

2011-2015 Strategic Response Outreach White Paper

Executive Summary

Overview

In 2006, the National MS Society declared: 'We are people who want to do something about MS NOW.' This simple, yet bold statement laid the foundation for the development of the 2007-2010 Strategic Response. The Strategic Response is not simply a plan for the organization, but instead, answers the question, 'What must be accomplished to respond to the affects of multiple sclerosis?'

It requires all of us to consider the human and financial resources that must be mobilized, the necessary collaborations that must be formed and the breakthrough performance that must be achieved for us to address the challenges of living with MS. Now.

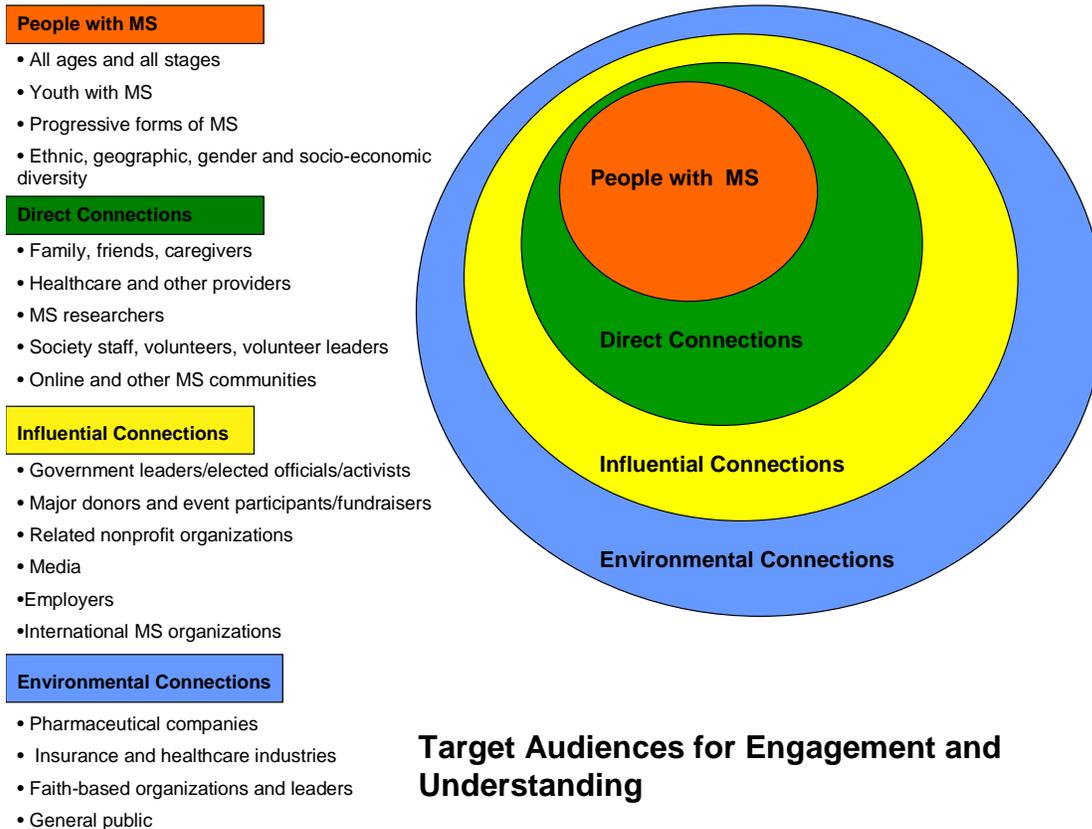
The 2007-2010 Strategic Response focuses on five key goal areas:

- We are a driving force of MS research, relentlessly pursuing prevention, treatment and cure
- We address the challenges of each person whose life is affected by MS
- We mobilize the talents and resources of the millions of people who want to do something about MS
- We are activists
- We will drive fundraising toward a \$1.25B goal

Each of these goals has better enabled the Society to focus resources and drive progress toward results that move us toward a world free of MS.

As the Society expands this response to 2011-2015 it is essential to understand the current impact of MS. We must learn about people's hopes, concerns, and experiences — whether they live with MS, raise money for the cause or conduct scientific research. The information, stories and advice will enable us to focus our efforts and drive necessary change where it is needed most for the next five years.

To ensure that we hear from key stakeholders, information has been gathered from various audiences using targeted surveys. People with MS were at the center of our efforts, followed by audiences that share and/or influence their experience of living with MS. Materials and toolkits were developed to facilitate feedback and conversations with these audiences.



Members of the 2011-2015 Strategic Response Planning Committee led outreach efforts to these audiences. They sent emails, conducted phone conversations, held in-person meetings and small group discussions. Feedback was collected via an online survey form that was filled out directly by the audience member or by the volunteer/staff conducting the interview. In addition, the Society solicited input from the public at large via the Internet. Outreach began in June and concluded in September 2009.

