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Advocacy Update

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2007 NATIONAL PUBLIC AFFAIRS CONFERENCE

The 2007 March of Dimes National Public Affairs Conference (NPAC) was held on October 17 and 18 in Arlington, Virginia. Over 400 March of Dimes volunteers and staff traveled to Capitol Hill to advocate in support of reauthorizing the State Children's Health Insurance Program, approval of the FY 2008 Labor Health and Human Services and Education Appropriation Bills, and to encourage Members to add their names as cosponsors of the "Newborn Screening Saves Lives Act" (S. 1858 and H.R. 3825).

At a luncheon event on October 18, Senators Lamar Alexander (R-TN), Richard Lugar (R-IN), and Orrin Hatch (R-UT) and Representatives Anna Eshoo (D-CA) and Lucille Roybal-Allard (D-CA) received the March of Dimes National Public Affairs Leadership Award and spoke to volunteers and staff.

March of Dimes volunteers and staff also presented awards to Senators Max Baucus (D-MT), Jeff Bingaman (D-NM), Hillary Clinton (D-NY), Christopher Dodd (D-CT), Michael Enzi (R-WY), Charles Grassley (R-IA), Edward Kennedy (D-MA), Blanche Lincoln (D-AR), John Rockefeller (D-WV), and Olympia Snowe (R-ME) and to Representatives Diana DeGette (D-CO), John Dingell (D-MI), Frank Pallone (D-NJ), and Fred Upton (R-MI) for their extraordinary legislative efforts to improve the health of women, infants and children.

Dr. Jennifer L. Howse, president of the March of Dimes, National Ambassador Zeek Taylor, and his mother, Betty Taylor, met with Speaker of the House Nancy Pelosi (D-CA) and with Representative David Price (D-NC).

Dr. Howse, the National Ambassador family and about two dozen volunteers then went to the House gallery at the invitation of the Speaker to watch the House debate overriding President Bush's veto of the bill to reauthorize the State Children's Health Insurance Program (SCHIP/CHIP).

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Dr. Jennifer L. Howse, Representative David Price, Speaker Nancy Pelosi, Betty Taylor, and 2007 March of Dimes National Ambassador Zeek Taylor



Senator Lamar Alexander (R-TN) with volunteers and staff from Tennessee

FEDERAL UPDATES

The United States Congress is considering several bills that include provisions important to the March of Dimes mission. Further action on each bill is expected

before the end of the year. Additional information can be found in previous issues of the Advocacy Update, available at www.marchofdimes.com/advocacy under Public Affairs News.

Reauthorization of the State Children's Health Insurance Program (SCHIP) continues to elude negotiators. A compromise bill approved by a bipartisan majority in the House of Representatives and Senate was vetoed by the President. On October 18 the House fell 13 votes of overriding the veto. Changes were made to the earlier bill and the House and Senate approved the modified measure but the margin was not sufficient to overcome a second veto promised by the White House. For more than a year, March of Dimes volunteers and staff have been deeply engaged in the effort to reauthorize SCHIP, an effort recapped by March of Dimes President Dr. Jennifer L. Howse during a national radio address on the importance of the program to improving the health of women, infants and children.

The Senate committee on Health, Education, Labor and Pensions is scheduled to consider the "Newborn Screening Saves Lives Act" (S. 1858) on November 14. If enacted, the bill would reauthorize funding for the expansion and improvement of state newborn screening programs and would require the development of federal guidance on a "core" list of disorders by the U.S. Department of Health and Human Services. Currently, the number of conditions for which newborns are screened varies by state. Additionally, as a result of March of Dimes volunteers and staff requests to Members of Congress, the list of cosponsors of the "Newborn Screening Saves Lives Act" has grown to 37 – 14 in the Senate and 23 in the House.

On another key March of Dimes issue, the Senate and House have approved the fiscal year 2008 Labor, Health and Human Services and Education (LHHS) Appropriations bills, both of which include funding for the PREEMIE Act (P.L. 109-450). More specifically, the bills propose increased federal support for the Centers for Disease Control and Prevention to expand research on prematurity and the report that accompanies the bill underscores Congress' support for a Surgeon General's Conference on the growing problem of preterm birth. Both bills also propose to fully fund the next phase of the National Children's Study. Members of the House and Senate Appropriations Committees have begun negotiations to reconcile differences between the two bills.

