



NATIONAL MULTIPLE SCLEROSIS SOCIETY ORGANIZATIONAL REPORT

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THE *FASTERCURES* PHILANTHROPY ADVISORY SERVICE

FASTERCURES / THE CENTER FOR ACCELERATING MEDICAL SOLUTIONS

FasterCures / The Center for Accelerating Medical Solutions is a nonprofit “action tank” whose mission is to identify and implement global solutions to accelerate the process of discovery and clinical development of new therapies for the treatment of deadly and debilitating diseases. *FasterCures*, as a center of the Milken Institute, is nonpartisan, nonprofit, and independent of interest groups.

Barriers to progress in accelerating cures exist all along the research continuum—from basic research to development, from medical education to medical practice, from investment capital to human capital. *FasterCures* is working to clear the path to faster progress, not just by analyzing barriers, but by overcoming them through action. A force to catalyze systemic change, *FasterCures*:

- Evaluates current systems of disease prevention, research, development, and treatment;
- Identifies barriers to efficiency, effectiveness, and expediency in those systems;
- Creates achievable action plans to improve those systems; and
- Provides seasoned leadership and expertise in implementing those action plans in concert with organizations searching for new medical solutions.

To guide its efforts, *FasterCures* developed a Blueprint for Change focused on the transformation needed in three areas of medical research: research leadership and innovation; research tools and resources; and the medical research environment. The **Philanthropy Advisory Service (PAS)** aims to promote progress in all three areas through more informed philanthropic investment.

HELPING PHILANTHROPISTS MAKE INFORMED INVESTMENT DECISIONS

The lack of independent, reliable data about nonprofit disease research opportunities is a major barrier to encouraging significant support for such research and to improving the efficiency and productivity of philanthropy. With grants from the Bill & Melinda Gates Foundation and the Pioneer Portfolio of the Robert Wood Johnson Foundation, *FasterCures* has developed the **PAS** to address this problem.

The objectives of PAS include:

- Helping philanthropists align their goals and expectations with the capabilities and approaches of research organizations;
- Identifying gaps in funding for areas crucial to the success of specific disease research efforts; and
- Promoting among potential donors a “continuum of cure” perspective that can help develop cures for deadly and debilitating diseases.

PAS creates an information marketplace to support informed philanthropic investment. It improves the efficiency and productivity of both philanthropists and the nonprofit disease research organizations that depend on their support, especially in areas where there are demonstrated funding gaps in research and development.

PHILANTHROPY ADVISORY SERVICE ANALYST REPORTS

PAS provides two types of reports—disease and organization reports.

- **Disease Reports** discuss the burden, progression, and existing treatments for a given disease; highlight priority research areas; and provide an overview of relevant activities in the commercial and nonprofit research sectors. These reports provide a broader understanding of the disease, its toll on the greater society, and any potential products in the pipeline, as well as describe promising research areas. This information establishes the contextual knowledge for readers to consider as they evaluate nonprofit organizations in a specific disease area, particularly with regard to whether an organization is addressing key research areas and challenges.

PAS develops disease reports using desktop research. Each report is reviewed and validated by a Scientific Advisory Board, or SAB, composed of leading researchers and clinicians in that disease area.

- **Organization Reports** are developed describing the activities of nonprofit organizations involved in disease research. For diseases primarily affecting the developed world, organizations reviewed include those funding research, as well as those providing tools to support research efforts. For diseases primarily affecting the developing world, the organizations reviewed include product development partnerships as well as academic and private research organizations.

These reports provide detailed information on strategy, research portfolio, management, and financials. They also include an assessment of the organization's practices according to a set of metrics that *FasterCures* believes contribute to the acceleration of biomedical research. Readers can use this information together with the context outlined in the disease report as an aid to making philanthropic investment decisions.

Organization Reports are developed based on information collected in the public domain, augmented by discussions with representatives of the organization, with input from the relevant **PAS** SAB.

With regards to the National MS Society, the **PAS** analysts accessed all references included in the document and spoke with the National MS Society's CEO Joyce Nelson, executive leadership, research staff, and Fast Forward staff in October 2008. The National MS Society also had an opportunity to review and provide input to the report.

