



Legislative Update #50 January, 2010

2009 was an exciting year! One of the Legislative Committee's immediate priorities for 2009 was the mentoring of new members on the committee while giving full support to our members on their questions and concerns regarding congressional delegation, communicating their family's needs to congress, the National Institutes of Health (NIH), the U.S. Food and Drug Administration (FDA) and other governing bodies that pass legislation which affect our MPS population. The Legislative Committee was able to fund a number of trips to Washington, DC, including sending a number of Society members to advocate for our MPS needs. As a collective group, our members attended more than 100 meetings on Capitol Hill in 2009. Our advocacy efforts focused on increasing funding from the NIH, increasing funding for local respite care providers, urging the Social Security Administration to include all lysosomal diseased persons to qualify for compassionate allowances without a long and arduous process. We launched our Policy with Partners (PwP) program and have nearly 100 members and friends who will help us on a moment's notice. As 2010 arrived, our Society joined the Rare Disease Congressional Caucus (see below). Our focus for 2010 will continue to support families through federal legislation and partnering with other organizations and nonprofits on common issues.

"I am not going to walk away just because it's hard." - President Obama (on Healthcare Reform)

President Obama made it clear to an enthusiastic crowd on Jan. 28, 2010, that he is not giving up the fight for health reform that protects consumers from insurance company abuses, lowers costs, and help businesses and families around this country.

"I didn't take up this issue to boost my poll numbers or score political points—believe me, if I were, I would have picked something a lot easier than this," said President Obama. "No, I'm trying to solve the problems that folks here in Elyria and across this country face every day. And I am not going to walk away just because it's hard. We're going to keep on working to get this done with Democrats, Republicans—anyone who is willing to step up. Because I am not going to watch more people get crushed by costs, or denied the care they need by insurance company bureaucrats, or partisan politics, or special interest power in Washington."

The president told the crowd he is working closely with Congress to complete work on healthcare reform that will bring security and stability to Americans who have insurance and provide affordable options to those who don't.