

March of Dimes Foundation

Office of Government Affairs

1401 K Street, NW, Suite 900A

Washington, DC 20005

Telephone (202) 659-1800

Fax (202) 296-2964

**March of Dimes Foundation
Public Testimony – Senate Committee on Appropriations**

Driving Innovation through Federal Investments – April 29, 2014

The three million volunteers and 1,200 staff members of the March of Dimes Foundation appreciate the opportunity to submit testimony prior to the April 29, 2014 hearing, “Driving Innovation through Federal Investments.” The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with chapters in every state, the District of Columbia and Puerto Rico. Our mission is 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 commends the Appropriations Committee for its focus on utilizing federal investment to drive innovation in the field of health and medicine. As a grant-making organization that funds tens of millions of dollars in medical research each year, the March of Dimes must make difficult choices in selecting which of the many promising research applications we will fund. Research funded by the March of Dimes spans the full range of maternal and child health, including genetics, social and behavioral science, and cell lineage and differentiation, as well as support targeted to young investigators and sponsorship of conferences. Recently, the March of Dimes has launched a set of highly innovative strategies around research into the prevention and treatment of preterm birth that we believe will not only lead to major strides in this field, but provide a ground-breaking new model for the investigation of complex, multifactorial health issues.

Preterm birth is one of the most vexing health problems facing mothers, infants and families in the United States and worldwide. One in 9 infants is born preterm (before 37 weeks gestation) in the United States; an estimated 15 million are born preterm worldwide. Prematurity is the leading cause of neonatal death (death in the first month of life) and, among those who survive, one in five faces health problems that persist for life such as cerebral palsy, intellectual disabilities, chronic lung disease, and deafness. In 2005, the annual societal economic cost (medical, educational, and lost productivity) associated with preterm birth in the U.S. was estimated to be at least \$26.2 billion, or \$51,600 per infant born preterm.

Preterm birth is a complex phenomenon that may be caused by diverse genetic or environmental factors, or combinations thereof. The March of Dimes strongly believes a coordinated public-private partnership is needed to discover the causes of preterm birth and to implement prevention strategies. For the past six years preterm birth rates have declined, resulting in 176,000 fewer babies being born preterm and saving more than \$9 billion. Despite this significant



progress, however, many of the causes of preterm birth remain unknown and more research is needed. Reducing preterm birth will require increased and coordinated public and private investments into understanding the causes of preterm birth and promoting known interventions.

Developing a Public-Private Research Agenda

To meet this challenge, the March of Dimes, the Bill & Melinda Gates Foundation, the Global Alliance to Prevent Prematurity and Stillbirth, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the World Health Organization convened meetings of experts to develop a research agenda that spans the range of discovery, development, and delivery science needed to drive global change. This resulted in the joint statement, "A Solution Pathway for Preterm Birth: Accelerating a Priority Research Agenda," which appeared in the December 2013 issue of *The Lancet Global Health*. The Solution Pathway calls for: (1) better understanding of the biology of pregnancy and novel targets for preterm prevention; (2) improving the survival of preterm infants in low-income and middle-income countries; (3) improving the epidemiological data needed to track prevalence, risk factors, and program effect; and (4) accelerating health gains by fostering innovation and collaboration.

The March of Dimes looks forward to working with members of the Senate Appropriations Committee to prioritize funding for innovative research that follows the elements outlined by the Solution Pathway. Toward that goal, we recommend at least \$32 billion for the National Institutes of Health and \$1.37 billion for the NICHD in FY 2015. This funding will allow NICHD to sustain its preterm birth-related research through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. It would also allow NICHD to invest in transdisciplinary research to identify the causes of preterm birth, as recommended in the Director's 2012 Scientific Vision for the next decade, the Institute of Medicine 2006 report on preterm birth, and the 2008 Surgeon General's Conference on the Prevention of Preterm Birth.

