

# **National MPS Society Strategic Planning Documents**

**This package contains the following documents related to the future direction of National MPS Society.**

- **Mission and Vision Statements**
- **Values Statement**
- **2011-2015 Strategic Plan**
- **Tactical Plans for 2011-2013 Related to Each Goal Area**

# National MPS Society Mission and Vision Statements

## **Mission** (Our purpose for existing)

The National MPS Society exists to find cures for MPS and related diseases. We provide hope and support for affected individuals and their families through research, advocacy, and awareness of these devastating diseases.



## **Vision** (Our dream for tomorrow)

The National MPS Society is universally respected, sought out and supported because of its research program, support to families, and advocacy efforts.

### ***We will know we are capable of achieving our vision when:***

#### **Strategic Relationships**

- Key constituencies view our Society as a “best practices” organization.
- We are achieving demonstrable success as compared to other rare disease-related organizations.
- We have expanded our programs to include growing numbers of allied organizations and collaborative partners working together to achieve common goals.

#### **Family Support**

- Our member families are demonstrating more commitment to the MPS Society, its programs and to helping each other.
- We are able to measure and quantify the positive impacts of our programs on both the individuals we serve and their families.
- We maintain successful bridges to the individuals and families we serve from diagnosis through the passing of the child and beyond.

#### **Governance**

- Our board is establishing strategy, ensuring that we have the people and the money to sustain the organization, the means to measure success and guiding the organization in keeping with its strategic plan.

#### **Research**

- Our investments in research are growing as well as resulting in tangible gains.

#### **Advocacy**

- Our legislative advocacy capabilities are steadily increasing.
- We are able to keep pace with emerging needs through cutting edge approaches to service, a growing base of knowledge and our associations with key medical researchers and practitioners.

#### **Awareness**

- The Society is known, respected and recommended among all key constituencies.
- We are providing critical information related to disease management, current MPS research, associated medical advances, and available treatments and therapies.
- We are successfully communicating our mission and marketing the organization effectively to all important audiences.

### ***Overarching Strategies:***

#### ***How we will address the needs of the children and families we serve:***

- Program service quality will always come ahead of numbers growth.
- Family support and development will be primary to all we do.
- We will focus on supporting modern therapies and advanced technologies.
- Our revenue generation focus will be on developing a pool of individual donors who are willing to make long-term commitments to the Society.

# National MPS Society Values and Operating Principles Statement

| <b>Values</b> (As an organization and as individuals)  |  |
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| <b><i>In everything we do, we will focus our efforts on direct benefits to the Society's Members and Stakeholders...</i></b> |  |
| <b>Through</b>   | <b>By</b>  |
| <b>Our Focus and Our Mandate</b>   | <ul style="list-style-type: none"> <li>• Maintaining as our principal areas of focus individuals and their families who are suffering from MPS and related diseases.</li> <li>• Pursuing only those activities that are in keeping with our mission as an organization dedicated to serving those who are suffering from MPS and related diseases.</li> <li>• Serving everyone regardless of gender, age, race, religion, sexual orientation, or national origin.</li> <li>• Following and reporting on all beneficial research undertaken worldwide.</li> </ul>   |
| <b>Our On-going Commitment to Meeting Individual Needs</b>   | <ul style="list-style-type: none"> <li>• Being entrepreneurs in developing innovative specialized niche approaches to treatment referral, education, advocacy, and continuing care for the patients and families we serve.</li> <li>• Maintaining a "best of service" policy towards every individual and family we touch.</li> <li>• Funding research for all MPS and related diseases.</li> <li>• Relying on the Scientific Advisory Board and other professionals for their guidance, assistance, and expertise.</li> <li>• Cooperating, collaborating, and communicating with all organizations and institutions that are dedicated to finding treatments and cures for all Lysosomal Storage Diseases.</li> <li>• Maintaining confidentiality of all member information.</li> <li>• Valuing interaction, feedback and constructive criticism from our members.</li> </ul> |
| <b>Our Approach and Our Innovative Agenda</b>  | <ul style="list-style-type: none"> <li>• Developing programming and service that is cutting edge.</li> <li>• Treating every patient and family with whom we interface with accountability balanced with dignity, compassion, and sensitivity.</li> <li>• Building collaborative relationships with other organizations critical to the growth and effectiveness of our programs.</li> </ul>  |
| <b>Our Stewardship of Contributed Resources</b>  | <ul style="list-style-type: none"> <li>• Maintaining financial strength and integrity so that we can carry out our mission.</li> <li>• Effectively and economically managing the resources entrusted to us.</li> <li>• Continually assuring that benefits of any activity are in keeping with the human and financial costs of delivery.</li> <li>• Valuing and practicing ethical fundraising.</li> </ul>   |
| <b>Nurturing and Developing Our Human Resources</b>  | <ul style="list-style-type: none"> <li>• Maintaining a committed Board of Directors along with an outstanding and caring staff.</li> <li>• Ensuring that our Board members and employees follow the highest ethical standards by making honesty and integrity non-negotiable for all board and staff.</li> <li>• Building on our commitment to help our staff become all they can be in advancing our mission.</li> </ul>  |
| <b>A Pursuit of Excellence in All We Do</b>  | <ul style="list-style-type: none"> <li>• Being viewed as a best practices organization by the communities we serve.</li> <li>• Maintaining unwavering compliance to all applicable rules and regulations.</li> <li>• Striving for excellence in all services, programs, and activities.</li> <li>• Complying with our organizational mandates both formal and informal in order to achieve the highest standards of service to our stakeholders.</li> <li>• Recognizing those who contribute to our success and to the quality of life of those we serve.</li> <li>• Measuring our success by outcomes and lessons learned</li> </ul>  |

