

Legislative Committee Members:

Ernie Dummann, Chair

Debbie Dummann

Laurie Turner

Steve Holland

Terri Klein

Stephanie Bozarth

Amy Barkley

Austin Noll

MaryEllen Pendleton

Barb Wedehase

Kim Whitecotton

Kelly Rose

Jeffrey Bardsley

Projects Completed YTD 2011

- Congressional Yellow Book and Training for Resource Guide
- Collaboration and Communication with SAB and NIH
- FY 2012 MPS Appropriations Language Request
- FY 2011 Public Policy Statement Update
- National MPS Awareness Day 2011
- DC Meetings with Congress and Policy Makers
- DC Meetings with Rare & Neglected Disease Caucus
- Requesting Full Funding for the Lifespan Respite Care Act (FY 2012)

Committee Priorities for 2011

- Appropriations Language Due March 2012 for FY 2013
- Annual Update of MPS Public Policy Statement
- National MPS Awareness Day 2012
- NIH and Congressional Meetings
- Social Security Administration Compassionate Allowance
- Increase Funding of Lifespan Respite Act
- Expansion of Policy with Partners Campaign (PwP)
- Rare and Neglected Disease Caucus
- Kakkis EveryLife Foundation Collaboration, Cure The Process
- PwP Direct Membership Advocacy Visits to Congress
- PwP Direct Communications and Input from Membership
- Attending the Rare Disease Legislative Advocates Meetings
- Track Proposed Legislation Affecting Families with MPS