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NATIONAL MS SOCIETY: EXECUTIVE SUMMARY

OVERVIEW

Mission and Approach

The National MS Society is a national organization with 53 chapters across the 50 states. The organization's mission includes funding research in multiple sclerosis (MS) and providing information and support for people affected by the disease. In its organizational strategy for 2007-2010, it outlines five goals including:

- *Be a driving force of MS research*
- *Address the challenges of each person living with MS*
- *Mobilize the talents of the millions of people who want to do something about MS*
- *Be activists*
- *Raise \$1.25 billion by 2010*

Key Research Accomplishments

With a long history and a large amount of research funding, the Society points out that it has enabled researchers to enter and pursue a career in MS research, contributed to research that resulted in major breakthroughs in MS, and helped shape the direction of MS research. The Society includes the following as its major achievements:

- Funding research that resulted in the six disease-modifying drugs approved by the U.S. Food and Drug Administration (FDA) and research that contributed to the development of the current therapeutic pipeline;
- Funding research and organizing meetings that led to new diagnostic criteria for MS and a standard for clinical trials design in MS;
- Supporting research on myelin and axonal repair, which demonstrated that both myelin and axonal repair are required to reverse the damage in the central nervous system;
- Supporting research that successfully leveraged human stem cells to induce myelination in mice;
- Funding the first clinical trials that demonstrated the benefits of aerobic exercise in MS;
- Funding research that led to the recognition of cognition, depression, and fatigue as major symptoms of MS and sponsoring rehabilitation trials to address them;
- Supporting research on sex differences in MS and sex hormone therapies; and
- Creating and supporting a consortium on MS genetics research, generating the first genome profile for the disease. Research results from the project led to the identification of new gene targets for treatment and understanding of the cause of the disease.

In addition to funding research projects, the Society also provides support for tissue banks, a clinical trials network for MS, a DNA bank, and a network of Pediatric MS Care Centers to enable research on treatments for juvenile patients and the early-life triggers of MS.

Research Portfolio

The Society issues approximately 160 new grants per year, which amount to new commitments of \$43 million, including multi-year commitments. At any given time, the Society provides support for over 400 active grants in its portfolio. The average grant provides \$384,000 over three years, or about \$485,000 for Research Grants, the

investigator-initiated grants for established investigators. Its research funding program employs a variety of mechanisms including:

- Traditional basic and clinical research grants, including clinical trials
- Collaborative Center Awards to foster collaborative research and attract new scientists to MS research
- Pilot awards to test innovative ideas yet to be applied in MS
- Fellowships to train and build career paths for young investigators
- Healthcare Delivery Research Contracts to increase research on care management and quality of life
- Requests for proposals (RFPs) for emerging yet underfunded research areas identified through the Society’s scientific workshops, taskforce meetings, and portfolio reviews
- Fast Forward, an initiative launched in 2007 to fund industry-led drug development programs following a venture fund model.

Management

Many members of the Society’s leadership have spent more than a decade working with the Society and have risen through its ranks. The national Board of Directors, with 35 members, is the ultimate governance body of the Society, and it is structured so that the majority of the members are also members of the chapters’ boards of trustees. Major advisory bodies for research and clinical activities include the Research Programs Advisory Committee (RPAC), which provides input on research strategy and operation, and the National Clinical Advisory Board (NCAB), which provides input on topics pertinent to clinical practitioners and patients. Fast Forward, a subsidiary focusing on funding early-stage ventures on MS, has separate governance and advisory bodies.

Financials

The Society has an annual budget of \$240 million and \$180 million in assets. Its annual program expenses, which amounted to \$187 million in 2007, consist of:

- **Research:** 27 percent
- **Patient support:** 43 percent
- **Public education:** 17 percent
- **Chapter services:** 9 percent
- **Professional education:** 4 percent

Its fundraising efforts are driven by special events, Bike MS and Walk MS. Major donors are an emerging focus of the Society’s fundraising practice. Donors can direct their giving to any programmatic area of interest, in which case the contribution is fully allocated to that area without deductions for administrative costs.