# National MPS Society Strategic Plan 2011-2015

| Principal Goal Areas           | Long-Term Goals<br>(Where we'd like to be in 3-5 years)   | Annual Goals for 2011-2013<br>(Major targets for current planning year)  | Barriers/Opportunities<br>(Inhibitors, boosters to progress toward goals this year.)   | Strategies<br>(Best approaches for addressing barriers, opportunities.)   |
|--------------------------------|---|--|--|---|
| <b>Governance Committee</b>    |   |  |  |   |
| <b>Governance</b>              | <p>Our board will be capable of raising the resources necessary for us to fulfill our mission and pursue our vision on a sustained basis.</p> <p>Establish a resource board with a focus on fundraising or specific tasks</p> <p>Maintain representation on the board among the disease syndromes</p> | <ul style="list-style-type: none"> <li>Consider expanding the board from the current 13 members to the 15 allowed under the by-laws.</li> <li>Brainstorm on potential uses/tasks for a resource board.</li> </ul>  | <ul style="list-style-type: none"> <li>&lt;O&gt; We have a committed board of which everyone has a stake in curing MPS.</li> <li>&lt;B&gt; Increased costs and logistical complexities.</li> </ul>                         | <ul style="list-style-type: none"> <li>Ensure that every board member understands his/her duties.</li> <li>Create a board performance scorecard to track board engagement.</li> <li>The board will spend 50% of its time focusing on improving organizational sustainability and supporting fundraising.</li> <li>Conduct an annual review of bylaws.</li> <li>Conduct an annual board self-assessment.</li> <li>Create a job description and charge for each committee.</li> <li>Evaluate the need and potential for board expansion.</li> <li>Board members continue/increase visibility in promoting the Society.</li> <li>Maintain the broad diversity that is now represented on the board.</li> </ul> |
| <b>Executive Committee</b>     |   |  |  |   |
| <b>Talent and Organization</b> | <p>Have a human resources complement that is fully capable of fulfilling the mission of the Society in place and fully funded, including family support, education, development, and legislative/regulatory advocacy.</p> <p>Oversee committee structure and activities.</p>                          | <ul style="list-style-type: none"> <li>Determine staffing needs to meet projected growth.</li> <li>Establish realistic goals for staff in keeping with resources.</li> <li>Contract with firm for legislative/regulatory advocacy assistance in 2013.</li> </ul> | <ul style="list-style-type: none"> <li>&lt;O&gt; Increased staffing would allow us to take on and successfully carry out major additional programs.</li> <li>&lt;B&gt; Increased administrative/staffing costs.</li> </ul> | <ul style="list-style-type: none"> <li>Ensure annual performance evaluations are performed on every staff member, including the ED, in relation to plan-related targets set at the beginning of the year.</li> <li>Look at cost sharing with other organizations as a means of reducing our costs associated with the future hiring of a legislative staff person.</li> <li>Determine the limits of our expenditures related to legislative advocacy.</li> <li>Determine what we need to do to ensure ongoing staff development.</li> </ul>   |
| <b>Succession Planning</b>     | <p>Create an "Emergency Succession Plan"</p>  | <ul style="list-style-type: none"> <li>Define and agree upon the process to be used to find a successor in the event we lost our executive director as well as what decisions need</li> </ul>  | <ul style="list-style-type: none"> <li>&lt;B&gt; We are staffed by long-term employees who will be difficult to replace.</li> </ul>  | <ul style="list-style-type: none"> <li>Design a simple plan for Board leadership and Executive Director succession.</li> <li>Develop a one or two page set of guidelines that can be immediately implemented in the case of an emergency or unexpected event</li> </ul>   |

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|                                 |  | <p>to be made organizationally in preparation for launching the succession process by July 2013.</p> <ul style="list-style-type: none"> <li>• Complete a brief emergency Succession Plan outlining the assignment of responsibilities in the case of a sudden loss of the Executive Director or the President by July 2013.</li> <li>• Complete a risk assessment for the Society.</li> </ul>  |   | <p>that forces a change in top management.</p> <ul style="list-style-type: none"> <li>• Conduct an organizational risk assessment.</li> <li>• Ensure all critical electronic data is automatically backed up and maintained off site.</li> </ul>  |
| <b>Program Oversight</b>        | <p>Develop projects with the pharma companies to increase early diagnosis and improve the lives of patients</p>  | <ul style="list-style-type: none"> <li>• Launch the rheumatology initiative to target unidentified patients.</li> <li>• Support inclusion of MPS conditions in new born screening activities conducted by states</li> <li>• Facilitate member attendance at clinic patient meetings.</li> </ul>  |   | <ul style="list-style-type: none"> <li>• Participate in periodic rheumatology initiative meetings.</li> <li>• Identify processes for adding MPS conditions to new born screening panels.</li> <li>• Notify members of patient meetings and provide Society representation when needed.</li> </ul>   |
| <b>Family Support Committee</b> |  |  |   |   |
| <b>Family Support</b>           | <p>Be responsive to the needs of the families we are in business to serve, particularly newly diagnosed families.</p> <p>Develop a long-term strategy for keeping the Society relevant to the following subgroups: young adults with MPS, families receiving treatments (BMT or ERT), bereaved families, and siblings as they become adults.</p> | <ul style="list-style-type: none"> <li>• Determine what adjustments and/or additions to programming need to be made in order to expand our community of families, including targeted subgroups, and the support they feel they need.</li> <li>• Make greater use of the internet, web site and social media in reaching out to parents.</li> <li>• Reach out to young adults with MPS to identify needed supports</li> <li>• Evaluate success of ongoing programs and consider new programs based upon needs of the families.</li> </ul> | <ul style="list-style-type: none"> <li>• &lt;B&gt; Limited funds restricted for family support programs as most families prefer to restrict funds for research.</li> </ul>  | <ul style="list-style-type: none"> <li>• Develop a strategy for informing families of the many ways we can and do support them.</li> <li>• Create a landing page on our web site that is tailored to the prospect's emotional state, the information most sought after and the resources that are available.</li> <li>• Maintain ongoing contact with bereaved families and develop strategies aimed at keeping them engaged.</li> <li>• Reconnect with families who have moved away from the Society.</li> <li>• Begin making broader use of seasoned members to "mentor/advise" newly diagnosed families.</li> <li>• Utilize members whose affected children have passed as host families.</li> <li>• Focus on super-siblings of the children we serve and consider how to keep them involved once they become adults.</li> </ul> |
| <b>Conferences</b>              | <p>Maintain high quality of conference experience and consider ways to increase attendance.</p> <p>Make outcomes and the value of research grants more visible at conferences.</p>   | <ul style="list-style-type: none"> <li>• Evaluate all aspects of current conference experience and consider whether changes are desired.</li> <li>• Increase the exposure of our sponsored research at</li> </ul>  | <ul style="list-style-type: none"> <li>• &lt;O&gt; Average conference attendance is 300 with 700-800 attending the conferences that we hold at Disney.</li> <li>• &lt;B&gt; Travel costs to attend conferences for the entire family can be expensive.</li> </ul> | <ul style="list-style-type: none"> <li>• Determine how we can restructure our conference to attract more people.</li> <li>• Offer more opportunities for families to attend sessions of interest and run them concurrently.</li> <li>• Determine the feasibility of bringing in a nationally known motivational speaker.</li> </ul>   |