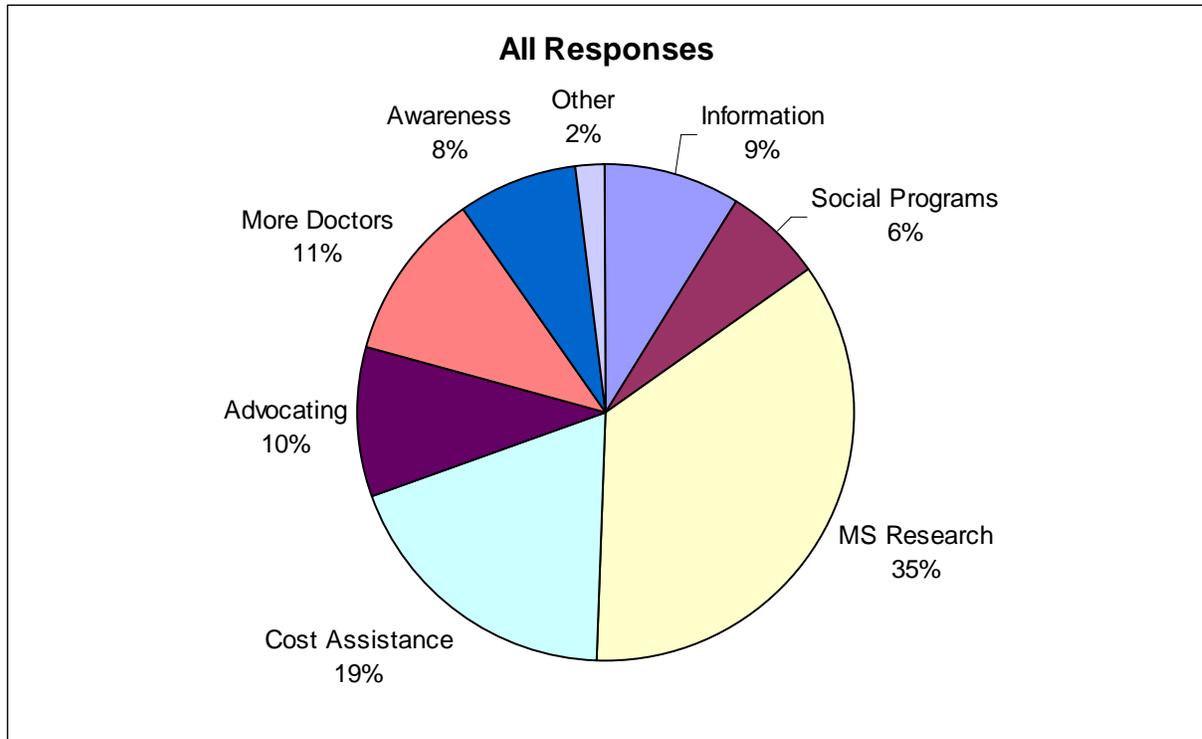
The outreach process to identified target audiences resulted in over 9,300 completed surveys and interviews, generating volumes of feedback. This meaningful and relevant information will not only serve to guide the development of our strategic response but many aspects of our ongoing work.

Findings

Although these audiences brought a diverse set of perspectives and experiences to the process, the overall results are quite consistent in their views of resource allocation, key issues and what we can do to become a better Society.

Resource Allocation

All audience groups, when asked to allocate resources across key Society focus areas, overwhelmingly identify the number one need as MS research – and more of it. Research to understand more about the disease – research to find new treatments – research to help impact people’s quality of life – constituents expect the Society to not just participate, but to blaze the trail.



Also consistent was the number two selection of cost assistance. Not surprisingly, all groups must deal with the financial burden of MS, and those in lower income groups and rural areas, feel it even more significantly. The third selection can be most appropriately represented by the next four categories – as each one individually appeared throughout different audience groups – Advocacy, More Doctors/Professionals, Awareness, and Information/Education. In general, the categories from this group that received the most comments about what the Society should be doing now, were Awareness and More Doctors/Professionals.

Other key survey areas included questions to acquire open ended input about the following; 1) what is most needed now, 2) what else should we know, and 3) what has your experience been with the Society. Again, a number of consistent themes surfaced.

Major Themes, Ideas and Messages to Guide the Response

- Need more public awareness – want to be involved in helping to raise that awareness.
- Better advocacy for health care and insurance change – and more responsibility/opportunity for people affected to advocate for that change.
- Do more to attract scientists and professionals to the field of MS and provide critical training and education – there simply can't be enough minds put toward critical research or informed and specialized care for people with MS/chronic disease.
- Don't lose focus on quality of life – regardless of disease stage, more simply must be done for those living with, as well as affected by, MS.
- Collaboration needs to accelerate – whether it's with other MS organizations, community organizations that people with MS and their families rely upon, or similar disease and fundraising organizations – competition for mindshare and dollar share is only going to increase.
- Recognize the needs of people in rural areas and those living with progressive MS – these groups feel disconnected, underserved, and many use the words 'isolated' and 'forgotten'.
- Increase relevant opportunities for people affected by MS to connect – whether that be through social and educational programs, or online via social media.
- The Society is well-regarded in general as reliable, credible, and out in front – however, many identified the need for true inclusivity and engagement. Experiences have demonstrated disparity across the country and the perception of 'exclusivity' and local favoritism.

Viewpoints and Advice

- The Society must provide clarity on our role and relationship with pharmaceutical companies. Lack of information about funding, influence, and role of these companies leave constituents to draw their own conclusions.
- Information for those newly diagnosed is essential – but don't forget about everyone else – it no longer feels balanced across everyone affected, and especially for those with progressive forms.
- There is a continued lack of connection and understanding of available resources at a local level. The Society offers much, but there is not consistent knowledge – and better relationships are needed with those in local communities.
- The pressure to give is inordinate – solicitation volume is creating guilt and anxiety.
- The Society does not do a good job of demonstrating how we are really driving forward, how we are on the cutting edge, or how we are the innovators.