ASSESSMENT

Results Summary

FasterCures believes the four areas outlined below are characteristics of innovative nonprofit medical research funders. Assessment results for the National MS Society are outlined below.

Metric Category	Assessment Summary
Accountability	<ul style="list-style-type: none"> ▪ The Society’s performance in accountability metrics is mostly strong. ▪ The Society undergoes a strategic planning process every three years and monitors the impact of its research grant programs on regular intervals employing measures specific to each program.

Metric Category	Assessment Summary
	<ul style="list-style-type: none"> In addition to the board of directors and peer reviewers, the Society's Research Program Advisory Committee guides its research operations, as do other advisory groups that it convenes for specific issues as needed.
Collaboration	<ul style="list-style-type: none"> The Society's performance in collaboration is outstanding and strong. Fast Forward seeks to accelerate industry development of MS treatment by funding early-stage research, and it has entered into a partnership with EMD Serono. The Society has played an important role in knowledge sharing in MS research, especially through its Scientific Workshops and Taskforces. In addition, the Society has established the Collaborative Center Awards to foster collaboration in the field.
Research Effectiveness	<ul style="list-style-type: none"> The Society's performance in research effectiveness metrics is strong. PAS's scientific advisors point out that it has been the single organization serving as a catalyst for new research in MS. The Society's grant program aims to increase collaboration and provide support for under researched and promising areas, and grant mechanisms that target these areas account for a significant portion of the Society's grant portfolio. However, the Society could have additional efforts in place to electronically track and measure the impact of the publications resulting from research the Society has funded.
Resource Building	<ul style="list-style-type: none"> The Society's performance in resource building is outstanding and strong. The Society has played an important role in supporting the development of new investigators in MS. The Society provides support for multiple tissue banks in MS and also ensures that they use a compatible protocol.

Scientific Contribution

The table below indicates how the Society contributes to the field of MS research by addressing key challenges that inhibit the development of a cure. The challenges were developed in conjunction with the PAS MS Scientific Advisory Board and are noted in bold. For more information about the state of MS research, please see the MS disease report.

Spectrum	Scientific Contribution
Care Continuum	
Disease Understanding	Limited understanding of the causes of the disease is an underlying challenge in MS research, and the Society invests a large portion of its research funding in this area. In addition, the Society's MS Lesion project, recognized by the PAS advisors for its potential, is likely to contribute to better understanding of the drivers of disease progression as well as the differences among disease subtypes .
Prevention	In addition to funding research on risk factors and epidemiology, which will contribute to the development of prevention measures, the Society also is supporting a research grant focusing on the role of vitamin D , an area identified by PAS's scientific advisors as having potential to lead to a prevention tool in the short term.
Diagnostics	Major challenges to development of diagnostics and disease markers for MS include the lack of tools to monitor disease activities as well as tools to measure disease progress and treatment effectiveness, including neurodegeneration and neuronal repair . In addition to the investigator-initiated grants that focus on this area, the Society's Nervous System Repair and Protection Initiative includes research to develop markers to measure treatment effectiveness, including tools that might contribute to direct observation of myelin .

Spectrum	Scientific Contribution
Treatment	The Society's research strategy calls for funding research across the disease process and its portfolio includes projects focused on neuronal repair and neuroprotection, as well as symptomatic treatments, in addition to strategies focused on inflammation . In particular, the Society's Nervous System Repair and Protection Initiative is expected to make great contributions to understanding neuronal repair and developing neuroprotection treatments.
Delivery	The high cost of treatments and access to specialists is a major issue for MS patients. The Society collects quality of life data through its Sonya Slifka Longitudinal Study to help address this issue. It also implements advocacy and patient support activities.
Research Tools	
Biospecimens and Data	The Society has provided support for three biospecimens repositories and ensured compatibility in sample collection. This will help address challenges posed by the small number of samples, limiting the power of analysis, and difficulties caused by differences in collection protocols .
Clinical Trials	As treatment options have been introduced in MS, placebo-controlled trials have become increasingly difficult to conduct . The International Advisory Committee on Clinical Trials, convened by the Society, discusses and seeks solutions to issues related to trial design and outcome measures.
Animal Models	The EAE model, the dominant animal model in MS research, focuses only on the immunologic aspects of the disease , and therefore is not adequate for research focused on other aspects of the disease. Through its investigator-initiated grant mechanism, the Society has funded grants aiming to validate animal models that allow investigations beyond immunology, such as axon degeneration,
Research Training	The Society has established several grant mechanisms to address the need for multidisciplinary talent and the need to increase young scientists' interest in a career in MS research , including the Collaborative Center Awards, Pilot Awards, and various career development awards.