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|   |   | conferences.  |   | <ul style="list-style-type: none"> <li>We will attempt to support as many people interested in attending conferences as we can.</li> <li>Conduct lay poster sessions at our conferences to give families and researchers a chance to connect.</li> </ul>   |
| <b>Legislative Committee</b> (consider adding ongoing responsibilities from old SP)         |   |   |   |  |
| <b>Legislative/Regulatory Advocacy</b>  | People important to our legislative agenda on Capitol Hill will have a growing awareness of MPS and our goals.  | <ul style="list-style-type: none"> <li>Increase our capabilities to a level where we can be effective in promoting our legislative agenda.</li> <li>Expand our PWP Program and grow the number of active participants by 10%.</li> </ul>  | <ul style="list-style-type: none"> <li>&lt;B&gt; If NIH money dries up, our researchers will lose funding.</li> </ul>   | <ul style="list-style-type: none"> <li>Evaluate firms that can provide legislative/regulatory advocacy assistance in 2013 and recommend firm for engagement.</li> <li>Advocate change within the FDA that will eliminate the need for the pharma companies to hold trials in Europe and limit the size of trial participants for rare disease clinical trials.</li> <li>Encourage Congress to increase their funding of NIH for research and advocate within the NIH that those funds be directed towards areas benefitting MPS conditions.</li> <li>Focus heavily on Congressional appropriations committee staffs.</li> </ul>                  |
| <b>Strategic Relationships</b>  | <p>We will develop strong, face to face relationships with those organizations and individuals who can positively or negatively impact our progress and sustainability.</p> <p>Build better relationships with peer and related nonprofits and establish collaborative initiatives in those cases where both parties can benefit.</p> | <ul style="list-style-type: none"> <li>Identify and initiate or improve relations with the top 10 organizations and individuals with whom we must have positive relationships or with whom relationships must be improved if we are to grow.</li> </ul>   |   | <ul style="list-style-type: none"> <li>Explore and improve our relationships with organizations that deal with and/or provide treatments/therapies for individuals with MPS.</li> <li>Develop closer relationships with Commissioner Michael Astrue, Nancy Schoenberg of Compassion Alliance group, Catherine Sebalias, and Commissioner Margaret Harberg of the FDA.</li> </ul>   |
| <b>Education/Publicity Committee</b> (consider adding ongoing responsibilities from old SP) |   |   |   |  |
| <b>Marketing and External Communications</b>  | Create national awareness of the Society and MPS (MPS Awareness Day), especially in the professions (social workers, genetic counselors, researchers, teachers, pediatricians), so as to become the go-to organization serving MPS patients and their families.   | <ul style="list-style-type: none"> <li>Develop a marketing plan and strategy that leads to and supports the Society's awareness and reputation building needs.</li> <li>Do a better job of capturing and promoting our successes</li> <li>Complete the strengthening of our web site and ensure that it is effective as a membership building, donation receiving vehicle and source of information.</li> </ul> | <ul style="list-style-type: none"> <li>&lt;B&gt; Few people outside of the MPS community know us and many have no awareness of our programs or needs; nor do they know what we do. We are not known across the general community.</li> <li>&lt;B&gt; We are not making effective use of social media.</li> <li>&lt;B&gt; We are not as effective as we can be using blast e-mails.</li> </ul> | <ul style="list-style-type: none"> <li>Create a PR/Marketing plan for a campaign to educate the public about MPS.</li> <li>Create a set of key messages to be included in all communications.</li> <li>Develop a specialized packet of materials to drive people to the Society.</li> <li>Ask all labs that do testing to include a recommendation at the bottom of every positive results report that includes a referral to the National MPS Society and its web address and phone number.</li> <li>Utilize Google as a membership development tool and adjust the language we use so it drives people to a special landing page on</li> </ul> |