In general, the Society is looked to as the leader and facilitator – regardless of audience – of research, advocacy, awareness, and education and programming to meet the needs of people affected by MS. People expect to see the organization driving all aspects of the MS community forward, and they expect to see that not only in what we say, but also in the way that we behave as an organization of individuals, and as a whole.

Feedback Reports by Audience

All Ages and All Stages

Process

- Total Responses = 7,083
- Who = All ages and all stages
- How = 211 by phone and 6,872 online surveys. One to two surveys a day were conducted “live” on the web.

Major Themes to Guide the Strategic Response

- Consistent themes about the impact of MS included feelings of isolation, financial and future insecurity, and loss of relationships and career.
- In the online surveys Research was cited by 34% as their top priority followed by Assistance with daily costs (19%), Ensuring there are more doctors and healthcare professionals who understand and can treat MS (11%), Advocating with government officials about issues faced by people with MS (10%), Information and education resources (10%), Public awareness and understanding about MS and its effects (8%) and Social and recreational programs (6%). Rankings in phone surveys were similar.
- Other issues that were mentioned include access to affordable healthcare, medications, housing, homecare services and mental health and financial counselors. People also cited interest in education about alternative/complementary forms of treatment and more programs for people with progressive MS, and training for caregivers.

Compelling ideas, messages, and perspectives

- People want to see more research and funding for oral medications, stem cell therapy, low-dose naltrexone, and medical marijuana.
- MS doesn't get the public exposure and support that is given to cancer. Need a “celebrity” as a spokesperson.
- People in small or rural communities don't feel they get the same support as those in larger cities. Need more programs in small towns/cities or “isolated” areas.
- Better medications to manage common symptoms are needed.

Viewpoints and advice

- Concern about the “conspicuous” presence of the pharmaceutical companies in the Society's brochures, website, etc.
- Desire for more Society presence in small communities “Don't like chapter consolidation. I feel abandoned.”
- Access to SSDI is cumbersome. Need advocacy for quicker access to Social Security Disability and Medicare “Too many requests for donations.” “Waste of paper and resources.”
- Need more programs on wellness, invisible symptoms, progressive forms of MS, daily living solutions, education and support for caregivers, for families and kids as well as more communication about upcoming programs.

Youth with MS

Process

- Total Responses = 139
- Who = Youth with MS under the age of 24
- How = Distributed to 600+ in the MS pediatric population, yielding a ~23% response. Conducted three by phone and 136 online. Families sent invitations to submit surveys via email and mail. Teens at Stony Brook camp completed survey on paper.

Major Themes to Guide the Strategic Response

- Need non-injectable medications and treatments.
- Overwhelmingly, the need for research in the pursuit of treatment, prevention and a cure rated highest in priority for resource allocation and individual priority, followed by assistance to help with daily expenses, and ensuring there are more doctors and healthcare professionals who understand and can treat MS.
- Need more support and counseling for kids with MS and their families.
- Young people want to help raise public awareness about MS and its affects on the lives of people living with it.

Compelling ideas, messages, and perspectives

- Concern over obtaining and maintaining health insurance.
- MS has completely changed lives by being unpredictable, and forces kids to “grow up fast.”
- Need to support kids with MS through activities and network resources. This audience responds to knowing that they are not alone through connections with their peers in person or through online social networking.
- There is a fear of the unknown and not experiencing a “normal life,” that includes finding a spouse and having a family.
- A sense of hope and determination to keep a “positive attitude,” seek counseling and/or support, be proactive, and “don’t let MS control your life or knock you down.”
- Desire a “big movement” to increase public awareness about MS. “Teach us how to educate our peers about MS.”

Viewpoints and advice

- School educators need to be more educated about MS.
- Feel unprepared for the “what ifs” and want Society/MS practitioners to better prepare kids with MS through improved communication.
- Encourage young people with MS and their families to get support.
- There is concern that the Society is too closely aligned with pharmaceutical companies “whose interests lie not in eradicating MS, but maintaining it.”
- Need more financial assistance for medical care and equipment, but also scholarships.

People Living with Progressive Forms of MS

Process

- Total Responses = 1,625
- Who = People living with progressive forms of MS (Primary Progressive, Secondary Progressive and Progressive Relapsing).
- How = 119 by phone and 1,506 by online survey. Because the complexity of needs is greater for people living with progressive forms of MS, the outreach strategy utilized key chapter staff, such as Service Managers, to reach clients.

Major Themes to Guide the Strategic Response

- Overwhelmingly, loss of independence, mobility, and ability to continue work are devastating for people living with progressive forms of MS.
- All aspects of people's lives - personal, professional, and financial - have been devastated.
- MS research ranked highest in priority for allocation of resources and importance, followed by assistance to help people cope with the costs, ensuring more doctors and healthcare professionals understand and can treat MS, advocating with government officials and last, increasing public awareness and education on MS.
- People living with progressive forms of MS expressed concern that they are not a high priority for research, advocacy, and support. "We feel forgotten."

