put an “onerous” burden on charities due to the considerable paperwork needed to fulfill the requirement.

In its comments, the March of Dimes supported several of the proposals, including a requirement that the IRS make it possible for

charities to submit tax filings electronically by January 1, 2006. The Foundation also “strongly encourages and supports” the recommendation that the IRS standardize filing for the Form 990. Currently, charities submit significantly different materials when filing 990 forms.

According to a Senate Finance Committee spokesman, comprehensive reform legislation is unlikely this year but individual proposals included in the “white paper” may be included in other tax bills as a way of offsetting revenue losses to the US treasury.

2005 Public Affairs Issues and Advocacy Priorities

Public Affairs Issues and Year 2005-Advocacy Priorities

The March of Dimes Public Affairs agenda focuses on public policies and programs that relate to the Foundation's mission — improving the health of babies by preventing birth defects and infant mortality — 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 advocacy priority for the year 2005. 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 and protect 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 PREMATUREITY, 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.

Iowa and Texas Receive 2003 Public Affairs Chapter of Year Awards

Iowa and Texas received the 2003 Public Affairs Chapter of the Year Award. Iowa (Northern Region) won in the “small chapter” category and Texas (Western Region) received the “large chapter” award.

Iowa Chapter volunteers and staff led an advocacy effort to protect funding for the state Birth Defects Surveillance Registry. Working with several sympathetic legislators, the Chapter secured an increase in the birth certificate fee that will be earmarked to fund the registry. Iowa volunteers and staff also worked closely with legislators to authorize universal newborn hearing screening. Enactment of this bill means that Iowa now tests

for all 10 ‘core’ conditions as recommended by the March of Dimes.

Texas Chapter volunteers and staff spearheaded the advocacy effort that led to three significant changes in law. The first was a bill to restore \$2.8 million to the birth defects surveillance program (\$1.4 million for each of two years). The second was approval that permanently authorizes the program. Finally, the Chapter worked to enact legislation making it possible for the Department of Transportation to produce a March of Dimes license plate. Revenue generated from the sale of the MOD license plates will go toward support of the state birth defects registry.

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

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