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|  |   | <ul style="list-style-type: none"> <li>Complete the updating of the MPS video including various modules that can be used in a variety of venues.</li> <li>Launch and/or strengthen a speaker's bureau and secure at least 12 forums for the coming year that will put us before important constituencies.</li> </ul>   |  | <ul style="list-style-type: none"> <li>our web site.</li> <li>Go through an exercise to optimize search engines in order to increase contact and promote new membership development.</li> <li>Develop a strategy for getting in front of more people who can become donors and supporters.</li> <li>Board members will conduct public presentations to groups to expand the sphere of influence.</li> </ul>  |
| <b>Education and Member Communications</b> | Increase the value of our overall communications and educational programs targeted to members.  | <ul style="list-style-type: none"> <li>Develop a CD with information and resources all in one place to be used by parents.</li> <li>Develop materials to be used specifically to engage newly diagnosed parents.</li> <li>Make more effective use of the internet and social media, (Facebook in particular) in serving parents.</li> <li>Create a major social media initiative and launch in 2011.</li> </ul>  |  | <ul style="list-style-type: none"> <li>Slowly begin to shift the volume of communications from heavily print to more on-line communications.</li> <li>Produce the member directory on line through our website.</li> </ul>   |
| <b>Fundraising Committee</b>               |   |  |  |  |
| <b>Fundraising</b>                         | <p>Raise \$2 million in contributions by 2016.</p> <p>Increase the endowment from the current \$1 million to \$1.1 million by 2016.</p> | <ul style="list-style-type: none"> <li>Raise \$1 million from all sources including: <ul style="list-style-type: none"> <li>\$40k from memberships.</li> <li>\$90k from the annual fund.</li> <li>\$XXXk from pharma companies.</li> <li>\$40k in operating grants.</li> <li>\$300k from Walk/Runs.</li> <li>\$160k from fundraising events.</li> </ul> </li> <li>Complete the annual updating of the fund development plan. We will emphasize multiyear commitments (ideally three to five years) when asking for gifts from individuals and businesses.</li> <li>Create a canned presentation for use in promoting the Society.</li> </ul> | <ul style="list-style-type: none"> <li>&lt;O&gt; our average gift is \$193.</li> <li>&lt;O&gt; Every year, the results of our annual fund drive have increased</li> <li>&lt;O&gt; The current endowment produces \$40k annually for operating expenses.</li> <li>&lt;B&gt; income from walk/runs has been on the decline in recent years.</li> </ul> | <ul style="list-style-type: none"> <li>Increase the level of face-to-face contact with corporate and foundation prospects.</li> <li>A board member will be available at events (when financially feasible) to present the MPS story and to thank the participants for their support.</li> <li>Ensure that the board continues to engage in its fundraising role and ask each member to complete the annual pledge and to host a fundraising event.</li> <li>Expand our young philanthropist program.</li> <li>Develop close relations with Medtronic's, Johnson &amp; Johnson, Integra, Durable medical Equipment companies, and Novatis.</li> <li>Determine what other companies can offer potential benefits to us and us to them.</li> <li>Invite potential target companies to exhibit at our conferences.</li> <li>Board members will personally call to thank all donors of \$XXX or more.</li> <li>Secure contact information from everyone who attends our events and the families we serve.</li> <li>Begin to look for ways to tap individual donors</li> </ul> |

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|  |   |   |  | beyond our families and events.   |
| <b>Grants</b>                                    | Strengthen our performance in securing grants from government, foundations and businesses.  | <ul style="list-style-type: none"> <li>Identify at least 3 new institutional grant sources with better than average potential for granting to the Society.</li> </ul>   | <ul style="list-style-type: none"> <li>&lt;B&gt; We have not had success in securing grants.</li> </ul>  | <ul style="list-style-type: none"> <li>Utilize the board in developing potential granting targets.</li> <li>Link business grant soliciting to businesses that supply products to MPS families.</li> </ul>   |
| <b>Major Donor Development</b>                   | By 2015, develop a base of major donors and donor prospects with the potential of providing \$.5 million in annual support of the Society.  | <ul style="list-style-type: none"> <li>Add three new major donors at \$10k or above in 2013.</li> <li>Identify five potential high dollar donors (\$2,500) and develop a specific strategy for connecting with each.</li> </ul>   |  | <ul style="list-style-type: none"> <li>Identify high potential giving partners across the MPS spectrum (particularly wealthy individuals or business owners who may have family members with MPS).</li> <li>Identify at least three major donor prospects from every Run/Walk event.</li> <li>Continue to use Courage as a vehicle for asking constituents to help identify major donor prospects.</li> <li>Task the board with helping to identify new large donor prospects.</li> <li>Create a quarterly publication for major donors.</li> </ul> |
| <b>Planned Giving</b>                            | Develop a fully functioning planned giving program that consistently provides key funding each year.  | <ul style="list-style-type: none"> <li>Roll out planned giving program to membership.</li> <li>Obtain ten commitments for membership in the Rising Sun Legacy Circle.</li> </ul>  | <ul style="list-style-type: none"> <li>&lt;B&gt; New program starting from scratch.</li> </ul>   | <ul style="list-style-type: none"> <li>Cull the donor list and create a planned giving target donor list of those who have given to the Society for five years or more.</li> </ul>  |
| <b>Membership Development and Sustainability</b> | <p>Retention levels for members (in terms of average months of membership) will increase steadily over the next several years.</p> <p>Over time, reduce the annual cost per member.</p> <p>Develop a long-term strategy for keeping the Society relevant to affected young adults and</p> | <ul style="list-style-type: none"> <li>Develop the protocols that make it easy for families to contact us and to remain engaged.</li> <li>Reach out to young adults as a key membership development strategy.</li> <li>Resolve the question of charging for memberships versus asking families for donations and bring the recommendation to the</li> </ul> | <ul style="list-style-type: none"> <li>&lt;B&gt; Families are not aware of the range of services we offer, or the impact of those services.</li> <li>&lt;B/O&gt; we have approximately 750 members families today.</li> <li>&lt;B&gt; We do not know the size of our target market.</li> </ul> | <ul style="list-style-type: none"> <li>Work with the pharma companies to try to quantify the size of our target market.</li> <li>Evaluate the practice of free memberships for newly diagnosed parents.</li> <li>Consider creating a lifetime membership.</li> <li>Determine how we might improve upon our ability to communicate with clinicians as a means of connecting with newly-diagnosed families.</li> <li>Better adapt the web site for promoting membership development.</li> </ul>   |

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|  | siblings as they become adults. | board by the Fall 2013 BOD meeting. |  | <ul style="list-style-type: none"> <li>• Begin asking for sibling information as part of our membership application process.</li> <li>• Consider offering complimentary memberships to adult siblings living outside of the home.</li> <li>• Focus on our mentors and “fellow travelers” as a most important contact for newly diagnosed families.</li> </ul> |
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### Technical/Research Committee