CHAPTER OF YEAR AWARD WINNERS

The 2007 Chapter of the Year Award Winners were announced at the National Public Affairs Conference held in Arlington, Virginia on October 17 and 18.

Rhode Island – Small

In Rhode Island, volunteers and staff led a successful advocacy campaign to enact legislation requiring insurers to pay for medications used to help enrollees stop smoking. In addition, the bill raises the excise tax on tobacco products with the proceeds earmarked to fund the Tobacco Control Program. While they worked as

part of a larger coalition, the Chapter focused its efforts on making certain that pregnant women and adolescents would qualify for the new coverage. Chapter volunteers and staff also succeeded in moving legislation to simplify the RIte Care (SCHIP) recertification process so that children who meet the eligibility guidelines are not arbitrarily dropped from the program.

South Carolina – Medium

In South Carolina, volunteers and staff led the advocacy campaign to increase state funding for the Birth Defects Monitoring Program by \$852,000 – \$608,000 of which is in recurring funds, with the remainder a one time appropriation to upgrade data collection capability. This accomplishment is particularly noteworthy as the new state funds will replace a March of Dimes Chapter grant that will no longer be needed to maintain the Monitoring Program. In addition, the Chapter led the advocacy drive to expand the state’s newborn screening panel to include all 29 treatable conditions, as recommended by the American College of Medical Genetics and endorsed by the March of Dimes.

California – Large

The California Chapter led a successful advocacy campaign to add Cystic Fibrosis and Biotinidase to the newborn screening panel and secured \$8.5 million in state funding to implement the expansion. Volunteers and staff also secured enactment of a bill requiring that newborns be screened for hearing impairments. The hearing screening requirement is scheduled to take effect in early 2008, at which time newborns in California will be screened for all 29 “core” conditions as recommended by the March of Dimes.

2006 CENSUS DATA ON UNINSURED WOMEN AND CHILDREN

The Census Bureau each year compiles exclusively for the March of Dimes specific data runs on the health insurance status of women of childbearing age and children under age 19 (which matches SCHIP eligibility). The number of uninsured children increased for a second year in a row and is central to the current debate in Congress to reauthorize SCHIP. Moreover, the MOD Census data breaks out women ages 15-44 separately finding that one in five women of childbearing age—12.6 million—was uninsured in 2006. These women accounted for 27% of all uninsured Americans.

HIGHLIGHTS OF NATIONAL DATA FOR 2006

Women of Childbearing Age (15-44):

- One in five women of childbearing age—12.6 million—was uninsured in 2006, showing no improvement over 2005.
 - These women accounted for 27.2% of all uninsured Americans.
 - At 20.4%, the uninsured rate for women of childbearing age is greater than that for Americans under age 65 overall (17.8%).

- Hispanic women in this age group were nearly 3 times as likely as non-Hispanic whites to be uninsured—39.5% compared with 14.3%. Native American (38.9%), African-American (24.0%) and Asian/Pacific Islander women (18.2%) were also more likely than whites to be uninsured.
- Among Hispanics, Mexican (43.4%) and Central/South American (39.9%) women were uninsured at the highest rates, compared with 20.9% of Puerto Ricans and 27.3% for all other Hispanic women.

Children Under Age 19:

- In 2006, 9.4 million (12.1%) of the nation's 78 million children under 19 were uninsured—an increase of more than 700,000 children over last year's figures and an increase for a second consecutive year.
- Hispanic children were three times as likely as non-Hispanic whites to be uninsured—22.8% compared with 7.6%. Native American (23.9%), African-American (14.6%) and Asian/Pacific Islander children (12.3%) were also more likely than whites to be uninsured.
- Among Hispanic children, Mexicans (24.9%) and Central/South Americans (23.5%) were uninsured at the highest rates, compared with 11.5% of Puerto Ricans and 15.0% for all other Hispanic children.
- Medicaid and the State Children's Health Insurance Program remain critical sources of health insurance for children—covering 26.5% of those under age 19, according to the Census data.

