Our first trip to Washington, DC, for 2009 was very eventful and productive. Ernie Dummann, Kim Whitecotton, Barbara Wedehase and Debbie Dummann divided this trip into four main areas of attack. Visiting the Senate, House, National Institutes of Health (NIH) and Social Security Administration (SSA), focusing our advocacy efforts on National MPS Awareness Day, increased funding to the NIH, language submission to the Labor Health and Human Service subcommittee and increased funding for the Life Span Respite Care Act. Debbie and Kim did a tremendous job and had many productive meetings including our old friends in the Senate offices of Specter (D-PA), Feinstein (D-CA), Kennedy (D-MA) and Murkowski (R-AK). This team also began dialog with the House of Representatives to seek support and cosponsors for H.R. 1441, the Ryan Dant Healthcare Opportunity Act of 2009.

Debbie Dummann, Taryn Morrissey, legislative health aid to Sen. Ted Kennedy, and Kim Whitecotton

Ernie Dummann and Barbara concentrated their efforts on the NIH and SSA focusing on partnering, collaboration and access to services. It was extremely gratifying meeting with the directors of the National Institute of Neurological Disorders and Stroke, National Institute of Diabetes and Digestive and Kidney Diseases, National Center for Research Resources and Office of Rare Diseases. This group has been very supportive and helpful in our interest to increase research funding to help find cures and effective treatments for all our member who are affected with this devastating disease. We also had a very productive meeting with Nancy Schoenberg, the acting program director of the Social Security Administration Compassionate Allowance Program, who was very supportive of our MPS families that need to apply for Supplemental Security Income (SSI) benefits. In many states this is the first step in receiving Medicaid services.

Thanks to Les Sheaffer, Sissi Langford and Kym Wigglesworth whose past efforts made our jobs so much easier.

As your Legislative Committee continues to support and advocate for your families, we welcome our newest committee members: Kim Whitecotton, MaryEllen Pendleton, Austin Noll, Steve Holland, Steve Chesser and Stephen Frye. They all bring a wealth of knowledge from their families' MPS experiences and will take their advocating skills on a national level.

Legislative Committee:
Ernie Dummann, chair
Steve Chesser
Debbie Dummann
Stephen Frye
Tom Gniazdowski
Steve Holland
Terri Klein
Austin Noll
MaryEllen Pendleton
Laurie Turner
Barbara Wedehase
Kim Whitecotton

The 111 Congress

Legislations we continue to follow and support:

H.R. 1441 The Ryan Dant Healthcare Opportunity Act of 2009

This proposed legislation will amend Title XIX of the Social Security Act to allow states to permit certain Medicaid-eligible individuals who have extremely high annual lifelong orphan drug costs to continue on Medicaid notwithstanding increased income. The state will have options to waive the annual earnings restrictions on individuals like Ryan who will have already qualified for Medicaid due to their disability. The objective is to allow these individuals the opportunity to become employed, pay taxes and become whatever their abilities allow them. To qualify for H.R. 1441, an individual must have expired an insurance lifetime cap of at least $1 million and have a prescription orphan drug cost of at least $200,000 annually. This legislation is being sponsored by Rep. Kenny Marchant (R-TX-24). Thank you to Mark Dant, Steve Holland, Eric and Vicki Merrell, Melissa Bryant and Dawn Checrallah who secured co-sponsors during their trip to Washington in May.

continued

S.726 & H.R. 1427 Legislation Introduced to Promote Development of Generic Biologics

Henry Waxman (D-CA), with Health Subcommittee Chair Frank Pallone (D-NJ) and Ranking Member Nathan Deal (R-GA), introduced the "Promoting Innovation and Access to Life-Saving Medicine Act," H.R. 1427. The bill creates a regulatory pathway for the U.S. Food and Drug Administration (FDA) to approve generic biologics, or biotechnology products, given that there are "no clinically meaningful differences" between the generic and an already approved biotech drug. The legislation provides a five-year exclusivity period to the manufacturer of the original biologic, or reference product, and also grants six months of market exclusivity to the first maker of the generic biologic. The bill was referred to the House Committee on Energy and Commerce.