Compelling ideas, messages, and perspectives

- Life-altering and limiting financial impact due to health care expenses and loss of work for people with MS, and their families. Need more financial assistance for cost of medications, durable medical equipment, assistive technology, physical and occupational therapy, home health care/chore services, and home modifications.
- A need for more support and quality of life activities and information specifically created for people living with progressive forms of MS, and their families/caregivers.
- A need for symptom management as well as more research and clinical trials for prevention, treatment, and a cure, including alternative/non-traditional therapies, stem cell research and myelin repair.
- Need more high profile advocates to educate public and gain attention of government. "We need a Michael J. Fox. Someone who can put it out there, in your face."
- Advance legislative priorities and advocate on behalf of people living with and affected by progressive forms of MS?
- Need for swift and less complicated access to Social Security benefits, eliminating the two year waiting period for Medicare.
- Need more affordable housing and transportation options.
- More direct services and programs geared toward people with progressive forms of MS including social and wellness programs.

Viewpoints and advice

- A sense that MS does not get the public attention and support of other diseases, such as cancer. "It would sure be nice to see a national MS presence with orange grocery

bags, orange cereal boxes, orange hats, orange awareness days ... Why shouldn't we get the same attention (and \$\$) as the cancer foundations?"

- Needs to be more public discussion about progressive forms of MS and their effects. "Too much attention is given to people with relapsing/remitting MS."
- There's a perceived lack of attention given to the needs of National MS Society clients with progressive forms of MS. The sentiment was expressed in various forms but many felt that success stories of active people with MS did not reflect the effects that progressive forms of MS have on them. "The smiling faces, walks, etc. in your magazine don't reflect the true devastation of this disease". There needs to be more practical information on how to deal with insurance companies and hospitals, how to handle changing physical effects, and "annoying" and "embarrassing" symptoms.
- Some expressed that the Society was not forceful enough in pushing cutting-edge treatment research for progressive forms of MS.
- Offer more resources to people with progressive forms of MS living in rural areas.

Ethnic, Gender, Geographic, and Socioeconomic Diversity

Process

- Total Responses = 6173
- Who = Ethnic, Gender, Geographic and Socioeconomic Diversity
- How = 203 by phone, 5,970 by online surveys

Major Themes to Guide the Strategic Response

- All groups ranked research as the top priority, followed by assistance for daily costs. Individual priorities varied slightly, with most groups ranking at the top either research, assistance, or ensuring that there are doctors and professionals who know about and can treat MS.
- Most groups considered public awareness and support, such as recognition and financial, as important.
- Many groups stated that there is a need for more medical professionals to have a greater awareness of MS or there was a “shortage of qualified doctors.”
- Job loss was a consistent theme among groups and especially important to men who noted they were no longer able to “provide for their family.”

Compelling ideas, messages, and perspectives

- Females were more willing to see the positives or “bright” side and seek more social and family support. Men had highest number of “angry” comments.
- Family issues, such as the effect MS has on financial stability, were a common theme among all groups.
- Need for more social activities for people with MS and their families.
- Assistance with basic living requirements such as affordable and accessible housing and transportation, in addition to financial support were consistent among all groups.
- Need more summer programs for teens and respites for parents with MS and/or with kids with MS.
- The Society web site is a good source for information and overall received positive comments on content and usefulness.

Viewpoints and advice

- Some groups felt they were underserved and that the Society was an “exclusive club for those with means.”
- Some complaints about the Society’s support of embryonic stem cell research.
- “The Hispanic/Latino community is very heterogeneous, and we need to be sensitive to different perspectives, national origins, religions, education, and dialects.”
- “Tries to do everything itself, little real collaboration with other disability organizations, not too much support for long termers with MS and progressive types.”

Family, Friends, and Caregivers

Process

- Total Responses = 1,747
- Who = Individuals from diverse backgrounds, including scholarship recipients, caregiver self-help groups, National Family Caregivers Association, and personal outreach at chapter-sponsored programs for families.
- How = 70+ phone and in-person interviews, two focus groups, and online survey.

Major Themes to Guide the Strategic Response

- Overwhelmingly, fund more research. Focus on a cure, followed by treatments to reverse damage and prevent the risk for future generations.
- Provide family, friends, and caregivers with direct assistance for relief from both financial and emotional devastation.
- Help keep people with MS living at home whenever possible.
- The impact of the disease is far reaching – teenagers as caregivers, impact on marriages, aging parents caring for adult children with MS, and more. Help provide a better quality of life for *all* people, *all* roles, *all* ages touched by MS.

Compelling ideas, messages, and perspectives

- Overwhelming financial impact. Impoverished by the disease. Loss of income, loss of career, debt, treatment cost, home modification cost, insurance co-pays, deductibles, and lack of coverage.
- Overwhelming emotional impact on the person with MS and the caregiver. Most common feelings/reactions include isolation, heartache, grief, worry, anger, frustration, fear, exhaustion, loneliness, helplessness. Also, expressed was gratitude, guilt, anxiety.
- Overwhelming personal, household, transportation, financial, and other responsibilities, with “no relief in sight.”
- Need appropriate, affordable, dependable home health care resources.
- Need clear and consistent help navigating the system, including Social Security, Medicare, Medicaid, insurance coverage, local and state programs, and other health care systems. For those seeking long term care, most cannot find age-appropriate and MS-knowledgeable options.
- Need affordable, accessible coverage, with no pre-existing conditions. Coverage is inadequate, expensive, inflexible, and tied to full-time employment. Need access to occupational, physical, and mental health therapy.
- Need clear and consistent guidance on Society programs and services. This audience mentioned many needs (financial assistance, marital support, education, assistance navigating healthcare systems, etc.) that the Society/chapter could already provide.