HIGHLIGHTS OF STATE DATA

- The rates of uninsured vary by state. (See table attached.) For example, Texas (31.3%) and New Mexico (29.7%) had the highest average rates of uninsured for women of childbearing age over the 2004-2006 period, while Minnesota (10.8%), Hawaii (10.8%) and Maine (11.4%) had the lowest.
- For children under 19, Texas (20.7%) and Florida (17.8%) both continued to increase and had the highest rates, and Hawaii (5.5%) and Michigan (5.6%) had the lowest.
- The attached state data are the best and latest available Census Bureau estimates. Census presents these state data using a three-year average (2004-2006) because small sample sizes make single-year state data less reliable. While the March of Dimes has computed state rankings based on

the percentage of uninsured, differences in the rates among states are often small and may not be significant.

Source: U.S. Census Bureau, March 2007 Current Population Survey Annual Social and Economic Supplement. Data prepared for the March of Dimes.

PUBLIC AFFAIRS ISSUES AND YEAR 2008 ADVOCACY PRIORITIES

This document, which was developed under the direction of the National Board of Trustees, is intended to guide Chapters, States and OGA in setting advocacy goals and in establishing criteria for Chapters to qualify for the Public Affairs component of the President's Team Award. Specifically, the document should be used by Chapters to create Public Affairs plans and to allocate volunteer and staff time and financial resources to advocacy activities for 2008. The selection of a short list of Foundation-wide advocacy issue priorities is intended to help ensure that all Chapters and the National Office speak with one voice about the Foundation's legislative and regulatory agenda.

The March of Dimes Public Affairs agenda focuses on public policies and programs that relate to the Foundation's mission -- improving the health of infants and children by preventing birth defects, premature birth and infant mortality -- and on issues that pertain to tax-exempt organizations. In addition, Public Affairs initiatives are designed to support the March of Dimes priority that racial and ethnic health disparities be reduced or eliminated wherever possible. Issues are organized into the four general categories listed below and specific examples are cited for each category. A star in the left margin indicates that the issue is a Foundation-wide advocacy priority for the year 2008. Federal advocacy on any issues listed may also require participation by Chapters.

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

- ❖ Federal and state initiatives to expand newborn screening as well as treatment.
- ❖ Federal and state policies regarding health coverage including Medicaid, the State Children's Health Insurance Program (S-CHIP), other publicly supported coverage, as well as private insurance to protect and improve access to and quality of 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, prevention and treatment programs at the state, federal, and international level.
- 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, alcohol and substance abuse prevention and cessation initiatives affecting women of childbearing age and children.
- 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.
- 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 collect data on and reduce exposure to environmental and reproductive hazards associated with birth defects.

IV. INSTITUTIONAL CONCERNS FOR TAX-EXEMPT ORGANIZATIONS

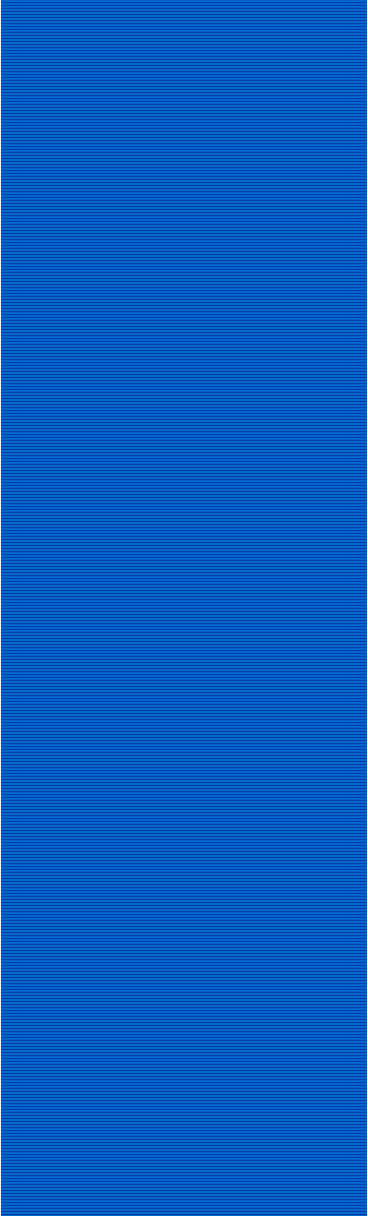
- ❖ Federal and state laws and regulations related to tax-exempt organizations.
- Postal reform and rate changes.
- Tax treatment of charitable contributions.