Following are excerpts from a letter the National MPS Society, along with 46 other non-profits, sent on May 1, 2009, requesting further funding of the Lifespan Respite Care Act of 2006 for FY 2010:

The Honorable David Obey
Chair
Subcommittee on Labor, HHS and Education
Committee on Appropriations
U.S. House

The Honorable Todd Tiahrt
Ranking Member
Subcommittee on Labor, HHS and Education
Committee on Appropriations
U.S. House

Dear Chairman Obey and Ranking Member Tiahrt:

We, the undersigned national organizations, are writing to request that the Subcommittee include funding for the Lifespan Respite Care Act (PL 109-442) in the FY 10 Labor, HHS and Education Appropriations bill at its modest authorized level of $71.1 million. Despite its widely supported enactment in 2006, the program received only $2.5 million in FY09. The Lifespan Respite Care Act is the only federal law which mandates respite services, the only federal program which could help ensure respite quality or choice, and the only federal program which allows funds for respite start-up, training and coordination. As the only federal program to address basic accessibility and affordability issues for families regardless of age or disability, it serves a critical and unique purpose.

In these times of serious budget constraints, the economic value that accrues from respite is exceptional. Respite, the most frequently requested family support service, has been shown to provide family caregivers with the relief necessary to maintain their own health, bolster family stability, keep marriages intact, and avoid or delay more costly nursing home or foster care placements. Delaying nursing home, institutional or foster care placement of just one individual for several months can save Medicaid, child welfare or other government programs tens of thousands of dollars.

For families and individuals who may not qualify for any public or private respite funding, including children with severe disabilities, and many other chronic physical and mental health conditions, these programs may be holding out the only helping hand.

We urge you to fully fund the program at $71.1 million. Please join us in sending a message to our nation's family caregivers that we value their health and well-being and that help is on the way in these economically challenging times.

Sincerely,

National MPS Society

HOW TO CONTACT YOUR CONGRESSIONAL LEADERS

For senators go to **www.senate.gov**, in the upper right-hand corner, click on your state.

For representatives go to **www.house.gov**, in the upper left-hand corner put in your ZIP code.

American Recovery and Reinvestment Act of 2009: IDEA Recovery Funds for Services to Children and Youths with Disabilities

The American Recovery and Reinvestment Act of 2009 (ARRA) appropriates significant new funding for programs under Parts B and C of the Individuals with Disabilities Education Act (IDEA). Part B of the IDEA provides funds to state educational agencies and local educational agencies (LEAs) to help them ensure that children with disabilities, including children ages 3 through 5, have access to a free appropriate public education to meet each child's unique needs and prepare him or her for further education, employment and independent living.

The IDEA recovery funds under ARRA will provide an unprecedented opportunity for states, LEAs, and early intervention service providers to implement innovative strategies to improve outcomes for infants, toddlers, children and youths with disabilities while stimulating the economy. Under the ARRA, the IDEA recovery funds are provided under three authorities: $11.3 billion is available under Part B Grants to States; $400 million is available under Part B Preschool Grants; and $500 million is available under Part C Grants for Infants and Families. Preliminary information about each state's allocation is available at **www.ed.gov/about/overview/budget/statetables/recovery.html**. This Web site also provides information about the State Fiscal Stabilization Fund under the ARRA, which is separate from the IDEA recovery funds described in this fact sheet. This document focuses on Part B; additional information on Part C will be available shortly.

Overview of ARRA

PRINCIPLES: The overall goals of the ARRA are to stimulate the economy in the short term and invest in education and other essential public services to ensure the long-term economic health of our nation. The success of the education part of the ARRA will depend on the shared commitment and responsibility of students, parents, teachers, principals, superintendents, education boards, college presidents, state school chiefs, governors, local officials and federal officials. Collectively, we must advance ARRA's short-term economic goals by investing quickly, and we must support ARRA's long-term economic goals by investing wisely, using these funds to strengthen education, drive reforms, and improve results for students from early learning through college. Four principles guide the distribution and use of ARRA funds:

a. **Spend funds quickly to save and create jobs.**
b. **Improve student achievement through school improvement and reform.**
c. **Ensure transparency, reporting and accountability.**
d. **Invest one-time ARRA funds thoughtfully to minimize the "funding cliff."**

ADDITIONAL INFORMATION

The Department will provide updates as additional information becomes available regarding the details of the IDEA recovery funds.