Viewpoints and advice

- Many expressed willingness to help. This audience clearly wants the Society to engage them in meaningful ways. However, they receive excessive mail and e-mail. And they feel constant pressure to donate and guilty when not able to. "We're giving all we can."
- People with Primary Progressive MS "feel forgotten." Need more personal attention, more resources, more supports, more treatment, and more services.
- Need additional online tools on accessibility info, resources, and networking groups.
- High staff turnover and "focus is changing constantly." Need to be responsive — calls not returned, volunteers not thanked, issues not followed up on.
- Some have been inspired to be more involved with activism. Need to better engage clients, get them to take greater stake in their care, and move their agenda forward. Need to "empower them to engage the decision-makers in their lives."

Healthcare and Other Providers

Process

- Total Responses = 130
- Who = Healthcare and Other Providers
- How = One in-person, 124 online, and 5 phone surveys conducted. Surveys were emailed but also an in-person discussion was held with the Clinical Affiliation Review Committee and a phone conference held with the Pediatric MS Centers of Excellence Steering Committee.

Major Themes to Guide the Strategic Response

- Low reimbursement rates reduce the quality of care throughout the disease course.
- Need more access to legal and financial aid from those with knowledge and/or expertise in disability and chronic illness. Comments related to the challenges of people with MS note frequent financial and legal problems.
- Overwhelmingly, research ranked highest in importance, followed by assistance to help people cope with the daily costs, and then ensuring that there are more doctors and professionals who understand and can treat MS.
- Need more and improved long-term care options as well as better access to mental health care and rehabilitation.

Compelling ideas, messages, and perspectives

- Need better insurance options for people with MS. "It is painful and frustrating to try to provide high-quality, comprehensive care to patients who are underinsured or uninsured."
- A couple comments referred to treating people with MS as "eye opening."
"As a health care provider, treating people with MS has allowed me to develop a treatment philosophy based on looking at the whole person, not just the disease."
- Too many insurance company hurdles for people with MS to navigate. These hurdles can cause interruptions in treatment and waste the time of healthcare professionals.
- Society services and activities vary too much between communities. There has been a disparity across the Society in terms of levels of staff expertise, dependency on the local pharmaceutical reps, and quality of client programming/education.
- Need improved community access, including public transportation.

Viewpoints and advice

- "The MS population with severe disabilities is invisible to the world at large and does not receive enough attention from the Society."
- "I do not think the Society needs to be everything to everyone with MS. There needs to be better local and federal support for all of chronic illness care, not only with MS."
- Because people with MS and their families often experience financial difficulties and loss of employment, there is a need for more vocational rehabilitation opportunities.
- Those who have had little success interacting locally tend to feel that the Society is less effective and less helpful than it could be.

MS Researchers

Process

- Total Responses = 108
- Who = MS Researchers
- How = Two in-person, 106 online surveys. The in-person surveys were conducted in a small group setting. Of note, 40% of respondents indicated they were MS Researchers when in fact, they were individuals living MS.

Major Themes to Guide the Strategic Response

- Concern that the Society isn't allocating enough funding toward research at a time when science is moving forward at an accelerated pace.
- Many stated that the limited funding for research has been challenging to keep the labs going and feared that it could lead to many MS scientists leaving the field.
- Overwhelmingly, concern that new researchers and neurologists are not attracted to the field of MS research, which could lead to a future "gap." Many were very worried about the future of MS research due to the lower budget allocation toward MS research.
- Many say that knowing people with MS gives their professional life direction and has deeply affected them.
- Overwhelmingly, the need for more research with funding for the prevention, treatment and cure of MS ranked highest in resource allocation. The gap between that and the second ranked focus – assistance for daily expenses – was substantial.

Compelling ideas, messages, and perspectives

- Top three challenges expressed by many: find the cause of MS and understand the progression, translate genetic findings to etiological consequence, and identify biomarkers.
- Need more research to determine why MS is more common among women.
- Need more research on the progressive forms of MS.
- The responses to a question relating to individual experiences with the Society ranged from "outstanding" to "very positive interaction."
- A greater understanding of the disease, such as identifying features of early MS, is critical and requires more research.

Viewpoints and advice

- Research only accounts for 20% of the Society budget. "This would come as a shock to those who support research and the Society."
- The perceived shift from research support to home health care, financial assistance, and community based initiatives is a concern. "This could impact research negatively and ultimately impact patients in the long term."

- Many suggested that there should be more direct contact between people with MS and investigators actively engaged in research. Researchers experience with local offices appeared inconsistent - attributed to high turnover and their focus constantly changing.
- The guidelines for supporting research activities are becoming increasingly bureaucratic.

Online and Other MS Communities

Process

- Total Responses = 9157
- Who = Online Audience
- How = 30 in-person 8812 online and 315 phone surveys. Audience reached through e-newsletters, Action Alert emails, posting on national home page, and social media channels.

Major Themes to Guide the Strategic Response

- Overwhelming belief in research
- Assistance with medications

NOTE: As a primary method of collecting information, specific feedback from the online and other MS communities, including blogs, social networks, etc., are largely reflected throughout ALL audience groups.

Government Officials and Staff

Process

- Total Responses = 25
- Who = Government Officials and Staff
- How = 10 by phone and 15 in-person surveys.

