

March of Dimes

January 2003



Advocacy Update

from the Office of Government Affairs

A Message from President Howse

The March of Dimes continues to lead state and federal advocacy initiatives that advance the Foundation's mission and improve government policies pertaining to non-profit organizations. Each year the Board of Trustees Public Affairs Committee selects 3 or 4 Foundation-wide advocacy priorities that Chapters are encouraged to incorporate into their Public Affairs plans. Board of Trustees Chairman Gary Forsee and Public Affairs Committee Chair Anna E. Roosevelt join me in thanking you for making 2002 an outstanding year for achievements in

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Charities Exempted from National 'Do Not Call' Registry

On December 18, 2002, the Federal Trade Commission (FTC) released a regulation that, among other things, establishes a national "do not call" registry. The regulation exempts charities from participation and also exempts commercial telemarketing firms when they are working on behalf of a non-profit organization.

Telemarketers hired by non-profit organizations will be required to maintain their own lists of people who do not wish to be called again. Also, when charities and their commercial telemarketers call potential volunteers or donors, they must identify themselves and state

clearly that the purpose of the call is to recruit volunteers or solicit a donation.

Exemption from this registry is a significant victory for charities since the original FTC proposal had contemplated imposing requirements on commercial telemarketers that solicit on behalf of charities. The original proposal would have increased significantly the cost of volunteer recruitment and requests for donations. In the formal comments filed by the March of Dimes when the proposed rule was published,

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House Committee Holds Hearing on Accutane

The Oversight and Investigations Subcommittee of the U.S. House Committee on Energy and Commerce held a hearing December 11, 2002 to explore issues relating to the safety of the drug Accutane. Subcommittee members were particularly interested in the testimony of a Food and Drug Administration (FDA) witness about risk management associated with the use of Accutane. Accutane is a drug prescribed for acne and is therefore



used by women of reproductive age. Accutane is a known and potent teratogen (an agent with a high risk of causing birth defects), on the same scale as thalidomide.

Dr. Nancy Green, Medical Director of the March of Dimes, testified at the hearing on behalf of the Foundation. In her remarks to the Subcommittee, Dr. Green said “No pregnant women should take Accutane, and no women taking Accutane should get pregnant. De-

spite current voluntary safety measures taken by the manufacturer, many pregnant women and their developing fetuses are ... unnecessarily exposed to this drug causing major birth defects in their babies.” Dr. Green urged Subcommittee members to support more aggressive measures to regulate Accutane and its generic equivalent, isotretinoin. Specifically, to reduce the risk of babies being born with birth defects, the Foundation’s recommended using the same rigorous FDA regulatory system currently applied to thalidomide.

New Faces in Congress and State Houses

As a result of the 2002 elections, there are many new faces in Congress and state capitals. There are eleven new U.S. Senators and fifty-four new Members of the U.S. House of Representatives. The arrival of new members means there will be changes in the leadership of both chambers. The Senate leadership for the 108th Congressional Session includes Majority Leader William Frist, M.D. (R-TN); Democratic Leader Tom Daschle (D-SD); Majority Whip Mitch McConnell (R-KY); and, Democratic Whip Harry Reid (D-NV). The House leadership team includes Speaker, Dennis Hastert (R-IL); Majority Leader Tom Delay (R-TX); and, Democratic Leader Nancy Pelosi

(D-CA).

At the state level, the National Conference of State Legislatures (NCSL) reports that legislatures have experienced the highest turnover in at least 30 years. NCSL attributes the turnover primarily to term limits and redistricting. According to NCSL’s latest count, this year there will be approximately 1,750 new state legislators and 120 of the top 320 state legislative leadership posts will be occupied by new members of state legislatures. Not only are there new faces in state legislatures but also in governor’s mansions across the country. Thirty-six states held gubernatorial elections in 2002 and twenty-four new governors are being sworn in.