Establishing March of Dimes Prematurity Research Centers

In addition to building consensus around a research agenda and advocating for federal research funding, the March of Dimes has also launched the nation's first Prematurity Research Centers dedicated to solving the mysteries of premature birth. These March of Dimes Centers — at Stanford University School of Medicine and the Ohio Collaborative — are pioneering a brand new way of engaging in "team science" by bringing together hundreds of scientists, researchers, physicians, faculty and staff to identify and prevent the causes of preterm birth. These research centers represent the largest and most wide ranging effort ever created to solve the problem of preterm birth and will produce numerous potential areas of scientific inquiry that need to be accelerated through funding from the National Institutes of Health and other federal agencies.

In March 2011, the March of Dimes and Stanford University created the nation's first transdisciplinary research center dedicated to identifying the causes of premature birth. Over 130 scientists in fields ranging from neonatology and genetics to computer science and bioinformatics are pursuing this revolutionary model of scientific inquiry to find answers. Center scientists meet weekly as a group to present research concepts and progress and to discuss issues actively across multiple disciplines. This approach attracts top investigators who might never otherwise study preterm birth and compels them to learn about each other's fields and share ideas, insights, and strategies. Initial areas of inquiry make use of Stanford's unique capabilities and include:

- Infection/inflammation discovery to characterize microorganisms in the body, their genetic components, and their reactions during pregnancy, and to examine whether they

- are in any way associated with preterm birth
- Bioinformatics gene-environment discovery to utilize bioinformatics methods, as well as genomic and environmental measurements, to study the causes of, and develop diagnostics for, preterm birth
 - Transcriptome discovery to identify markers of preterm pregnancies from the genetic material of the mother and the fetus using a non-invasive approach

For example, with regard to infection/inflammation discovery, the Stanford Prematurity Research Center is working with women to collect samples throughout their pregnancies to study the microbiome, the ecological community of microbes living in the human body. Determining the profile of bacteria present in women who go on to deliver preterm will open rich new avenues of inquiry. The bacteria themselves may cause preterm birth by initiating a certain immune response by the mother or they may provide predictive power for diagnostic purposes.

In May 2013, the March of Dimes joined with Ohio's leading universities and hospitals to launch the second Prematurity Research Center, aimed exclusively at finding the unknown causes of preterm birth. The Ohio Collaborative (comprised of Case Western Reserve University, Ohio State University, and the University of Cincinnati, along with five associated hospital systems) brings together an unprecedented array of disciplines, specialties and research themes to examine biological, social and environmental factors that might contribute to prematurity.

Initially, the Ohio Collaborative will focus on five research topics:

- Evolution of human pregnancy
- Genetics of unique human populations
- The molecular developmental biology of pregnancy
- Progesterone signaling in pregnancy maintenance and preterm birth
- The sociobiology of racial disparities in preterm birth

The Ohio collaborative will utilize similar team-based approaches to those developed at Stanford to bring together scientists across multiple disciplines to investigate these specific contributors to preterm birth.

The March of Dimes anticipates establishing three additional Prematurity Research Centers in the next three years, for a total of five centers and an investment of over \$30 million. Each Center will be selected for scientific expertise that complements or fills gaps in those of the others, and all of the Centers will be networked to share new concepts, approaches, and discoveries. The March of Dimes fully expects that these innovative approaches will lead to significant advances in our understanding of pregnancy, childbirth and prematurity within a decade.

Conclusion

The March of Dimes appreciates this opportunity to share our exciting new research approaches related to preterm birth. The problem of preterm birth is serious, but we have built consensus around the research agenda and priorities for investigation. Federal funding has made significant contributions to the field of preterm birth research and will continue to play a key role moving forward. We urge the Appropriations Committee to prioritize funding for the National Institutes of Health and the NICHD, particularly around preterm birth and other important maternal and child health research.

For more information contact:

Emil Wigode
Director, Federal Affairs
March of Dimes
1401 K Street, NW, Suite 900
Washington, DC 20005
ewigode@marchofdimes.org
(202) 659-1800