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| <b>Maintain Communications with SAB</b>  | <p>Working together with the SAB we will define the optimal direction for our research program.</p> <p>Through our relationships with the SAB we are apprised of current research.</p> | <ul style="list-style-type: none"> <li>• Take recommendations of “future directions” SAB committee to the full SAB for discussion and subsequent board approval,</li> <li>• Inform members about cutting edge research</li> </ul> | <ul style="list-style-type: none"> <li>• Social media is empowering people to independently raise and distribute research funds. The Society must maintain relevance as a funding organization.</li> <li>• Decreases in research dollars to the Society reduces available grants</li> </ul> | <ul style="list-style-type: none"> <li>• Educate our membership about the benefits of the proposed research direction</li> </ul>   |
| <b>Administer Research Grant Program</b> | <p>Determine grants to be offered in February, based on SAB recommendations. Money is awarded July 1<sup>st</sup>.</p>   | <ul style="list-style-type: none"> <li>• Apprise committee of status of grants program through all stages.</li> </ul>   |   | <ul style="list-style-type: none"> <li>• Establish SAB review committee</li> <li>• Announce submission deadline for letters of intent</li> <li>• Review LOI, request full proposals, review proposals</li> <li>• Technical committee reviews SAB committee funding recommendations via conference call and makes final recommendations to BOD</li> <li>• Following BOD vote, grants are funded after we received signed Research Policy</li> <li>• Second year funding dependent on receiving first year review and financial review.</li> </ul> |

## Instructions for Completing the Tactical Sections of the Plan

- First, assign someone from the board or key staff the responsibility for overseeing each tactical plan section. The individual assigned to manage/oversee each section should be the most senior staff or board person (for example: Board Governance would go to the Chair of the Nominating Committee, Programs to the senior staff person in charge of programs, etc.)
- Next, the individuals charged with overseeing each tactical section should meet with the appropriate staff and board team members and review the action steps, eliminating any that are not relevant, have been completed or cannot be done. Other action steps should be changed as appropriate.
- Each action step should be assigned a priority level. Use the Shading feature in Word (the little paint bucket) to fill in the appropriate colors.
- Next, assign a due date or target completion date for each action step in the Date Due Column.
- Indicate who will have primary responsibility for each action step. In the Primary responsibility Column (names or initials may be used).
- List any team members who will be supporting the action step in the Column labeled Team Members.
- If there is an incremental cost (not budgeted) associated with the action step, enter the estimate in the Estimated Incremental Cost Column.
- Finally, assign a status level in the extreme right hand column that indicates the current status. Each responsible individual is assigned the responsibility of updating the status column at the end of every month by inserting the appropriate fill color. Brief comments may be made in these cells as well related to status. For example if an action step is in the Red you might want to enter the reason.

## National MPS Society (Governance Committee) Tactical Plan 2011-2013

| Target/Strategy<br>(From Annual Goals and Right-Hand Column of Strategic Plan Goal Areas)                            | Action Steps for Each Target and/or Strategy   | Date Due | Primary Responsibility | Team Members | Estimated Cost | Priority          | Current Status                           |
|--|--|----------|------------------------|--------------|----------------|-------------------|--|
|  |  |          |                        |              |                | TOP<br>MID<br>LOW | ON PLAN<br>BEHIND<br>AT RISK<br>COMPLETE |
| <b>Governance - General</b>  |  |          |                        |              |                |                   |  |
| Consider expanding the board from the current 13 members to the 15 allowed under the bylaws.                         | Determine what skills are needed to round out the board in terms of organizational need going forward and charge the Governance committee with identifying candidates.                                 |          |                        |              |                |                   |  |
| Brainstorm on potential uses/tasks for a resource board.   | Identify areas where the Society is in need of assistance and identify resources to meet those needs, especially by individuals interested in working on projects rather than being full boardmembers. |          |                        |              |                |                   |  |
| Ensure that every board member understands his/her duties.   | Publish a list of board member roles and responsibilities and ask each member to sign them.  |          |                        |              |                |                   |  |
| Create a board performance scorecard to track board engagement.  | "Review Bill Bennington's board engagement tracking tool to see if it would be helpful as a board performance scorecard.   |          |                        |              |                |                   |  |
| The board will spend 50% of its time focusing on improving organizational sustainability and supporting fundraising. | Ensure that a review of where the Society stands in relation to its fundraising goals are a prominent portion of every board meeting.  |          |                        |              |                |                   |  |
| Conduct an annual review of bylaws.  | Complete the review and bring the recommendations to the board by the last board meeting of each year.   |          |                        |              |                |                   |  |
| Conduct an annual board self-assessment.   | Conduct a performance assessment of the board for the prior year to be presented at the first meeting of the next year.  |          |                        |              |                |                   |  |
| Create a job description and charge for each committee.  | Consider using information from Bill Bennington and the bylaws to develop a committee job description and charge.  |          |                        |              |                |                   |  |
| Evaluate the need and potential for board expansion beyond the 15 members allowed by the bylaws.                     | Determine if an expansion of the board is called for and if yes, determine what the size and structure might look like.  |          |                        |              |                |                   |  |
| Board members continue/increase visibility in promoting the Society.   | Determine how board members can be more engaged in promoting the organization and then take the recommendations to the full board for approval.  |          |                        |              |                |                   |  |
| Maintain the broad diversity that is now represented on the board.   | When considering adding new members, ensure that the diversity balance and goals are being considered.   |          |                        |              |                |                   |  |

