

March Summer of Dimes 2004



Advocacy Update *from the Office of Government Affairs*

Dr. Jennifer Howse Testifies On Prematurity

On May 13, 2004, March of Dimes President Dr. Jennifer L. Howse testified before the Senate Subcommittee on Children and Families. Citing premature birth as one of the most common, serious, and costly problems facing

America's infants, she spoke in support of S.1726, the 'PREEMIE Act', introduced by Subcommittee Chairman Lamar Alexander (R-Tenn) and Ranking Member Christopher Dodd (D-Conn). The March of

Dimes worked closely with the Senators and their staff in drafting this bill and Dr. Howse called for its passage at the hearing .

Dr. Howse said, "As a nation, we must address this growing crisis in infant health and make it a priority. We urge swift passage of S.1726, the PREEMIE Act, which will authorize expanded research, education, and services into the causes and prevention of premature birth.

"Premature birth accounts for about half of all infant hospitalization charges. In 2001, the total national hospital bill for premature babies was \$13.6 billion. And we know that overall hospital charges are increasing so we expect this cost to rise.



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Prematurity affected 1 in 8 babies born in 2002 — over 480,000. That's an unacceptable 29 percent increase since 1981. In addition, CDC reported the first increase in infant mortality since 1958. "This legislation provides for much needed federal support of research and education that will help reduce the rates of preterm labor and delivery.

"The 'PREEMIE Act' is needed to expand resources for research into the causes of prematurity. March of Dimes volunteers and staff look forward to working with the Senate and House sponsors, and our Prematurity Campaign Partners—the Academy of Pediatrics, the American College of Obstetrics and Gynecology, and the Association of Women's Health, Obstetric and Neonatal Nurses—to obtain swift approval of this measure."

Additional witnesses at the hearing were:

·Duane Alexander, M.D., Director, National Institute of Child Health and Human Development, NIH;

·Peter van Dyck, M.D., Associate Administrator, Maternal and Child Health Bureau, HRSA;

·Eve Lackritz, M.D., Chief, Maternal and Infant Health Branch, Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, CDC;

·Charles Lockwood, M.D., Chairman, Department of Obstetrics and Gynecology, Yale University;

·Kelly Bolton Jordan of Memphis, TN, a March of Dimes volunteer. At just under 26 weeks of pregnancy, Mrs. Jordan delivered a 1-pound, 10-ounce baby girl.

Breaking News

As we go to press, the Governor of California is scheduled to sign a budget bill that would expand the state's newborn screening program to cover "all detectable" metabolic disorders (over 40 tests). Several other key March of Dimes proposals are included in the bill. Details next issue.

G. Brent Minor and David R. Smith, M.D. Appointed to National Public Affairs Committee

G. Brent Minor and David R. Smith, M.D., are new members of the National Public Affairs Committee.

Mr. Minor has volunteered for the March of Dimes since 1980 when he became a Team Captain for WalkAmerica. Minor was one of the first members of the National Office of Volunteers (NOV) and was its Chair from 1992 to 1995. Minor then became NOV Chair of the Northern Region. For more than 9 years he represented the NOV as liaison to the National Public Affairs Committee. In recognition of his many years of national service, Minor received

the first March of Dimes Elaine Whitelaw Volunteer Service Award in 1992.

Minor is currently Vice President of Business Development for LaSalle Bank. He previously was Chair, and is now Vice Chair, of the Greater Chicago State Street Council. In July of 2000, Mayor Richard Daley appointed him Chairman of the State Street Commission. In 2003, the City of Chicago honored him by designating the corner of State Street and Adams as "Brent Minor Way".

Dr. David R. Smith, elected to Board of Trustees in 2004, has volunteered for the March of Dimes since 1994. He is a member of the Texas Chapter Board of Directors

and is the Texas Prematurity Campaign Chair.

Since 2002, Dr. Smith has been Chancellor of the Texas Tech University System. Before that, he was the Texas Commissioner of Health and President of the Health Sciences Center at Texas Tech.