Major Themes to Guide the Strategic Response

- Government relies on nonprofit groups to educate them on issues. The information should be specific and targeted, and the Society needs to spend more time lobbying government officials using data and knowledge of what people with MS need.
- Need to collaborate with other organizations, and consider a central site for all information related to MS. This would lower cost and reduce duplication of services.
- Need more education, resources, and awareness on the affects of the disease and life changes experienced by people with MS.
- MS is financially devastating and there is a need for financial assistance for medications and costs of daily care. A point made was that people with MS should not be forced into poverty because of health care costs and then have to rely on financial assistance.
- The Society is universally held in high regard as a solid informational resource and reliable partner.

Compelling ideas, messages, and perspectives

- Biggest need is electronic medical records.
- Lack of government programs and services are a barrier to getting help. Need to build a knowledge base of district workers.
- HIPPA and ADA laws that ensure privacy and non-disclosure.
- NIH noted that increasing recruitment and/education on clinical trials may create more opportunities for scientific research.

Viewpoints and advice

- Society needs a strong public information campaign and to spend more time lobbying.
- Newsletters and one or two meetings a year to update on issues and priorities.
- Look to Christopher Reeve Foundation for examples of good partnerships.
- Government needs to make disability process less cumbersome. Work with Social Security Administration to improve on current system.

Grassroots Activists

Process

- Total Responses = 1,108
- Who = Grassroots activists
- How = 22 by phone and 1,086 online surveys.

Major Themes to Guide the Strategic Response

- Financial impact due to loss of employment, cost of medications, and health care. Need more assistance.
- Need emphasis on finding the cause and a cure for MS.
- Need for better accessibility in public places, buildings, and homes.
- More information, research, and treatments are needed for progressive forms of MS.

Compelling ideas, messages, and perspectives

- Want more access to rehab therapies and medications that are easier to tolerate.
- Provide a 24-hour a day information hotline.
- Increase in public awareness of MS. This includes more information shared with employers regarding the affects of MS.
- Work directly with schools to educate healthcare students on MS and interest them in advocacy efforts. Many people who are involved in advocacy consider it a positive experience.

Viewpoints and advice

- "Hate the 'moving' language and campaign. Feel beaten with this message."
- "Staff cutbacks at local chapters and mergers are affecting services to clients and advocacy efforts."
- Need to send frequent updates on new programs and/or resources.

Major Donors, Fundraisers, and Event Participants

Process

- Total Responses = 2019
- Who = Major donors, fundraisers, and event participants.
- How = 1,974 online and 45 phone surveys.

Major Themes to Guide the Strategic Response

- Difficulty adjusting to diminution of independence and/or reliance on others for assistance. Overarching theme of fear, uncertainty, and loss.
- Essential health requirements: affordable and available insurance, more comprehensive MS specialty care, research advancements toward oral drugs and progressive MS.
- Understanding the disease. Relentless frustration in the lack of understanding and knowledge about the disease in both the medical community and general population.
- MS is expensive and we need help. Financial assistance with: medical both medicine and equipment costs as well as living expenses.
- Don't neglect the positive: diagnosis can and does lead to new friends, personal achievements life changes, and blessings.

Compelling ideas, messages, and perspectives

- A majority feels proud of their Society involvement and strongly supports the efforts. People are vocal about being available and willing to help and or participate further.
- Need more information on MS for healthcare professionals and those newly diagnosed with MS.
- Need more health centers with "multiple specialties" and a staff of doctors and healthcare professionals with a focus on MS care and treatment.
- Need more done to help people with secondary progressive MS. "We NEED your help to STOP our progression."
- Continue the positive and motivational messages
- Overall healthcare reform was a common theme i.e. cost, availability.

Viewpoints and advice

- Too many requests by the Society for donations. "All I ever get from NMSS are requests for more money."
- There is a lack of access to support in rural locations.
- "If the MS society has to put us all in a pool to lower the costs, that would be great. NOT a government run health care program."
- "The Society should form coalitions/collaborate with other organizations."

Related Nonprofits

Process

- Total Responses = 29
- Who = Related nonprofits, which includes organizations of which the Society is a member, share similar missions/peer organization, other MS organizations, and local collaborative organizations.
- How = 29 by phone

Major Themes to Guide the Strategic Response

- MS research and advocating to help people cope with the daily costs of MS ranked at the top of the level of importance, followed by information and education resources, with public awareness following.
- The Society is an efficient and effective organization.
- The next five years will see an increase in competition for research dollars and donations, reevaluation of business models, and need to collaborate/cooperate with other nonprofit and governmental agencies. Health care reform will set the tone.
- Dealing with long-term chronic issues will continue to be the focus.

Compelling ideas, messages, and perspectives

- The Society reaches a high percentage of people with MS and is a credible source of information about the diagnosis, treatment, and cure for MS.
- The Society's web site is one of the best among nonprofit voluntary health organizations.
- Excellent leadership, quality staff, and volunteers.
- Collaborative organization, easy to work with, and highly respected.
- Mission remains "out in front" and focused.

Viewpoints and advice

- Though informative, the Society sends out too much email.
- "Buttoned down, strong staff, steady, but not innovative or cutting edge."
- Nonprofits need to "stop doing outdated services and focus on changing treatment paradigms and options for people with diseases."
- As competition for resources increases, nonprofits need to pull together, partner on common issues of interest, and open up dialogue between all levels of the organizations.

Media

Process

- Total Responses = 50
- Who = Media
- How = 10 phone and 40 online surveys.

Major Themes to Guide the Strategic Response

- There were several respondents who indicated that they have MS or a loved one/close person in their life has MS.
- Need better awareness for the general public and healthcare professionals to help people living with MS.
- Need more information for people newly diagnosed.
- The Society is a helpful resource for information and support.