REPORTS FROM THE REGIONS

NORTH

Massachusetts Governor Deval Patrick signed a \$26.8 billion FY2008 state budget which included \$450,000 to fund the state's Birth Defects Monitoring Program (BDMP). Massachusetts Chapter volunteer and staff worked closely with the Department of Public Health as well as key legislators to secure support for the appropriation. These funds will allow the program to continue its work to identify and monitor the prevalence of birth defects in Massachusetts and to make follow-up recommendations for intervention and treatment.

The Vermont Chapter successfully advocated for a \$609,000 increase in funding for the Tobacco Control Program (TCP), the most significant in several years. The Chapter highlighted smoking cessation at Lobby Day, focusing especially on the relationship of maternal smoking and second-hand smoke to premature birth. Chapter representatives testified before House and Senate Committees throughout the legislative session.



Iowa Governor Chet Culver signed a bill providing a \$100,000 increase in funding for the Iowa Department of Public Health Phenylketonuria (PKU) Food Program, which funds metabolic formula and food for PKU patients. March of Dimes volunteers shared their personal stories with legislators, demonstrating the financial hardship incurred by PKU patients and their families. The Chapter featured the issue at Lobby Day and worked with legislative leadership to secure the increase in funding.

Ohio Governor Ted Strickland signed a bill raising the Medicaid eligibility cap for pregnant women from 150% to 200% of the Federal Poverty Level (FPL), making it possible for an estimated 2,850 uninsured women to obtain needed health coverage. The Ohio Chapter, with coalition partners, advocated for this change in law with Chapter volunteer Dr. Chris Hayes testifying before the House Finance Health and Human Services Subcommittee. Advocates also worked with key legislators to include funding for the expansion in the state budget.

Donna Zimmerman received the March of Dimes Distinguished Volunteer Service Award at the national Volunteer Leadership Conference. A member of the National Office of Volunteers (NOV) and liaison to the National Public Affairs Committee, Zimmerman has been a March of Dimes volunteer for more than 15 years. She works with Chapters to develop advocacy initiatives that advance the Foundation's public policy priorities, partnered with Senior Regional Public Affairs Director Amy Richardson to develop a comprehensive volunteer and staff Public Affairs leadership training course, and continues to lead the Minnesota State Public Affairs Committee as its chair. During her six year tenure, the Committee has successfully advocated for creation of a Birth Defects Information System and guided the Chapter's effort to expand the state Newborn Screening program. Throughout her volunteer career, she has served in many roles, including Minnesota Chapter Chair and member of the Program Services Committee. Zimmerman is Vice-President of Government and Community Relations at HealthPartners, a nonprofit consumer-governed health care organization headquartered in Bloomington, Minnesota.



Donna Zimmerman

SOUTH

Delaware Governor Ruth Ann Minner invited Chapter volunteers and staff to attend a signing ceremony for a bill that requires insurance coverage of certain medical formulas and food for individuals with PKU and other inherited metabolic disorders. The Chapter activated its Advocacy Network, deflected opposition, crafted creative messaging, and worked with the state's Division of Public Health to garner support for the bill among legislators.

At the bill signing ceremony, the Chapter took the opportunity to present Gov. Minner the new March of Dimes Award for National Leadership in Newborn Screening. This special award, given for the first time this year, recognizes states that screening newborns for 29 treatable metabolic and functional disorders as recommended by the March of Dimes.



From left: Delaware Senator Margaret Rose Henry, a primary sponsor of the PKU bill; Governor Ruth Ann Minner; Betsy Voss, Delaware Newborn Screening Program Coordinator and a Chapter Public Affairs Committee Member; Pat Scott, Delaware Newborn Screening Lab Manager and former Chapter Public Affairs Committee Member; and Leslie Kosek, Delaware State Director.

