

Testimony on Behalf of **March of Dimes Birth Defects Foundation**
Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
FY2007 Funding -- Department of Health and Human Services

The 3 million volunteers and 1400 staff members of the March of Dimes appreciate the opportunity to submit the Foundation's federal funding recommendations for Fiscal Year 2007 (FY07). The March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to prevent polio. Today, the Foundation works to improve the health of mothers, infants and children by preventing birth defects, premature birth and infant mortality through research, community services, education, and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community, and other volunteers affiliated with 52 chapters in every state, the District of Columbia and Puerto Rico.

The volunteers and staff of the March of Dimes are deeply concerned that the funding recommendations in the President's Budget are not sufficient to meet the challenge of improving the health of women and children across the nation. Continued under-funding of critical research and public health programs imperils the health of mothers and children today and in the future. In our judgment, the funding increases recommended below would lead to an immediate positive impact on reducing the incidence of preterm birth and birth defects, as well as making newborn screening for treatable metabolic and functional disorders more widely available.

National Institutes of Health

The March of Dimes joins the larger research community in recommending a 5% increase in funding for the National Institutes of Health (NIH), bringing total federal support to just under \$30 billion. The Administration's FY07 budget recommendation would necessitate absolute reductions in research investments as the levels of funding proposed are insufficient even to keep up with inflation and certainly will not sustain the necessary investment in medical research.

National Institute of Child Health and Human Development

The March of Dimes recommends a 5% increase for NICHD in FY07 and an increase of at least \$100 million over the next five years to boost prematurity-related research. Additional resources are needed to support research on the causes of preterm labor and delivery and on strategies for improving the care and treatment of infants born prematurely or at low birth weight. In addition, funding should be provided to enable the Institute to work with the Office of the Director of NIH to create a comprehensive strategic plan for this research that includes coordination of strategies and studies across multiple Institutes.

Since 1981, the preterm birth rate has increased 33% resulting in more than 500,000 premature births in 2004 -- that is 1 in 8 births. Preterm birth is the leading cause of death in the first month of life and, for those babies who do survive, one in 5 experiences multiple health problems including cerebral palsy, mental retardation, chronic lung disease, and vision and hearing loss. Preterm labor can happen to any pregnant woman, and the causes of nearly half of all premature births are unknown. This growing problem is a tragedy for families and expensive for the nation. In 2003, the national hospital bill for the care of babies with a primary or secondary diagnosis of prematurity exceeded \$18 billion, half of which was borne by Medicaid and other public programs and the remainder was charged to employers and families. Until we

know how to prevent preterm labor, the worsening incidence of prematurity means that overall hospital charges will also spiral upward.

In recent years, the NICHD has made a major commitment to increasing our understanding of the factors that result in premature birth and to developing strategies to prolong pregnancy. But additional work is needed and adequate funding is key.

An area deserving more support is the collaborative Maternal-Fetal Medicine Units (MFMU) and Neonatal Research (NR) collaboratives. One clinical trial funded through the MFMU network reported a promising preventive intervention that relies on a derivative of the hormone progesterone. The incidence of preterm delivery was reduced by up to 30 percent in women who received weekly injections of the compound compared to the women who were given a placebo. The results of this intervention are impressive and additional funding is needed to support further clinical trials of this promising intervention.

Finally, the March of Dimes urges the Subcommittee to include in its bill an increase of \$57 million for the National Children's Study (NCS). While the amount may seem substantial, it is dwarfed by the cost of treating the diseases and conditions the study is designed to address. If allowed to go forward, the NCS will generate groundbreaking research that greatly increases our knowledge of the role family genetics and the environment play in the health and development of children. Planning for this study has been completed; the Vanguard sites have been designated. The project is poised to start implementation which will yield critical information for research on preterm birth. The NCS will prove a rich and ongoing information resource for use by scientists and clinicians to develop treatments and preventive measures tailored for the pediatric population. Failure to provide the resources needed for this study would be extremely shortsighted.