Earlier in his career, he held positions as Senior Vice President of Parkland Memorial Hospital in Dallas, CEO and Medical Director of Parkland's Community-Oriented Primary Care Program, and Deputy Director of the US Department of Health & Human Services' Division of Special Populations and Program Development in Washington, DC.

Chapter Advocacy Highlights

March of Dimes Chapters are working hard across the nation to advance the Foundation's advocacy agenda.

In Indiana, Iowa, Kansas, Minnesota, and South Carolina volunteers and staff are moving birth defects surveillance initiatives. Kansas and Minnesota just enacted bills to establish surveillance programs while, in Indiana and South Carolina, expansion of existing programs is well underway. With strong support from the University of Iowa and the Department of Health, the Iowa Chapter led the advocacy effort to permanently earmark for the Birth Defects Registry revenue received from an increase in birth certificate fees. The fee

increase, authorized in 2003, will generate enough revenue to fund approximately ten percent of Registry operating costs.

This year the Connecticut Chapter has focused on repealing a 2003 initiative proposed by the Governor and approved by the legislature. Had the Chapter not been successful in deflecting the proposal, the state would have been poised to apply for a federal waiver to impose premiums on low-income pregnant women and families of children who rely on Medicaid for their health coverage. Had the premium proposal gone into effect, an estimated 2,000 pregnant women would

have lost their maternity coverage.

As part of its ongoing effort to address racial health disparities, the Florida Chapter, together with the Dream Foundation, Inc., drafted and promoted a bill to create a license plate honoring the Reverend Martin Luther King, Jr. The bill allocates 25% of the proceeds from sale of the plate to the Chapter's Prematurity Campaign. The initiative, signed into law on June 18th, is projected to raise \$250,000 annually for the Chapter. Funds will be used to support the chapter's health education and community programs.

Nancy Green, M.D. Speaks At Capitol Hill News Conference

On June 16, Nancy Green, M.D., Medical Director of the March of Dimes, spoke at a Capitol Hill news conference. The conference, sponsored by Representatives Bart Stupak (D-MI) and Chris Smith (R-NJ), was called to announce the introduction the "Accutane Safety and Risk Management Act" (H.R. 4598).

On behalf of the March of Dimes, Doctor Green called for

tighter regulation by the Food and Drug Administration of accutane and other brands of isotretinoin. She said, "Major birth defects caused by exposure to Accutane and other brands of isotretinoin, an acne therapy drug, continue to occur in the United States each year because of the failure of voluntary safety measures meant to prevent them. Unfortunately, there have been at least 2,000 exposed pregnancies reported since this drug was introduced, and the real figure may be much higher."

Other speakers at the event included Representative Stupak, Representative Dave Weldon (R-FL), Lisa Crosland, and Carter Crosland. Carter Crosland spoke on behalf of families affected by isotretinoin.



Joe Luchok New Editor Of Advocacy Update

Advocacy Update has new editor. Mr. Luchok is the new Public Affairs Communications Manager at the National Office of Governmental Affairs. His background includes two years as the communications manager for the Health Insurance Association of America (HIAA) where he was a spokesman for the nearly 300 members, 18 years as a speech professor in Georgia and Missouri where he taught courses on persuasion theory and on public relations, and two years as communications consultant, during which he worked on several health care projects.

Newborn Screening Report Card Released

On June 30, in conjunction with a Today Show appearance by Dr. Jennifer Howse, President of the March of Dimes, the March of Dimes released the latest Newborn Screening State Report Card.

The report card shows which of March of Dimes "core" tests each state offers. Findings as of June, 2004, include:

21 states screen for the list of metabolic disorders recommended by the March of Dimes.

68% of all newborns are born in states that do not meet the March of Dimes recommendation that all newborns be screened for 10 "core" conditions.

14 states, plus the District of Columbia, currently offer tests for six to eight of the conditions on the March of Dimes list.

15 states, plus Puerto Rico, currently offer tests for only five or fewer conditions.

7 states are testing only selected populations within the state, are running pilot programs that do not include all babies, or do not provide supplemental testing.

9 states have authorized expanded newborn screening, but testing implementation has not yet occurred.

Additional information about the report card and the report card can be found at: http://www.modimes.org/aboutus/10651_12339.asp

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

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