WEST

Governor Jim Gibbons signed legislation requiring universal HIV screening in Nevada as part of routine preconception and prenatal care for women. The Nevada Chapter advocated in support of the initiative at their Lobby Day and submitted testimony during its consideration by the legislature.

Nebraska Governor Dave Heineman signed legislation requiring preschoolers to have the invasive pneumonia vaccination in order to attend day care. The Nebraska Chapter advocated in support of the proposal at Lobby Day, sent letters to Senators, and submitted written testimony.

Governor Rick Perry signed a bill that restores 12 months continuous eligibility and eliminates the 90 day waiting period for children covered by the Texas State Children's Health Insurance Program. The Texas Chapter advocated for the bill during the March of Dimes Lobby Day, participated in the Texas CHIP Coalition's Lobby Day, reached out to key legislators, activated the Chapter's Advocacy Network, and included the message in all communications with Budget committee members.

Governor Jane Napolitano signed into law the state's budget bill, which includes an increase to 150% of the Federal Poverty Level (FPL) in the Medicaid income eligibility limit for pregnant women. The Arizona Chapter held a highly visible and successful Lobby Day, testified numerous times in committee, met

with key Budget committee officials, and activated their Advocacy Network to encourage Members of the legislature to approve these other initiatives to improve the health of women, infants and children. As a result, the budget includes an additional \$200,000 to fund folic acid education and \$661,000 to implement newborn screening for Cystic Fibrosis.

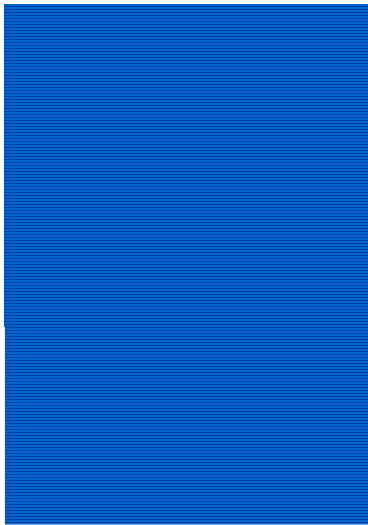
Hawaiian Governor Linda Lingle recently signed the state's budget bill, which included \$1,248,750 in new funding for preconception care and family planning services in each of the next two years. The bill also directed a transfer of \$463,000 per year for two years from the Department of Human Services to the Department of Health for health education and outreach to women. The Hawaii Chapter testified at legislative hearings and discussed the issue with legislators during Lobby Day.

The Idaho Department of Health and Welfare added screening for Cystic Fibrosis to the state's newborn screening panel. The Chapter held frequent discussions with Health Department staff on the issue. Idaho now screens all newborns for 28 of the 29 "core" treatable conditions as recommended by the American College of Medical Genetics and endorsed by March of Dimes and the American Academy of Pediatrics.

The Oklahoma Board of Health added 19 disorders to the state's newborn screening panel, bringing Oklahoma into alignment with the March of Dimes and the American College of Medical Genetics recommendation that all newborns be screened for 29 treatable conditions. Implementation of the expansion will be phased-in beginning in 2008. The Chapter advocated before the Department of Health (DOH), continuously communicating with DOH staff and meeting with the Director of Health, to advance the initiative.

California Governor Arnold Schwarzenegger signed the state's budget bill into law. The bill contains \$2.1 million to implement newborn hearing screening and \$4.1 million for the California Birth Defects Monitoring Program. The California Chapter advocated in support of these two budget items, testifying at budget hearings, and working closely with Members of the Budget committees and with the Governor to ensure their inclusion in the final bill.

The California Chapter, Los Angeles Division, hosted a NICU tour for Assembly member Betty Karnette at Long Beach Memorial, site of the March of Dimes NICU family support center. Assembly member Karnette toured the NICU for about an hour where she heard about the NICU Family Support project, legislation related to interconception care and coverage of medical foods, as well as the impact of prematurity on business and education.



From left: Sandy King, Government Relations Coordinator at Long Beach Memorial, Dr. Arthur Strauss (Director of Neonatology), Assemblymember Karnette and Erica Quijada-Barrera, March of Dimes NICU Specialist