## National MPS Society (Executive Committee) Tactical Plan 2011-2013

| Target/Strategy<br><i>(From Annual Goals and Right-Hand Column of Strategic Plan Goal Areas)</i>  | Action Steps for Each Target and/or Strategy  | Date Due | Primary Responsibility | Team Members | Estimated Cost | Priority          | Current Status                            |
|---|---|----------|------------------------|--------------|----------------|-------------------|---|
|   |   |          |                        |              |                | TOP<br>MID<br>LOW | ON PLAN<br>BEHIND<br>AT RISK<br>COMPLETED |
| <b>Talent and Organization</b>  |   |          |                        |              |                |                   |   |
| Determine staffing needs to meet projected growth.  |   |          |                        |              |                |                   |   |
| Establish realistic goals for staff in keeping with resources.  |   |          |                        |              |                |                   |   |
| Contract with firm for legislative/regulatory advocacy assistance in 2013.  |   |          |                        |              |                |                   |   |
| Ensure annual performance evaluations are performed on every staff member, including the ED, in relation to plan-related targets set at the beginning of the year.  |   |          |                        |              |                |                   |   |
| Look at cost sharing with other organizations as a means of reducing our costs associated with the future hiring of a legislative staff person.   |   |          |                        |              |                |                   |   |
| Determine the limits of our expenditures related to legislative advocacy.   |   |          |                        |              |                |                   |   |
| Determine what we need to do to ensure ongoing staff development.   |   |          |                        |              |                |                   |   |
| <b>Succession Planning</b>  |   |          |                        |              |                |                   |   |
| Define and agree upon the process to be used to find a successor in the event we lost our executive director as well as what decisions need to be made organizationally in preparation for launching the succession process by July 2013. | Design a simple plan for Board leadership and Executive Director succession.  |          |                        |              |                |                   |   |
| Complete a brief emergency Succession Plan outlining the assignment of responsibilities in the case of a sudden loss of the Executive Director or the President by July 2013.   | Develop a one or two page set of guidelines that can be immediately implemented in the case of an emergency or unexpected event that forces a change in top management. Consider using Bill Bennett's Emergency Role Clarification Template as a guideline.<br><br>Create an ad hoc committee of the board (supplemented by outside volunteers) to conduct an organizational risk assessment) |          |                        |              |                |                   |   |

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| Conduct an organizational risk assessment.  |   |  |  |  |  |  |  |
| Ensure all critical electronic data is automatically backed up and maintained off site.   |   |  |  |  |  |  |  |
| <b>Program Oversight</b>  |   |  |  |  |  |  |  |
| Launch the rheumatology initiative to target unidentified patients.                       |   |  |  |  |  |  |  |
| Support inclusion of MPS conditions in new born screening activities conducted by states. | Identify processes for adding MPS conditions to new born screening panels.        |  |  |  |  |  |  |
| Facilitate member attendance at clinic patient meetings.                                  | Notify members of patient meetings and provide Society representation when needed |  |  |  |  |  |  |
|   |   |  |  |  |  |  |  |

# National MPS Society (Family Support Committee) Tactical Plan 2011-2013

| Target/Strategy<br>(From Annual Goals and Right-Hand Column of Strategic Plan Goal Areas)   | Action Steps for Each Target and/or Strategy  | Date Due | Primary Responsibility | Team Members | Estimated Cost | Priority          | Current Status                           |
|---|---|----------|------------------------|--------------|----------------|-------------------|--|
|   |   |          |                        |              |                | TOP<br>MID<br>LOW | ON PLAN<br>BEHIND<br>AT RISK<br>COMPLETE |
| <b>Family Support - General</b>   |   |          |                        |              |                |                   |  |
| Determine what adjustments and/or additions to programming need to be made in order to expand our community of families, including targeted subgroups, and the support they feel they need. | <ul style="list-style-type: none"> <li>Maintain ongoing contact with bereaved families and develop strategies aimed at keeping them engaged.</li> <li>Reconnect with families who have moved away from the Society.</li> <li>Focus on super-siblings of the children we serve and consider how to keep them involved once they become adults.</li> <li>Consider offering complimentary memberships to adult siblings living outside of the home.</li> </ul> |          |                        |              |                |                   |  |
| Make greater use of the internet, our web site and social media in reaching out to parents.   | Create a landing page on our web site that is tailored to the prospect's emotional state, the information most sought after and the resources that are available.   |          |                        |              |                |                   |  |
| Reach out to young adults with MPS to identify needed supports.   |   |          |                        |              |                |                   |  |
| Evaluate ongoing programs and consider new programs based upon needs of the families  | <ul style="list-style-type: none"> <li>Develop a strategy for informing families of the many ways we can and do support them</li> <li>Utilize Survey Monkey to determine if current FS programs are meeting needs or what needs to be changed/added.</li> </ul>   |          |                        |              |                |                   |  |
| Begin making broader use of seasoned members to "mentor/advise" newly diagnosed families.   | Utilize members whose affected children have passed as host families.   |          |                        |              |                |                   |  |
| <b>Conferences</b>  |   |          |                        |              |                |                   |  |
| Evaluate all aspects of current conference experience and consider whether changes are desired.   | <ul style="list-style-type: none"> <li>Determine how we can restructure our conference to attract more people.</li> <li>Offer more opportunities for families to attend sessions of interest and run them concurrently.</li> <li>Determine the feasibility of bringing in a nationally known motivational speaker.</li> </ul>   |          |                        |              |                |                   |  |
| We will attempt to support as many people interested in attending conferences as we can.  | Determine the limits of support for conference scholarships.  |          |                        |              |                |                   |  |
| Increase the exposure of our sponsored research at conferences.   | Conduct lay poster sessions at our conferences to give families and researchers a chance to connect.  |          |                        |              |                |                   |  |
|   |   |          |                        |              |                |                   |  |