The Department also will provide further information on the government-wide data collection and reporting requirements as this information becomes available.

Send an e-mail to IDEARecoveryComments@ed.gov with questions or concerns.

Kathleen Sebelius Sworn in as Health and Human Services Secretary

Kathleen Sebelius was sworn in as the 21st secretary of the Department of Health and Human Services (HHS) on April 29, 2009. The secretary governs one of the largest civilian departments in the federal government with more than 67,000 employees. HHS is the principal agency for protecting the health of all Americans by providing effective health and human services, especially for those who are least able to help themselves.

While her first focus will be responding to the H1N1 (swine) flu emergency, Secretary Sebelius will soon turn to the larger effort of helping to pass an overhaul of the U.S. healthcare system.

Sen. Edward Kennedy Working with HELP Committee Members to Introduce, Mark up Healthcare System Overhaul Legislation before August Recess

Senate Health, Education, Labor and Pensions (HELP) Committee Chair Edward Kennedy (D-MA) and a group of five other committee members hope to unveil their universal healthcare legislation for early summer. Kennedy's group includes Senate HELP Committee ranking member Mike Enzi (R-WY) and committee members Sens. Christopher Dodd (D-CT), Orrin Hatch (R-Utah), Judd Gregg (R-NH) and one of three other senators—Sens. Jeff Bingaman (D-NM), Tom Harkin (D-IA) or Barbara Mikulski (D-MD), who previously were named to working groups focusing on insurance coverage, prevention and quality improvements, respectively.

Kennedy's staff has been holding stakeholder meetings, which include 20 interest groups, and members and aides from the Senate HELP Committee and the Senate Finance Committee have been holding joint and separate meetings to discuss reform. However, nothing from those meetings has been made available to the public. Kennedy's drafting group is scheduled to have legislation ready by early summer and to the floor before the August recess.

Obama Names Leadership at FDA

President Obama announced his appointment of Dr. Margaret Hamburg as commissioner of the FDA and Dr. Joshua Sharfstein as principal deputy commissioner at the agency. Dr. Hamburg currently is the senior scientist at the think-tank Nuclear Threat Initiative. Her diverse background includes serving as New York City commissioner of health, assistant secretary for planning and evaluation at the Department of Health and Human Services during the Clinton Administration, and assistant director of the Institute of Allergy and Infectious Diseases at the NIH. Prior to taking her leadership post at the FDA, Dr. Hamburg must be confirmed by the full Senate.

Dr. Sharfstein currently serves as Baltimore's health commissioner, and his leadership has won the Health Department and affiliated agencies numerous national and regional awards for innovation and model practice, among others. He is a member of the Board on Population Health and Public Health Practice of the Institute of Medicine. He also served as a health policy advisor on the Democratic staff of the Government Reform Committee of the U.S. House of Representatives for Congressman Henry Waxman (D-CA).

Removing Barriers to Responsible Scientific Research Involving Human Stem Cells

President Obama signed an executive order on March 9, 2009, to remove federal funding restrictions on embryonic stem cell research, thereby expanding the NIH support for exploring the potential of human stem cell research. More specifically, the law reverses the Bush presidential statement of Aug. 9, 2001, and the Bush executive order of June 20, 2007, that prohibited federal funding of embryonic stem cell research conducted on cell lines created after Aug. 9, 2001. Under the executive order signed by President Obama, the Director of the NIH will develop guidelines for "the support and conduct of responsible, scientifically worthy human stem cell research, including human embryonic stem cell research, to the extent permitted by law." After reviewing scientific data and published best practices, the NIH will post draft guidelines for public comment, with the intention of having a final guidance ready within 120 days of passage of the Obama executive order.