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With President Obama taking his oath on Jan. 20, 2009, as the 44th president of the United States, Americans are extremely anxious to see if promises made during his two-year campaign and in his inaugural address will become reality. Your Legislative Committee is eagerly awaiting President Obama's budget, focusing our attention on many of our MPS and related disease concerns: health-care, special education, respite, and the pledges made to increase funding research to the National Institutes of Health (NIH) and the U.S. Food and Drug Administration.

In 2008, according to NIH statistics, MPS researchers received approximately \$7.6 million from the NIH for direct research. President Obama in campaigning stated he feared the loss of researchers due to lack of funding and feared our country would fall behind other countries with respect to research and development. With the new president promising more research dollars and lifting some past restrictions, we are looking for some exciting research to emerge.

Following are excerpts from the new administration's Web site: www.whitehouse.gov:

Disabilities—Support independent, community-based living for Americans with disabilities by enforcing the Community Choice Act, which would allow Americans with significant disabilities the choice of living in their community rather than having to live in a nursing home or other institution, creating a voluntary, budget-neutral national insurance program to help adults who have or develop functional disabilities to remain independent and in their communities, and streamline the Social Security approval process.

Education—*Zero to Five Plan:* The Obama-Biden comprehensive "Zero to Five" plan will provide critical support to young children and their parents. Unlike other early childhood education plans, the Obama-Biden plan places key emphasis at early care and education for infants, which is essential for children to be ready to enter kindergarten. Obama and Biden will create Early Learning Challenge Grants to promote state Zero to Five efforts and help states move toward voluntary, universal preschool.

Students with Disabilities—Obama and Biden will work to ensure the academic success of students with disabilities by increasing funding and effectively enforcing the Individuals with Disabilities Education Act, and by holding schools accountable for providing students with disabilities the services and supports they need to reach their potential. Obama and Biden also will support early intervention services for infants and toddlers, and will work to improve college opportunities for high school graduates with disabilities.

Insurance—Require insurance companies to cover pre-existing conditions so all Americans regardless of their health status or history can get comprehensive benefits at fair and stable premiums.

Establish a National Health Insurance Exchange with a range of private insurance options as well as a new public plan based on benefits available to members of Congress that will allow individuals and small businesses to buy affordable health coverage.

Science & Technology—Invest in the sciences: Double federal funding for basic research over 10 years, changing the posture of our federal government to one that embraces science and technology.

Invest in university-based research: Expand research initiatives at American colleges and universities. Provide new research grants to the most outstanding early-career researchers in the country.

Lower healthcare costs by investing in electronic information technology systems: Use health information technology to lower the cost of healthcare. Invest \$10 billion a year over the next five years to move the U.S. health care system to broad adoption of standards-based electronic health information systems, including electronic health records.

Advance the biomedical research field: Support investments in biomedical research, as well as medical education and training in health-related fields. Fund biomedical research, and make it more efficient by improving coordination both within government and across government/private/non-profit partnerships.

Advance stem cell research: Support increased stem cell research. Allow greater federal government funding on a wider array of stem cell lines.

Senate Passes Health Insurance Bill for Children

The Senate overwhelmingly approved legislation to provide health insurance to 11 million low-income children, a bill that would for the first time spend federal money to cover children and pregnant women who are legal immigrants.

The State Children's Health Insurance Program, which is aimed at families earning too much money to qualify for Medicaid but not enough to afford private insurance, currently covers close to seven million youngsters at a cost of \$25 billion.

Lawmakers voted 66 to 32, largely along party lines, to renew the joint state-federal program and spend an additional \$32.8 billion to expand coverage to four million more children. The expansion would be paid for by raising the cigarette tax from 39 cents a pack to \$1.

The House approved similar legislation on Jan. 14, and President Obama signed the bill Feb. 4.

(This information was taken from the Washington Post, Jan. 30, 2009.)

Lifespan Respite Care Act of 2006 Update

Your Legislative Committee continues to follow the progress on the Lifespan Respite Care Act of 2006. This legislation was signed into law, but remains unfunded. On behalf of the ARCH National Respite Coalition, the Lifespan Respite Task Force and other national, state partners, the National MPS Society sent a letter to President Obama's transition team in December 2008 urging him to sign into law and fund within his first 100 days of office. The funding as requested is \$53.3 million for FY09 and \$71.1 million for FY10.

This law when funded will provide a tremendous benefit to our members and families.

HR 5748 - Ryan Dant Healthcare Opportunity Act — 2008 Update

Last year, Congressman Kenny Marchant (R-TX), introduced HR 5748, the Ryan Dant Healthcare Opportunity Act of 2008. This bill is named for our MPS member, Ryan Dant, who resides in Congressman Marchant's district. As with many of our members on enzyme replacement therapy, the drug costs can exhaust lifetime maximums of private healthcare insurance. It will then be necessary to enroll in the Medicaid program. This will greatly limit earning capacities.

HR 5748 will provide an alternative by allowing a Medicaid state an option that would permit individuals to be released from the qualifying earnings restrictions. As is currently written, this legislation will only apply to individuals who pay more than \$250,000 per year in drug costs and have exhausted their lifetime private insurance.

Ryan's father, Mark Dant, recently returned from Washington, DC, where all original cosponsors have agreed to sign on to this year's act. There will be some new language written in, and hopefully this will expedite this legislation to a hearing.

This legislation not only affects our MPS members, but also affected individuals with other rare diseases. We will be asking our members to request cosponsor support of this bill from their legislators.