## National MPS Society (Legislative Committee) Tactical Plan 2011-2013

| Target/Strategy<br>(From Annual Goals and Right-Hand Column of Strategic Plan Goal Areas)   | Action Steps for Each Target and/or Strategy  | Date Due | Primary Responsibility | Team Members | Estimated Cost | Priority          | Current Status                           |
|---|---|----------|------------------------|--------------|----------------|-------------------|--|
|   |   |          |                        |              |                | TOP<br>MID<br>LOW | ON PLAN<br>BEHIND<br>AT RISK<br>COMPLETE |
| <b>Legislative/Regulatory Advocacy</b>  |   |          |                        |              |                |                   |  |
| Increase our capabilities to a level where we can be effective in promoting our legislative agenda.   | Evaluate firms that can provide legislative/regulatory advocacy assistance in 2013 and recommend firm for engagement.   |          |                        |              |                |                   |  |
| Expand our PWP Program and grow the number of active participants by 10%.   |   |          |                        |              |                |                   |  |
| Advocate change within the FDA that will eliminate the need for the pharma companies to hold trials in Europe and limit the size of trial participants for rare disease clinical trials.              | Participate in collaborative change efforts including Kakkis Every Life Foundation and other FDA change efforts.  |          |                        |              |                |                   |  |
| Encourage Congress to increase their funding of NIH for research and advocate within the NIH that those funds be directed towards areas benefitting MPS conditions.                                   | Focus heavily on appropriations committee staffs. (Determine the who, when and how.)  |          |                        |              |                |                   |  |
| <b>Strategic Relationships</b>  |   |          |                        |              |                |                   |  |
| Identify and initiate or improve relations with the top 10 organizations and individuals with whom we must have positive relationships or with whom relationships must be improved if we are to grow. | Develop recommendations on how we can improve our relationships with organizations that deal with and or provide treatments/therapies for individuals with MPS. |          |                        |              |                |                   |  |
| Develop closer relationships with Commissioner Michael Astrue.  |   |          |                        |              |                |                   |  |
| Develop closer relationships with Nancy Schoenberg of Compassion Alliance Group.  |   |          |                        |              |                |                   |  |
| Develop closer relationships with Catherine Sebalias  |   |          |                        |              |                |                   |  |
| Develop closer relationships with Commissioner Margaret Harberg of the FDA.   |   |          |                        |              |                |                   |  |
|   |   |          |                        |              |                |                   |  |

# National MPS Society (Education/Publicity Committee) Tactical Plan 2011-2013

| Target/Strategy<br>(From Annual Goals and Right-Hand Column of Strategic Plan Goal Areas)  | Action Steps for Each Target and/or Strategy   | Date Due | Primary Responsibility | Team Members | Estimated Cost | Priority          | Current Status                           |
|--|--|----------|------------------------|--------------|----------------|-------------------|--|
|  |  |          |                        |              |                | TOP<br>MID<br>LOW | ON PLAN<br>BEHIND<br>AT RISK<br>COMPLETE |
| <b>Education/Publicity - General</b>   |  |          |                        |              |                |                   |  |
| Develop a marketing plan and strategy that leads to and supports the Society's awareness and reputation building needs.                                    | <ul style="list-style-type: none"> <li>• Create a PR/Marketing plan for a campaign to educate the public about MPS.</li> <li>• Create a set of key messages to be included in all communications.</li> <li>• Develop a specialized packet of materials to drive people to the Society.</li> <li>• Ask all labs that do testing to include a recommendation at the bottom of positive results report that includes a referral to the National MPS Society and its web address and phone number.</li> <li>• Utilize Google as a membership development tool and adjust the language we use so it drives people to a special landing page on our web site.</li> <li>• Go through an exercise to optimize search engines in order to increase contact and promote new membership development.</li> </ul> |          |                        |              |                |                   |  |
| Do a better job of capturing and promoting our successes.  |  |          |                        |              |                |                   |  |
| Complete the strengthening of our web site and ensure that it is effective as a membership building, donation receiving vehicle and source of information. |  |          |                        |              |                |                   |  |
| Complete the updating of the MPS video including various modules that can be used in a variety of venues.  |  |          |                        |              |                |                   |  |
| Launch and or strengthen a speaker's bureau and secure at least 12 forums for the coming year that will put us before important constituencies.            | <ul style="list-style-type: none"> <li>• Develop a strategy for getting in front of more people who can become donors and supporters.</li> <li>• Board members will conduct public presentations to groups to expand the sphere of influence. (Every board member will do at least one presentation)</li> </ul>  |          |                        |              |                |                   |  |
| <b>Education and Member Communications</b>   |  |          |                        |              |                |                   |  |
| Develop a CD with information and resources all in one place for use by parents.   |  |          |                        |              |                |                   |  |

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| Develop materials to be used specifically to engage newly diagnosed parents.                           |  |  |  |  |  |  |  |
| Make more effective use of the internet and social media, (Facebook in particular) in serving parents. |  |  |  |  |  |  |  |
| Create a major social media initiative and launch in 2011.   | <ul style="list-style-type: none"> <li>• Slowly begin to shift the volume of communications from heavily print to more on-line communications.</li> <li>• Produce the member directory on line through our website.</li> </ul> |  |  |  |  |  |  |
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# National MPS Society (Fundraising Committee) Tactical Plan 2011-2013