PHILANTHROPIC OPPORTUNITIES

The Society's strategic goals guide its funding priorities through 2010. The following initiatives require the most funding:

- **Discovery/Basic research:** The traditional mechanism of the Society's funding for MS research, focusing on investigator-initiated research in academia.
- **Promise: 2010:** A plan to invest \$35 million between 2005 and 2010 in four research areas in MS, which include the patterns of tissue damage in MS lesions, a longitudinal patient database on quality of life and rehabilitation, development of research and care centers for pediatric patients, and neuroprotection and nervous system regeneration.
- **Fast Forward:** An initiative to accelerate development of treatments for MS by funding industry-based efforts, following a venture capital model.

NATIONAL MS SOCIETY: STRATEGY

OVERVIEW

The National MS Society is a national organization with regional chapters that funds research in multiple sclerosis (MS), provides information and support for people affected by the disease, and conducts advocacy activities for affected people. In 1946, the organization was found by Sylvia Lawry, whose brother had MS.

Research has been a focus of the Society, given that finding a cure is a priority for the MS community. However, because of the nature of MS, which is a chronic disease that causes disability and affects patients throughout most of their adult lives, advocacy and support for patients and their caregivers also are core areas of investment by the Society.

The Society is a key player in MS research. With an annual research budget of over \$40M for 2009, it provides research funding equivalent to almost half of that provided by the National Institutes of Health (NIH) for MS. Through its research program, the Society aims to accelerate new discoveries for the development of a cure. To support this aim, the Society provides support for pilot studies with new research approaches, research career development of young scientists and physicians, and MS research by scientists from other fields. In addition, it has grant programs to increase collaboration among researchers and also funds development of research infrastructure, including tissue banks and research databases.

ORGANIZATIONAL STRATEGY

MISSION AND FOCUS

Established in 1946 as the Association for Advancement of Research in Multiple Sclerosis, the National MS Society is a national organization with 53 regional chapters and a national office. The Society's vision is "a world free of multiple sclerosis." The organization's Strategic Response for 2007-2010 defines itself through the following goals:

- *Be a driving force of MS research, relentlessly pursuing prevention, treatment, and cure;*
- *Address the challenges of each person whose life is affected by MS;*
- *Mobilize the talents and resources of the millions of people who want to do something about MS;*
- *Be activists;*
- *Raise a total of \$1.25 billion by the end of 2010 to be used in the fight against multiple sclerosis.*

When the current CEO, Joyce Nelson, came to the position in 2005, the Society reached out to 25,000 of its members and donors to conduct a survey to guide the strategic direction of the organization. A major outcome of the survey was that while research is a key priority of investment, the Society's stakeholders also wanted it to address the quality of life issues of MS patients and their caregivers, such as insurance coverage, economic and psychological impact, and implications for adolescent caregivers.

