We are formally kicking off our Policy with Partners (PwP) program, and by now you should have received correspondence from the Society on this exciting new legislative movement. With the 111th Congress abuzz with topics ranging from special education, healthcare reform, etc. this program exists to have Society members, their friends and supporters standing by committed to reaching out to our elected officials on programs, legislation and policies that will impact all of our families who live with MPS and related diseases. Through open dialogue from you, and possible collaboration with other non-profits, we will connect, educate and motivate our legislators to make a difference for our members. When we call upon you, we will supply you with a template for you to personalize with your family's specific information which can then be faxed, e-mailed or phoned in to your representatives. Please fill out your PwP form, and give us your ideas and suggestions as well as any legislation you find that can help our membership, or due harm to our families. If you have not received your PwP letter and form, please call our office or refer to our Web site.

In May, Legislative Committee member Steve Holland accompanied MPS members Mark Dant, Eric and Vicki Merrell, Dawn Chercrallah and Melissa Bryant to call on the House of Representatives to gain additional support for H.R.1441, The Ryan Dant Healthcare Opportunity Act of 2009. At printing this proposed legislation has 46 cosponsors and is growing by the day. These members, along with other MPS families, called in advance to make 50+ appointments during their brief visit. After returning from their trip Vicki and Eric

Society members join Mark Dant in Washington to support H.R.1441

Merrill sent this note to the Society: "I think we were received very well on Capitol Hill. Vicki and I had seven meetings ourselves, and were amazed by the way people responded to our plight. When we showed pictures of Sean and Cody, and discussed their struggles to date and the challenges they face in future, you could see that they understood the boys' struggles." We thank all our MPS families and staff for diligently writing, e-mailing and calling their representatives whenever we need our voices heard in our nation's capitol!

Vice President Joe Biden Announces Kareen Dale as Special Assistant to the President for Disability Policy

First time a president has had a special assistant focused exclusively on disability policy

Vice President Joe Biden recently announced Kareem Dale as special assistant to the president for Disability Policy. "The commitment that the president and I have to Special Olympics and people with disabilities is deep and abiding. And we are backing up those words with real action at the White House," said Vice President Biden. "This is our first step to ensure we have a strong advocate for people with disabilities at the highest levels of our administration."

Dale, who is partially blind, will have direct access to the president in this role and he will coordinate the administration's efforts to see that people with disabilities are on a level playing field with all Americans.

Originally from Chicago, Dale previously served as the National Disability Director for the Obama for America campaign. He also served on the Arts Policy Committee and the Disability Policy Committee for then-Senator Obama.

Department of Health and Human Services (HHS) Makes $75 Million Available to States to Expand Health Insurance Coverage

HHS announced the availability of $75 million to help states expand health insurance access to the uninsured.

"With these funds, states can look at the most effective ways to provide affordable health insurance to their uninsured residents," said HHS Secretary Kathleen Sebelius. "Many states have had great success in recent years instituting health reforms and these awards will make it possible for more states to extend coverage to more people."

Grants will be made in two categories. Target grants of $2 million to $4 million will be awarded to states with plans to target specific groups of uninsured, such as children, small businesses or uninsured seniors. Comprehensive grants of $7 million to $10 million will be awarded to states for extensive insurance coverage initiatives.

The application deadline was June 15; all applications needed the support of their state's governor.

The grants will be made over a five-year period and require a 20 percent match unless a state demonstrates a financial hardship. In addition, states must demonstrate their ability to sustain the program after federal funding has expired. The impact and results of state projects will be reported to Congress at the end of the five-year grant period.

This new program will be overseen by the HHS Health Resources and Services Administration and is an outgrowth of the agency's State Planning Grant program that operated from 2000–2007. The previous effort enabled many states to develop innovative plans that increased health insurance coverage for their uninsured residents.

New National Institutes of Health (NIH) Program Focuses on Developing Therapeutics for Rare and Neglected Diseases

The NIH has launched a $24 million initiative called The Therapeutics for Rare and Neglected Diseases Program (TRND, pronounced "trend") that aims to develop new treatments for rare and neglected diseases. TRND will focus on diseases that private companies have not been working on and stimulate collaborations between academic scientists to advance the process of preclinical research and product development. Relationships with patient advocacy organizations, disease-specific foundations and pharmaceutical companies also will be emphasized to efficiently move promising drugs to the clinical trial stage of development. The TRND program will be overseen by the NIH Office of Rare Diseases and administered by the National Human Genome Research Institute in collaboration with the NIH Chemical Genomics Center. Additional information is available at **www.genome.gov/27531962** or **www.rarediseases.info.nih.gov/TRND**.

