Checklist for a Potential Advocate:

☑ Do you feel access to treatments for MPS and related diseases should move faster?

☑ Is it important for our legislators to understand the complexities of MPS when making important decisions about healthcare coverage and disability laws?

☑ Should the National Institutes of Health and related government agencies prioritize research toward MPS and other related rare diseases that mostly affect children and save lives?

If you answered YES to any of these questions, than you are an MPS legislative advocate. This vital component of the National MPS Society's mission is easily accessible to you and all your friends and family through our "click and send" alerts. It only takes SECONDS to participate.

The Society's Committee on Federal Legislation tracks important legislation and ensures that our members are aware and engaged. Each action alert sent to Society members is a direct ask for you to contact your representatives to support legislation that will get us closer to research, treatments and, eventually, cures faster. It is critically important that you and as many people you know act on each and every action alert. You can even forward the action alert to your friends and family. The more clicks on the action alert equals the more likely your representative will take notice of what you are asking. Every single person counts!

Interested in revving up your advocacy efforts?

The Committee on Federal Legislation is looking for excited, engaged advocates to join our team. If you have a minimum of two hours a month to dedicate to MPS and related diseases advocacy, you are a prime committee candidate. Each month, the committee has a one-hour conference call to strategize and update on current advocacy legislation. Each committee member takes part in advocacy efforts during the time we have available in our lives each month.

To learn more about joining the Legislative Committee, contact:

Stephanie Bozarth
Chair, Committee of Federal Legislation
Vice President, Board of Directors
Stephanie.Bozarth@mpssociety.org
703.256.1980

Legislative Committee:

Stephanie Bozarth, *chair*
Amy Barkley
Jeff Bardsley
Austin Bozarth
Dawn Checrallah
Ernie Dummann
Lydia Edgal
Steve Holland
Terri Klein
MaryEllen Pendleton
Laurie Turner
Kim Whitecotton
Roy Zeighami
Barbara Wedehase

Super Advocates

Since February 2012, the MPS Society has launched nine "click and send" action alerts around important legislation to support MPS research, streamline the drug development and approval process and spread awareness. Following is a list of fabulous super advocates who are actively engaged in supporting important legislation. You can be a super advocate too! Respond to every MPS Society action alert and you will be a super advocate.

Sarah Asserude
mother of Ethan, MPS I

Amy Barkley
mother of Davis, MPS II

Austin Bozarth
father of Annabelle, MPS IV

Andrew Charest
father of Alan, MPS III

Bill Crocket
mother of Camden and Matthew, MPS II

Jerry Kanney
grandfather of Carter, MPS II

Kris Klenke
mother of Kraig, MPS II

Chuck Lukondi
father of Lacey and Allison, MPS III

Barry Mitchell
grandfather of Declan, MPS II

Sheila Morley
grandmother of Payton, MPS II

MaryEllen Pendleton
aunt of Allison, MPS III

Brooke Story
mother of Elijah, MPS II

Tracy Szemanski
mother of Clint and Zach, MPS III

David Tilsner
father of Max, MPS II

Laurie Turner
Program Director

Barbara Wedehase
Executive Director

Lisa Wells
mother of Matthew, MPS I

Kim Whitecotton
mother of Scotty, MPS II;
sister of Russell, MPS II

Policy with Partners: Time to Take Action!

Current Legislative Priorities and Action Items

• Ask your congressman to join the Rare Disease Caucus.

With the caucus now introduced in the 112th Congress, we need your help to drive membership. The caucus will help to further educate our legislators about the special needs of our MPS community and other rare disease communities with similar issues. This is where we start our search for advocacy champions who can greatly influence legislation important to us. You will be able to determine if your congressman is in the caucus at **www.rarediseaseadvocates.org**.

• Develop a relationship with your representative and let your voice be heard!

We asked our consultants at M+R Strategic Services to conduct an online training session for our members. The goal was to help our members learn how to meet with their members of Congress to advocate for research funding and other important policies related to MPS diseases. There's no better way for us to fight for funding and policies to advance new treatments and ultimately a cure for MPS than meeting with lawmakers and telling our stories.