Centers for Disease Control and Prevention (CDC)

Safe Motherhood/Infant Health

The National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health works to promote optimal reproductive and infant health. **The March of Dimes recommends a \$20 million increase in FY07 to support expansion of research** to identify risk factors and to develop strategies for preventing preterm birth. This can be accomplished with increased funding for the two programs described below:

1. The Pregnancy Risk Assessment Monitoring System (PRAMS) is a state-specific, population-based surveillance system designed to identify and monitor selected maternal behaviors and experiences before, during, and after pregnancy. Data collected through PRAMS is used to increase understanding of maternal behaviors and experiences and their relationship to adverse pregnancy outcomes, to improve maternal and child health programs, and to facilitate the dissemination of the latest research findings and clinical practice standards. **The March of Dimes recommends an increase of \$5 million to improve PRAMS so that CDC can develop national estimates on behavioral and demographic risk factors for preterm birth.**
2. Epidemiological research conducted at CDC is vital to the prevention of preterm labor and delivery. **The March of Dimes recommends an increase of \$15 million for the expansion of basic etiologic research, research on women at risk for preterm delivery and the social and environmental factors contributing to higher rates of preterm delivery in**

African-American women. Increasing CDC's research activities related to preterm birth will lead to improvements in screening and early detection and new interventions for women at risk for preterm labor.

National Center on Birth Defects and Developmental Disabilities

The March of Dimes recommends a minimum of \$135 million in FY07 funding for the National Center on Birth Defects and Developmental Disabilities (NCBDDD). NCBDDD conducts programs to protect and improve the health of children by: (1) preventing birth defects and developmental disabilities; and (2) promoting optimal development and wellness among children with disabilities. Of particular interest to the March of Dimes is NCBDDD's birth defects program that includes surveillance, research and prevention activities. For FY07, the March of Dimes requests an **increase of \$6 million to support surveillance and research and an additional \$2 million for folic acid education. These modest increases are vital to making progress in reducing the incidence of birth defects.**

In the United States, about 3% of all babies are born with a major birth defect. Birth defects are the leading cause of infant mortality accounting for more than 20% of all infant deaths every year. Children with birth defects who survive often experience long term physical and mental disabilities, and are at increased risk for developing other significant health problems. In fact, birth defects contribute substantially to the nation's health care costs. According to CDC, the lifetime cost of caring for infants born with one of the 18 most common birth defects exceeds \$8 billion annually.

NCBDDD provides funding to assist states with community-based birth defects tracking systems, programs to prevent birth defects and improve access to health services for children with birth defects. In 2006, CDC has been able to support only 15 states in their efforts to improve surveillance programs, down from 28 states in FY 2004. Additional resources are sorely needed to help states seeking assistance.

The causes of nearly 70% of birth defects are unknown and it is therefore critical that the Committee increase funding for the National Birth Defects Prevention Study. This groundbreaking CDC initiative is being carried out by 9 regional Centers for Birth Defects Research and Prevention located in Arkansas, California, Georgia, Iowa, Massachusetts, New York, North Carolina, Texas, and Utah. Each of these centers obtains data on infants with major birth defects through interviews with their mothers and biological samples that provide information about medical history, environmental exposures, and lifestyle before and during pregnancy. The study focuses on both genetic and environmental causes, including medication use during pregnancy, maternal diet and vitamin use. This study is an ongoing source of information for use in research on the causes of birth defects. With adequate funding this study has the potential to dramatically increase our understanding of the causes of birth defects and will provide information for developing effective preventive measures.

NCBDDD is conducting a national public and health professions education campaign designed to increase the number of women taking folic acid. CDC estimates that up to 70% of neural tube defects (NTDs), serious birth defects of the brain and spinal cord including anencephaly and spina bifida could be prevented if all women of childbearing age consume 400 micrograms of folic acid daily, beginning before pregnancy. Since fortification of grain products with folic acid in 1996, the rate of NTDs in the United States has decreased by 26%, but more must be done to educate every woman of childbearing age and the health professionals who treat them about the importance of taking folic acid daily.

Finally, the March of Dimes recommends that additional funds be provided to conduct surveillance and epidemiological research on cerebral palsy through the network already in place for autism (Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology). Cerebral palsy is one of the most common developmental disabilities and there is currently very limited surveillance and research being conducted.

National Immunization Program

If the nation is to meet the Healthy People 2010 goals of vaccinating 90 percent of children and adults, CDC, states and localities will need the resources required to reach those in need of immunizations. According to the CDC, nearly 25% of two-year-olds have not received all of the recommended vaccine doses. CDC's National Immunization Program provides grants to 64 state, local, and territorial public health agencies to reduce the incidence of disability and death resulting from 12 vaccine preventable diseases. The March of Dimes urges the Subcommittee to continue its longstanding policy of ensuring that federal vaccine programs are well funded. **For FY07, the March of Dimes recommends \$802.4 million to ensure that the National Immunization Program has the resources it needs to account for vaccine price increases, introduction of new vaccines, and to implement recommendations by the Institute of Medicine.**

Polio Eradication

The March of Dimes supports a funding level of \$101.254 million for CDC's FY07 global polio eradication activities. Level with FY06, this funding would allow CDC to continue its supplementary immunization activities in the remaining endemic and high-risk countries in Africa and Asia and to move quickly to interrupt polio transmission in these regions. The U.S. government must maintain its commitment to the worldwide eradication initiative that promises to save lives and reduce unnecessary health-related costs globally.