Compelling ideas, messages, and perspectives

- Frustration with the limitations they or their friends with MS face.
- Overwhelmingly, there is a need for more MS research.
- From those with MS, a general sense of having to “slow down” and to refocus, rebalance, and reprioritize parts of their lives.
- Maintaining healthcare insurance is a consistent concern, especially for those who can't work.
- Some people with MS have benefited from a MySpace page for people with debilitating conditions.
- Most journalists have had a positive experience and find the Society very resourceful.

Viewpoints and advice

- The tagline “Join the Movement” only makes sense if you're familiar with the disease.
- “The MS society is great at PR. Everyone is aware that you are there - your name recognition is vivid but your effectuality isn't.”
- “We need to learn how to live with MS. We are too dependent on doctors and other professionals.”
- Need more resources on how to maintain a good quality of life.
- Need a spokesperson that is a “real” person and can relate to “ordinary” people.

Employers

Process

- Total Responses = 25
- Who = Employers
- How = 25 online surveys. Found resistance to scheduled interviews.

Major Themes to Guide the Strategic Response

- Overwhelmingly, MS research ranked highest in priority followed by assistance for the daily costs, and then increased public awareness and understanding of the effects of MS.
- Many responses were focused on repositioning the Society as “thought leaders” and “innovators” in the nonprofit sector.
- Need more education on MS and its effects on people. This was expressed as a need for education within the public realm, but also for employers.
- Expansion of public education, identity of the Society, and “marketing” or outreach efforts.

Compelling ideas, messages, and perspectives

- Expand hiring practices to include “non traditional” hires. “Characterize the type of person the Society is looking for” and offer incentives in terms of compensation.
- Need to “ride national wave of volunteerism” and consider piggy backing on local and national public information campaigns. Focus on the “tangible effects of working with the Society” that is experienced by volunteers.
- Need improved awareness on what the capabilities are of people with MS. “Public needs to know what it’s like working with someone with MS.”
- Need to think differently about solving problems.

Viewpoints and advice

- Need to clarify outreach message to employers: is the Society asking for help or offering help? Can a meaningful partnership between nonprofit and private exist?
- There is concern over the effect an employee with MS might have on productivity.

International MS Organizations

Process

- Total Responses = 21
- Who = International MS Organizations
- How = 10 by phone and 11 online surveys. A custom survey was created with an invitation to provide feedback extended by the Multiple Sclerosis International Federation (MSIF) to all member societies.

Major Themes to Guide the Strategic Response

- Advocating with government officials about issues faced by people with MS ranked highest in importance followed by the need to ensure more doctors and healthcare professionals understand and can treat MS, and then improving public awareness about MS and its effects.
- Need for pooling of information among countries and organizations. Many countries – especially developing countries – lack the information or the resources to provide information to people with MS, healthcare professionals and the public. This was focused on information, practices, etc., available through the Society.
- Access to care and medications is limited in many countries, especially developing countries. Need to share information available through the Society and other organizations and find ways to disseminate.
- Quality of life for people with MS is particularly low in countries with limited financial resources, information, and professional medical care.

Compelling ideas, messages, and perspectives

- The Society should continue championing World MS Day, such as sharing expertise and being ambassadors for the global initiative, especially with countries who have not been so active.
- Because some countries do not have high incidence of MS there is less recognition of the disease and less established support for the MS organization.
- Some countries report needing an online support community for people with MS.
- Establish exchanges for professionals from around the world to come to the U.S. to learn how to structure their MS Centers. Also, match individuals and chapters with other societies.
- Need to persuade member organizations that don't raise as much money for research to start doing so.
- People have a difficult time knowing which organizations and medical advice (and treatments) to trust for advice.
- Not all Society staff are familiar with MSIF or exactly what the role is, or the fact there could be useful contacts in the global movement who could help share best practices. (i.e. planning stage of new campaigns)

Viewpoints and advice

- Lack of neurologists or properly trained medical professionals.
- Approach to support for people with MS varies from neglect to support through partial government subsidies to work for people with MS.
- Some people have very limited access to drug therapies and little understanding and recognition of the issues related to MS.
- Need for (international) seminars for medical professionals.
- Difficult to maintain the momentum of the work and demonstrate added value.
- Involve young people in MS organizations.

Pharmaceutical Companies

Process

- Total Responses = 44
- Who = National MS Society pharmaceutical partners
- How = 14 by phone and 30 in-person surveys.

Major Themes to Guide the Strategic Response

- The role of the Society, in terms of providing support and education on pharmaceuticals, and doing so without appearing biased.
- Attracting scientists and clinicians to the field of MS research through new reimbursement policies and increased research funding
- MS research ranked as high as assistance for daily costs, followed by increase in information and education resources for people with MS.
- Need targeted therapies for secondary medical conditions and biomarkers for disease; it was noted that the Society is in a “unique position to organize the biomarkers field.”

Compelling ideas, messages, and perspectives

- The cost for companies to pursue research in MS is prohibitive.
- “We cannot find a neurologist with sufficient experience in MS to hire”- Rick Russell, VP Neurology, EMDS
- A sense that some chapters play favoritism with reps, who would like to have more involvement in event planning and self help groups.
- Varying perspectives on the promotion of patient assistance sites. Some mentioned links should be more visible on the Society sites.
- The role of the Society in cost assistance received mixed responses.