A previously recorded training session is posted on the Society's website; it takes less than an hour to view. There also are lots of great handouts posted on the website that provide a step-by-step guide to meeting with your lawmakers in your home state. Go to our website under Members Only—Legislative Toolkit. Under "How to Webinar," click on "Guide to in-district Legislative Visits."

Legislation and Initiatives Supported by the MPS Society

The Kids First Research Act of 2013 (H.R. 2019). This bipartisan bill would eliminate taxpayer financing of presidential campaigns and party conventions and reprogram those savings to provide for a 10-year pediatric research initiative through the Common Fund administered by the National Institutes of Health.

Compassionate Allowances within Social Security Administration (SSA)—A National Organization for Rare Disorders letter to Acting SSA Commissioner Carolyn W. Colvin, as well as the U.S. senators and representatives with jurisdiction over SSA, urging continuation of this important program and continued expansion of the list of diseases.

The Orphan Drug Tax Credit (ODTC) is part of a package of provisions enacted in 1983 in the Orphan Drug Act that provide incentives for drug companies to develop products for rare diseases. Tax reform is planned for this Congress and the ODTC is on the table for elimination. Drug companies need more incentives to develop rare disease treatments, not less. Congress must hear from the patient community that this incentive is important.

Undiagnosed Diseases Research & Collaboration Network (H.R. 1591) will help reduce the length of time and number of physicians it currently takes to diagnose patients with a rare disease by creating a professional physician collaboration network and providing a means to collect and analyze information on undiagnosed cases.

The Newborn Screening Saves Lives Reauthorization Act (H.R. 1281) reauthorizes critical federal programs that provide assistance to states to improve and expand their newborn screening programs, support parent and provider education, and ensure laboratory quality and surveillance for newborn screening.

To read details about legislative initiatives, go to www.rareadvocates.org

Legislative Advocacy—A Member's Prospective

by Jeff Bardsley

I joined the National MPS Society's board of directors in the winter of 2011. While I was a new member and unfamiliar with many of the Society's programs and outreach efforts, it was obvious to me where my initial efforts should begin. As a resident and having spent all my youth in the Washington, DC, area, I already had a familiarity and comfort level with political discussions, public affairs and the unpredictable behaviors of our nation's elected officials. As a board member, I serve on committees committed to planning and executing strategies for the betterment of the Society and its membership. It felt only natural that I begin my time on the board working on the Society's Legislative Committee, having already joined previous Society leaders in their visits to congressional offices for discussions on current Society priorities, such as National Institutes of

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>> Health (NIH) research funding levels and new mechanisms for supporting commercial development of rare disease therapies.

Since then, I have seen the continued success of our legislative efforts. The recognition of May 15 as National MPS Day has continued year after year without a hitch. NIH funding designated for MPS-related research has grown approximately 13 percent since 2010, despite the extremely difficult and cost-conscious budget climate today. The National MPS Society has become a familiar name among rare diseases groups in congressional offices. Our collaboration with other rare disease organizations, such as the National Organization for Rare Disorders and the Kakkis EveryLife Foundation, improves our ability to help get important measures passed that affect the entire rare disease community and increase patient access to life-changing therapies.

However, we still can accomplish much more. A large part of our recent progress is that more members are being independent advocates and reaching out to their congressmen and senators on a personal level. There is power in numbers! The significance of pre-existing relationships with your congressman or senator is crucial. Staff liaisons are much more sensitive to the personal stories and challenges brought to their attention by their member's constituents. That's why one of the Legislative Committee's top ongoing priorities is making it easy for members to participate in the political process and develop relationships with their respective elected officials.

With the current efforts being made by the Legislative Committee and the growing advocacy being done by our members, I can't help but be excited about the potential impact the Society can make for our families in the future. With a well-established network of patient and family advocates, we can effectively add our voices to policy discussions and help bring positive change for the entire rare disease community.

REMEMBERING

our children

Cenia Adame
17, MPS I, 7/18/13

Rachel Barrett
25, MPS I, 8/2/13

Tad Harvey
14, MPS II, 8/21/13

Nathan Marquez
11, MPS VII, 5/22/13

Mindy Rennaker
45, MPS III, 7/11/13