National Center for Health Statistics

The National Center for Health Statistics (NCHS) provides data essential for both public and private research and programmatic initiatives. The National Vital Statistics System and the National Survey on Family Growth, for example, are major sources of information on the utilization of prenatal care and on birth outcomes, including preterm delivery, low birthweight and infant mortality. Increased funding would enable CDC to introduce web-based technology to facilitate more rapid and accurate compilation of data obtained from health professionals and facilities. This information is used to track trends in birth outcomes and to support state birth defects registries. Data from NCHS surveys are also used to identify emerging trends and to optimize use of existing program resources.

Health Resources and Services Administration (HRSA)

Newborn Screening

Newborn screening is a vital public health activity used to identify genetic, metabolic, hormonal and/or functional conditions in newborns that if left untreated can cause disability, mental retardation, and even death. Although nearly all babies born in the United States are screened for some genetic birth defects, the number of these tests varies from state to state. The March of Dimes recommends that every baby born in the U.S. receive, at a minimum, screening for a core set of 28

metabolic disorders plus hearing deficiencies.

In FY05 and FY06, Congress provided funding for implementation of Title XXVI of the Children's Health Act of 2000; specifically, to fund the Regional Genetic Service and Newborn Screening Collaboratives that work to address the maldistribution of genetic services and resources and bring services closer to local communities. **The March of Dimes supports an appropriation of \$25 million** to enable HRSA to improve the capacity of states to: (1) provide screening, counseling, testing, and special services for newborns and children at risk for heritable disorders; (2) educate health professionals and parents on the availability and importance of newborn screening; and (3) support states with technical assistance on the acquisition and use of new technologies and newborn screening services.

Healthy Start

The Healthy Start Initiative is a collection of community based projects focused on reducing infant mortality, low birthweight and racial disparities in perinatal outcomes. The March of Dimes strongly supports Healthy Start and urges continued funding for this important program to decrease this nation's tragically high rate of infant mortality.

Maternal and Child Health Block Grant

In recent years, Federal funding for Title V of the Social Security Act, the Maternal and Child Health (MCH) Block Grant, has not kept pace with increased demand for services. Although the MCH Block Grant provides assistance for a growing number of community-based programs (such as home visiting, respite care for children with special health care needs and "wrap around" services for pregnant women and children enrolled in Medicaid and SCHIP), the funding level was reduced by \$24 million in FY06. In order for maternal and child health programs to shoulder responsibility for additional beneficiaries and services, funding must be increased. **The March of Dimes recommends full funding of the MCH Block Grant at the authorized level of \$850 million.**

Consolidated Health Centers

Consolidated (Community) Health Centers are an important source of obstetric and pediatric care for more than 15 million individuals, approximately 40% of whom are uninsured. The Foundation recommends **new funding sufficient to increase the number of centers and to improve the scope of perinatal services provided.** Adding funds to this program would be consistent with the President's five-year plan to create and expand health center sites in 1,200 communities and to increase the number of patients served annually to more than 16 million.

Thank you for the opportunity to testify on the federally supported programs of highest priority to the March of Dimes. The Foundation's volunteers and staff in every state, the District of Columbia and Puerto Rico look forward to working with Members of the Subcommittee to improve the health of the nation's mothers, infants and children.

**MARCH OF DIMES
FY2006 FEDERAL FUNDING PRIORITIES
(Dollars in Millions)**

PROGRAM	FY2006 FUNDING	MARCH OF DIMES FY 2007 RECOMMENDATION
National Institutes of Health (Total)	28,428	29,849
National Institute of Child Health & Human Development	1,265	1,328
National Human Genome Research Institute	486	510
National Center on Minority Health and Disparities	195	205
Centers for Disease Control and Prevention (Total)	6,089	8,500
Center on Birth Defects and Developmental Disabilities	125	135
Birth Defects Research & Surveillance	14	20
Folic Acid Education Campaign	2	4
Immunization	520	802.4
Polio Eradication	101	101
Safe Motherhood/Infant Health (NCCDPHP)	44	64
National Center for Health Statistics	109	139
Health Resources and Services Administration (Total)	6,594	7,500
Maternal and Child Health Block Grant	693	850
Newborn Screening	2	25
Newborn Hearing Screening	10	10
Consolidated (Community) Health Centers	1,782	1,963
Healthy Start	102	102
Agency for Healthcare Research and Quality	319	440