American College of Medical Genetics (ACMG) Issues New Position Statement Regarding Newborn Screening

The ACMG has released a new position statement emphasizing the importance of retaining the dried blood spot filter cards obtained through newborn screening programs to ensure high-quality newborn screening in the United States. This statement is supported by newborn screening, consumer advocacy and public health officials from the Regional Genetics and Newborn Screening Collaborative established as part of the Newborn Screening Saves Lives Act (PL 110-204). The link to this new statement is **www.acmg.net/StaticContent/NewsReleases/Blood_Spot_Position_Statement2009.pdf**.

President Obama Announces Intent to Nominate Francis Collins as NIH Director

On July 8, 2009, President Barack Obama announced his intent to nominate Francis S. Collins as director of the NIH at the Department of Health and Human Services.

"The National Institutes of Health stands as a model when it comes to science and research," said President Obama. "My administration is committed to promoting scientific integrity and pioneering scientific research and I am confident that Dr. Francis Collins will lead the NIH to achieve these goals. Dr. Collins is one of the top scientists in the world, and his groundbreaking work has changed the very ways we consider our health and examine disease. I look forward to working with him in the months and years ahead."

Francis S. Collins, Nominee for Director, NIH, Health and Human Services

Francis S. Collins, MD, PhD, a physician-geneticist noted for his landmark discoveries of disease genes and his leadership of the Human Genome Project, served as director of the National Human Genome Research Institute (NHGRI) at the NIH from 1993–2008. With Dr. Collins at the helm, the Human Genome Project consistently met projected milestones ahead of schedule and under budget. This remarkable international project culminated in April 2003 with the completion of a finished sequence of the human DNA instruction book. In addition to his achievements as the NHGRI director, Dr. Collins' own research laboratory has discovered a number of important genes, including those responsible for cystic fibrosis, neurofibromatosis, Huntington's disease, a familial endocrine cancer syndrome and, most recently, genes for adult onset (type 2) diabetes and the gene that causes Hutchinson-Gilford progeria syndrome. Dr. Collins has a longstanding interest in the interface between science and faith, and has written about this in *The Language of God: A Scientist Presents Evidence for Belief* (Free Press, 2006). He has just completed a new book on personalized medicine, *The Language of Life: DNA and the Revolution in Personalized Medicine* (HarperCollins, to be published in early 2010). Collins received a bachelor of science degree in chemistry from the University of Virginia, a PhD in physical chemistry from Yale University, and an MD with honors from the University of North Carolina. Prior to coming to the NIH in 1993, he spent nine years on the faculty of the University of Michigan, where he was an investigator of the Howard Hughes Medical Institute. He has been elected to the Institute of Medicine and the National Academy of Sciences, and was awarded the Presidential Medal of Freedom in November 2007.

The 111th Congress: Legislation We Continue to Follow:

S.442 / H.R. 1085 The Health Insurance Coverage Protection Act
Introduced by Sens. Byron Dorgan (D-ND) and Olympia Snowe (R-ME), and Rep. Anna Eshoo (D-CA), this bill increases the minimum lifetime caps in private insurance plans to $10 million with an annual inflationary index. The legislation will allow people with bleeding disorders and other high-cost chronic conditions who have private insurance to maintain their coverage and not have to seek public assistance such as Medicaid or state high-risk pools.

H.R. 2866 Improving Access to Clinical Trials Act of 2009
This bill is aimed at aiding rare disease trials by allowing patients with rare diseases from losing their Supplemental Security Income (SSI) status by participating in clinical trials for which they are paid. Current laws prohibit SSI beneficiaries from accepting research compensation. The sponsor is Rep. Markey (MA-7) and was introduced June 15, 2009, with several cosponsors. This legislation was referred to the House Committee on Ways and Means.

S.726 & H.R. 1427 Promoting Innovation and Access to Life-Saving Medicine Act
Again, we continue to watch for progress on these bills which will create a regulatory pathway for the U.S. Food and Drug Administration to approve generic biologics, or biotechnology products. See page 44 for more information on biologics.

H.R. 2965/S.1233 Enhancing Small Business Research and Innovation Act of 2009
This bill amends the Small Business Act with respect to the Small Business Innovation Research and Small Business Technology Transfer programs to extend funding and revise provisions, including those concerning qualifications for program participation, research and development topics, nanotechnology, project goals for funded projects, project commercialization, second and third stage funding of projects, outreach to increase program participation, prioritization of applications, and federal administration and oversight.

Lifespan Respite Care Act (P.L. 109-442)
Although some funding was received for FY2009, we appreciate the members' support with their calls to legislators to fully fund Lifespan Respite at $71 million in FY2010 Labor/HHS/Education appropriations bill.