Viewpoints and advice

- Some felt continued focus on education and awareness is unnecessary, in spite of the fact it ranked second on level of importance
- Cognition not addressed enough as it has a major impact in even the mildest cases.
- Need more communication concerning medications.
- Continue MS research advocacy and governmental affairs activities. “MS patients have a nexus to elected officials that is unique and should be emphasized.”
- Need increased involvement and education of paraprofessionals.

Insurance and Healthcare Industries

Process

- Total Responses = 15
- Who = Insurance and other healthcare industries
- How = 15 telephone interviews

Major Themes to Guide the Strategic Response

- Educate case managers working in health plans on all aspects of MS to promote quality MS care and help improve relations with the 'MS community'.
- Educate people with MS to help them understand insurance plans and costs.
- Support better information for health plan case management (policies and procedures) and high quality specialty pharmacy services.
- Need for the Society to build relationships with health plan personnel in order to better disseminate information to people with MS.

Compelling ideas, messages, and perspectives

- Health plan personnel think of MS as an expensive chronic disease, but admit to little knowledge of MS diagnosis and treatment.
- Suggestions for the Society to collaborate with disease management and/or specialty pharmacy firms.
- Health plans are aware of the frustrations experienced by their members and clinicians regarding operations and decisions.
- Offer CME or other credits for MS-related educational activities.

Viewpoints and advice

- One respondent criticized the Society's unwillingness to initiate direct contact with newly diagnosed individuals with MS.
- Need for the Society to get the word out about all their insurance and appeals work.
- Do more health-insurance client support and "use the Medicare Rights Center as a model." Collect a database of coverage packages of different health plans to help clients negotiate prices and benefits." In general, the Society needs to be immersed in the economics of MS care.
- "Skip the health plans, go straight to the employers. Few people realize that health plans are at the mercy of the employers." (Note: This comment was made by a pharmacist in reference to so-called 'self-insured,' large employer health plans, and seems to incorrectly imply that employers control all health plans. In fact, forty-five percent of employer-based plans are 'fully insured' and controlled by health plan personnel.)
- "Tell the state (i.e., Medicaid) about the importance of multi-disciplinary, well-coordinated care for people with chronic illnesses like MS."

Faith-Based Organizations and Leaders

Process

- Total Responses = 285
- Who = Faith-based communities
- How = Six by phone 279 online surveys.

Major Themes to Guide the Strategic Response

- Need for mental health counseling and/or mental health interventions for people living with MS.
- Lack of insurance, high costs of care and medications, and difficulty in navigating the health care system. Many people said health care reform was necessary.
- Overwhelmingly, research for treatment, prevention and cure of MS ranked highest in importance in terms of allocation followed by assistance with costs of daily care. A smaller number responded to the individual ranking, which showed social and recreational services as most important followed by assistance to help with daily costs.
- Need for Society to work more closely with churches by coordinating events, making visits, and providing more opportunities for disabilities education. "The key word is relationships."

Compelling ideas, messages, and perspectives

- Need for more alternative living options.
- Transportation is an issue for many. Need for Society to organize transportation to church services for people with MS.
- Loss of employment and spontaneity in life, and some expressed their faith as a way to cope and referred to having MS as a "blessing."
- The SSDI system makes it difficult to access medications and therapies.
- Emphasis is on programs for newly diagnosed. Need more programs for people with "chronic" symptoms.
- Appreciation for the resources and support of the Society and quality of the website.

Viewpoints and advice

- Concern over the relationship of the Society with pharmaceutical companies. "We need to be careful about relying on the pharmaceutical industry to the extent that Society advice gets skewed excessively toward drug therapy."
- Group leaders would benefit from a website or newsletter that caters to their specific activities and needs.
- Society has a high rate of staff turn over.
- Need programs that include spirituality with healing/coping with MS.

General Public

Process

- Total Responses = 1,226+
- Who = General Public
- How = 1,226+ surveys. The online survey was made available over two days. Two prior consumer polls were referenced, as was the 2009 Cone Nonprofit Power Brand 100.

Major Themes to Guide the Strategic Response

- The general public's lack of knowledge about MS and the Society or any other MS-related organization. Cancer is the most recognizable, followed by diabetes and heart disease. This has barely changed since the 93/94 poll.
- Knowledge of MS varies among income levels, gender, and ethnic backgrounds. Younger age groups were most familiar with MS and 65+ were unfamiliar. African American, Asians, and higher income groups were most familiar with MS.
- Better treatments and medicines, improved quality of care, financial assistance and information/support services ranked highest with level of importance varying among ages, ethnic backgrounds, incomes, and U.S. regions.
- Doctors rank highest in primary source of information on MS among all groups, with the internet matching in the younger age groups. The Society as a source for information ranked highest among the 65+ group, though still following doctors.

Compelling ideas, messages, and perspectives

- According to the Cone Nonprofit Power Brand, the organization with the highest Brand Value and Revenue Rank was YMCA. The organization with the #1 Brand Image ranking was the American Cancer Society. The Society ranks 44th in revenue, yet 29th in Brand Image compared to the other 99 nonprofits rated in the report.
- There was an increase of 4% - compared to the 93/94 poll - of those who would turn first to the Society for information on MS.
- Genders were generally equal in their level of knowledge about MS with men dominating the "Not at All" category by a significant percentage.

Viewpoints and advice

- Low awareness of the Society compared to other higher profile health related organizations.