2012 promises to be a fun and exciting year for our legislative advocacy work. As I step down from chairing this committee for the past three years, I look forward to Steve Holland's new appointment to chair this committee and promise to continue working for the betterment of all with MPS and related disease. The Legislative Committee has been instrumental in several key areas. During the last several years this committee and Policy with Partners volunteers have been instrumental in working with members of congress to have our MPS Appropriations Language written into the Significant Items Report which governs the National Institutes of Health research priorities.

Committee members have been very successful spreading awareness to a new level "on the hill," expressing the needs of all affected with MPS. This motivated group of volunteers also has helped succeed in some of the MPS disorders being added to the Social Security Compassionate Allowances program.

In addition, we have been successful in having congress recognize National MPS Awareness Day, which in itself is no small feat. Then there is you—parents, doctors, relatives and friends—who have done so much in helping all who are affected with MPS. It is so gratifying when we send legislative action alerts to our membership and so many of you respond with very little notice. With your continued support the Society's legislative efforts will be successful; together we can improve the lives of our loved ones.

New for 2012 will be an exciting addition to the Legislative Committee which will provide an expansion into our advocacy on Capitol Hill. Look for the official announcement soon! My thanks to all of you.

Ernie Dummann

Newly Proposed Legislation

In early 2012 you will be asked to contact your congressional representatives to support new legislation proposed by the CureTheProcess Campaign, along with the 181 patient advocacy groups to streamline the regulations for rare diseases. This legislation, Fast Track Products for Ultra Rare Diseases, aims to improve the accelerated approval pathway for fast track products to serve the needs of individuals with ultra rare diseases.

More information will be provided soon.

Medicaid Information

In the United States, Medicaid is the largest source of financing for disabilities services. Many families have loved ones who are on Medicaid for a variety of reasons. For those with disabilities and for those who provide their care, Medicaid serves as a vital safety net. Medicaid is often the only source of financial assistance for healthcare, and plays a critical role for people with disabilities in providing coverage and access to care. Medicaid is, however, extremely complicated. At least half of the funds for Medicaid programs come from the federal government. The remainder comes from state funds. Federal law contains detailed requirements and limitations on eligibility, services and financing. State law varies widely from state to state. Although you must apply through your state for Medicaid funding, the Web site **www.acf.hhs.gov/programs/add/** is a very helpful tool. This site also provides a link to your state's information. Click on **www.acf.hhs.gov/programs/add/states/ddcs.html** to receive information locally.

Legislative Committee:
Ernie Dummann, chair
Debbie Dummann
Jeff Bardsley
Stephanie Bozarth
Chip Brady
Steve Holland
Austin Noll
MaryEllen Pendleton
Kim Whitecotton
Roger Chapin
Terri Klein
Kelly Rose
Laurie Turner
Barbara Wedehase

The next Legislative Update in *Courage* will provide information on the committee's January 2012 visit to the National Institutes of Health in Washington, DC.

Urge Congress to Join the Caucus!

Our membership has a great opportunity to expand congressional knowledge regarding MPS and related disease. For the new year, please write, e-mail or phone the message below to your congressional representative. To find out who your representative is, go to **www.house.gov** and type in your ZIP code in the upper right corner. Currently there are 14 members on this committee out of a possible 435 house members. Our disease still needs exposure!

Subject: Rare & Neglected Disease Caucus

Dear Congressman _____:

As my Congress member, I am writing to ask you to join the Rare Disease Caucus. This bipartisan caucus is co-chaired by Congress members Leonard Lance (R-NJ) and Joe Crowley (D-NY).

Your participation in the caucus will help give a voice to the more than 25 million Americans and their families affected by a rare disease. There are more than 7,000 rare disorders, however only 5 percent have treatments approved by the FDA. Since the Orphan Drug Act was enacted in 1983, 2,113 treatments have received orphan designation, however only 346 have been approved for marketing in 25 years. The science exists for many of these diseases to be treated; however, treatments may never be developed because of roadblocks in the development process, such as a lack of investment and a challenging regulatory environment.

[Insert a personal message of why this is important to you while referencing MPS or related disease. Example: "I am the father of _____ who was born with the rare disease MPS." Then reference how MPS affects your child and your family and the urgent need of beneficial treatments and cures.]

I hope you will become a champion for the rare disease community and help seek solutions that can spur the development of life-saving treatments for those who need it most. To join the caucus, please contact Nicole Cohen in Rep. Crowley's office at nicole.cohen@mail.house.gov, or Jeffrey Last in Rep. Lance's office at Jeffrey.Last@mail.house.gov. Please contact me with any questions you might have, or visit the National MPS Society Web site at www.mpssociety.org.

Sincerely,

Your name, address and contact phone number

If you would like to receive an electronic version of this letter, e-mail Laurie Turner at laurie@mpssociety.org.

Fun Ways to Connect with Your Congressmen

Contacting your senators or congressmen is easier than ever and takes very little time or effort. Of course, you will need a computer or a smart phone. Your congressmen are all on Facebook, Twitter, MySpace, Flickr and YouTube, and many of your elected officials now issue daily press briefings and monthly town hall meetings. Keep in contact! Instead of writing, e-mailing or calling to inform your elected officials, use these social media outlets to create more awareness of MPS and related disease. Just remember, information posted on these sites are not confidential, however, the information you receive can be extremely valuable. Your congressmen need to hear from you, whether on social Web sites, in person, by phone, etc. Take action. Get involved.

Here are some suggestions for using Twitter and Facebook to reach out to elected officials:

Facebook

- Keep content concise and on subject, 75 words or less, with the MPS Society link.
- Ask a question. It's the quickest way to involve your audience and make your content interactive.
- Make sure you are on the legislator's official page; this will be linked from their congressional Web site.
- Tell your representative to check out our Society's Facebook page and Web site.

Twitter

- Share in 140 characters or less. Links should almost always be posted with content on Twitter.
- Try to leave about 20 characters to spare, so people have a chance to retweet (repost) your content and add an optional comment.
- When appropriate, add a hash tag. Hash tags are a way to group tweets into a larger conversion. For more on hash tags, visit Twitter.