| Target/Strategy<br>(From Annual Goals and Right-Hand Column of Strategic Plan Goal Areas)   | Action Steps for Each Target and/or Strategy  | Date Due | Primary Responsibility | Team Members | Estimated Cost | Priority          | Current Status                           |
|---|---|----------|------------------------|--------------|----------------|-------------------|--|
|   |   |          |                        |              |                | TOP<br>MID<br>LOW | ON PLAN<br>BEHIND<br>AT RISK<br>COMPLETE |
| <b>Fundraising - General</b>  |   |          |                        |              |                |                   |  |
| <ul style="list-style-type: none"> <li>Raise \$1 million from all sources including:</li> <li>\$40k from memberships.</li> <li>\$90k from the annual fund.</li> <li>\$XXXk from pharma companies.</li> <li>\$40k in operating grants.</li> <li>\$300k from Walk/Runs.</li> <li>\$160k from fundraising events.</li> </ul> | <ul style="list-style-type: none"> <li>Determine the who, what and how related to increasing the level of face-to-face contact with corporate and foundation prospects.</li> <li>Develop close relations with: Medtronic's, Johnson &amp; Johnson, Integra, Durable Medical Equipment companies (identify 10 targets), and Novatis.</li> <li>Determine what other companies can offer potential benefits to us and us to them.</li> <li>Invite potential target companies to present at our conferences.</li> <li>Board members will personally call to thank all donors of \$XXX or more</li> <li>Secure contact information from everyone who attends our events and the families we serve.</li> <li>Begin to look for ways to tap individual donors beyond our families and events.</li> </ul> |          |                        |              |                |                   |  |
| Complete the annual updating of the fund development plan. We will emphasize multiyear commitments (ideally three to five years) when asking for gifts from individuals and businesses.   |   |          |                        |              |                |                   |  |
| Create a canned presentation for use in promoting the Society.  |   |          |                        |              |                |                   |  |
| A board member will be available at events (when financially feasible) to present the MPS story and to thank the participants for their support.  | Establish a calendar and recruit members to commit to each of the events. If any major events are uncovered, have a staff person or former board member fill in.  |          |                        |              |                |                   |  |
| Ensure that the board continues to engage in its fundraising role and ask each member to complete the annual pledge and to host a fundraising event   |   |          |                        |              |                |                   |  |
| Expand our young philanthropist program.  |   |          |                        |              |                |                   |  |
| <b>Grants</b>   |   |          |                        |              |                |                   |  |
| Identify at least 3 new institutional grant sources with better than average potential for granting to the Society.   | <ul style="list-style-type: none"> <li>Utilize the board in developing potential granting targets in their region.</li> <li>Link business grant soliciting to businesses that supply</li> </ul>   |          |                        |              |                |                   |  |

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|   | products to MPS families. (provide a list of suppliers to board members by region and ask them to initiate contact).   |  |  |  |  |  |  |  |
| <b>Major Donor Development</b>  |  |  |  |  |  |  |  |  |
| Add three new major donors at \$10k or above in 2013.   |  |  |  |  |  |  |  |  |
| Identify five potential high dollar donors (\$2,500) and develop a specific strategy for connecting with each.  | <ul style="list-style-type: none"> <li>Identify high potential giving partners across the MPS spectrum (particularly wealthy individuals or business owners who may have family members with MPS.</li> <li>Identify at least three major donor prospects from every Run/Walk event.</li> <li>Continue to use Courage as a vehicle for asking constituents to help identify major donor prospects.</li> <li>Task the board with helping to identify new large donor prospects.</li> </ul> |  |  |  |  |  |  |  |
| Create a quarterly publication for major donors.  |  |  |  |  |  |  |  |  |
| <b>Planned Giving</b>   |  |  |  |  |  |  |  |  |
| Roll out planned giving program to membership.  |  |  |  |  |  |  |  |  |
| Obtain ten commitments for membership in the Rising Sun Legacy Circle.  | Cull the donor list and create a planned giving target donor list of those who have given to MPS for five years or more.   |  |  |  |  |  |  |  |
| <b>Membership Development and Sustainability</b>  |  |  |  |  |  |  |  |  |
| Develop the protocols that make it easy for families to contact us and to remain engaged.   | <ul style="list-style-type: none"> <li>Begin asking for sibling information as part of our membership application process,</li> <li>Consider offering complimentary memberships to adult siblings living outside of the home. (Also in FSC.)</li> </ul>  |  |  |  |  |  |  |  |
| Work with the pharma companies to try to quantify the size of our target market.  |  |  |  |  |  |  |  |  |
| Reach out to young adults as a key membership development strategy.   |  |  |  |  |  |  |  |  |
| Resolve the question of charging for memberships versus asking families for donations and bring the recommendation to the board by the Fall 2013 BOD meeting. |  |  |  |  |  |  |  |  |
| Evaluate the practice of free memberships for newly diagnosed parents.  |  |  |  |  |  |  |  |  |
| Consider creating a lifetime membership category and bring recommendations to the board.  |  |  |  |  |  |  |  |  |
| Determine how we might improve upon our ability to communicate with clinicians as a means of connecting with newly-diagnosed families.                        |  |  |  |  |  |  |  |  |
| Better adapt the web site for promoting membership development.   |  |  |  |  |  |  |  |  |
| Focus on our mentors and "fellow travelers" as a most important contact for newly diagnosed families.   |  |  |  |  |  |  |  |  |

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## National MPS Society (Technical/Research Committee) Tactical Plan 2011-2013

| Target/Strategy<br><i>(From Annual Goals and Right-Hand Column of Strategic Plan Goal Areas)</i>  | Action Steps for Each Target and/or Strategy  | Date Due | Primary Responsibility | Team Members | Estimated Cost | Priority |     |     | Current Status |        |
|---|---|----------|------------------------|--------------|----------------|----------|-----|-----|----------------|--------|
|   |   |          |                        |              |                | TOP      | MID | LOW | ON PLAN        | BEHIND |
| <b>SAB Communications</b>   |   |          |                        |              |                |          |     |     |                |        |
| <ul style="list-style-type: none"> <li>Take recommendations of "future directions" SAB committee to the full SAB for discussion and subsequent board approval.</li> <li>Inform members about cutting edge research</li> </ul> | <ul style="list-style-type: none"> <li>Educate our membership about the benefits of the proposed research direction.</li> </ul>   |          |                        |              |                |          |     |     |                |        |
| <b>Grant Program</b>  |   |          |                        |              |                |          |     |     |                |        |
| <ul style="list-style-type: none"> <li>Apprise committee of status of grants program through all stages.</li> </ul>   | <ul style="list-style-type: none"> <li>Establish SAB review committee</li> <li>Announce submission deadline for letters of intent (LOI)</li> <li>Review LOI, request full proposals, review proposals</li> <li>Technical committee reviews SAB committee funding recommendations via conference call and makes final recommendations to BOD</li> <li>Follow BOD vote, grants are funded after we receive signed Research Policy</li> <li>Second year funding dependent on receiving first year review and financial review</li> </ul> |          |                        |              |                |          |     |     |                |        |