March of Dimes 108th U.S. Congress Handbook

A limited number of Handbooks will be sent to Chapters in April. The Handbook, produced especially for the March of Dimes, contains: biographical data on each elected official; key staff contacts; addresses telephone numbers; and photos of the U.S. Representatives and Senators. In addition, the Handbook lists the membership of all House and Senate Committees and Subcommittees and provides a glossary of legislative terms. Since this guide was prepared exclusively for the Foundation, it includes information about the March of Dimes advocacy agenda and public policy priorities for 2003.

Release of *March of Dimes Data Book for Policy Makers, 2003*

The *March of Dimes Data Book for Policy Makers, 2003* will be released in early February. This *Data Book* replaces the 2001 edition, and provides ready-to-use talking points, charts and tables with national and state data. Topics covered include infant mortality, preterm and low birthweight births, incidence of birth defects, timing and adequacy of prenatal care, and insurance coverage. The *Data Book* promotes *PeriStats* as a complementary online resource, using the *PeriStats* logo to highlight where more detailed or more recent national, state and county data might be available through the web site.

According to reports from volunteers and staff in every region, the *Data Book* has proven useful to chapter advocacy efforts, both in preparing testimony and other written materials, and in meetings with public officials, who are not always aware that the March of Dimes is an excellent source of maternal and child health data.

In order to help support the Prematurity Campaign, this edition includes more information on preterm births. For example, you will find the *Data Book* to be a rich source of national data on overall rates, risk factors, and costliness of preterm births, along with state-specific rates of preterm and very

preterm births. The most recent data available at the time of production of the *Data Book* was 2000 birth and infant death data. Updates for these data will be provided through *PeriStats*.

As a service to Chapters, the Office of Government Affairs will send copies of the *Data Book* directly to members of the U.S. Congress, Governors, Health Commissioners, and State Legislators on health care and budget committees when post-election mailing lists are available.

Copies are free to Chapters through the Fulfillment Center, which is ready to accept orders (item number 50-1749-03).

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Public Affairs.

Below is a quick summary of progress made by Chapters in advancing Foundation-wide advocacy priorities:

Access: 14 Chapters (Ark., Colo., D.C., Del., Hawaii, Kan., La., Mich., Mo., N.M., N.Y., Okla., S.C., Wash.) led State initiatives to expand Medicaid or SCHIP, more than double the previous year. Seven Chapter initiatives (Colo., La., Mich., Mo., N.Y., Okla., Wash.) to increase eligibility and/or benefits for pregnant women, infants and children were approved and are being implemented.

Newborn Screening: Currently, 7 states (Ill., Ind., Maine, Mass., N.Y., Ore., R.I.) conduct all 10 core newborn screening tests recommended by the March of Dimes. During 2002, nine Chapters (Conn., Fla., Ga., Idaho, La., Miss., Mo., Va., NCAC) worked successfully to increase the number of tests conducted.

Birth Defects Surveillance: 10 Chapters (Calif., Hawaii, Ky., Mass., La., N.C., Pa., S.C., Vt., W. Va.) twice as many as in 2001, led successful State initiatives to establish or expand surveillance programs.

Prematurity Campaign National Launch

On January 30, the March of Dimes will kick-off its new 5-year Prematurity Campaign at the National Press Club in Washington, DC.

The day will begin with a press conference followed by a luncheon hosted by Dr. Jennifer L. Howse and Dr. Louis Sullivan, former Secretary of HHS.

More information about the event in the February issue of Advocacy Update.

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the Foundation registered its concern that new costs associated with the proposal would mean that “... a greater percentage of the charity’s revenue [would] have to be devoted to fundraising and volunteer recruitment, leaving fewer resources for community services, research, education and other mission activities.” Moreover, the Foundation’s letter of comment also pointed out that consumers would ultimately be hurt because fewer dollars would go to the charitable cause because funds would have to be diverted to telemarketing compliance. With the exemption in the final regulation, charities such as the

March of Dimes will be able to continue to use telemarketing firms to support fundraising efforts.

The final regulation will be implemented as soon as Congress authorizes the FTC to collect fees from telemarketers so that the registry can be funded.

**Look for the
announcement of
Chapter Public Affairs
Grant Recipients in the
February issue of
*Advocacy Update.***

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

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