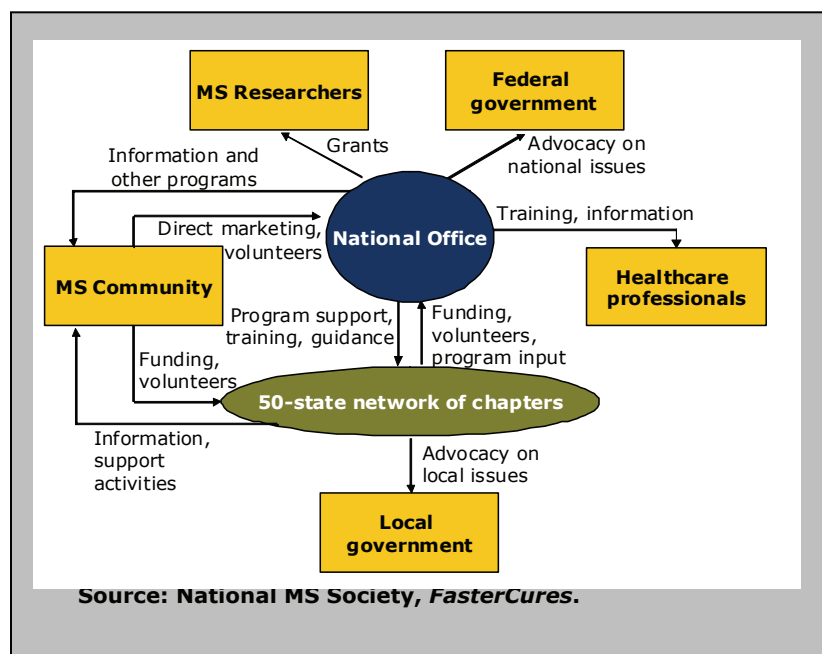
In addition to the survey, the Society leadership consulted individuals and other organizations with a stake in MS to understand their needs and views on the role of the Society. These included healthcare professionals and clinicians, pharmaceutical companies

involved in MS, members of the American Academy of Neurology, other nonprofit organizations focused on MS, and the Society's own boards of directors at the national and chapter levels.

As a result of this process, the Society determined that it needed to take a bolder approach, raising the visibility of the impact of MS, actively mobilizing volunteers and other organizations, driving the research on MS, and providing support for people affected by MS. At the same time, the Society undertook efforts to create a new brand and a common language and culture across its franchise.

Once the strategic response was finalized, the Society put in place cross-functional leadership to oversee each goal. Based on the strategic response, the national office and the chapter leaders collaborate to develop annual operational plans. The activities of both the home office and the chapters are organized and reported along these five goals, and the national board of directors and the head of chapters regularly hold meetings to assess progress against the goals. In addition, the MS community has the opportunity to provide input on the Society's programs and services, for example, through the townhall meeting held at the National Conference.

APPROACH AND STRUCTURE



The Society's home office coordinates activities across the organization, funds research programs, and conducts advocacy activities at the national level. It also organizes patient support programs, and develops education and advocacy materials for the MS Community, which it defines as people with MS, their family members and employers, and other community organizations (Figure 1).

The national office also maintains the Information Resource Center (IRC) and

the Professional Resource Center (PRC). The IRC is a call center focused on providing information for people with MS and the interested public, and it receives about 1,000 calls a day. The call center provides information about the disease, how to cope with it, and how to find support programs in local chapters. It also connects the callers with the appropriate local chapter and resources. The call center holds monthly teleconferences with each chapter to ensure ongoing exchange and information updates. The PRC is an MS library that also serves as an information dissemination center through phone and emails, but targeting healthcare professionals. It received over 6,000 inquiries in 2008. The PRC has a large collection of literature on MS and librarians to assist with literature searches, and it also releases expert opinion papers and bulletins on standards of care.

The chapters provide services to their constituents, engage in local advocacy efforts, and raise funds and awareness. Based on the Society-wide strategic plan, each chapter sets its own strategy taking into account the local circumstances. As back office operations are more consolidated in the national office, the chapters focus more on outreach and community building activities.

MS Research

Research Funding

The Society has been funding medical research on MS since 1947. Research funding is an integral part of its mission, as development of a cure is a key goal for all of the Society's stakeholders. Its funding covers a variety of topics, ranging from epidemiology to nerve repair, treatment development, and quality of life and care management. The Society defines its research strategy as accelerating research by providing funding for new and under researched areas, sharing research resources, encouraging cooperation within the MS research community, engaging other organizations, and developing new treatment and care by funding research at various stages and topics.

The Society's annual research budget is close to 50 percent of what NIH provides for MS. A major goal of its program is building a career path for junior researchers in MS and introducing new areas of research to the field.

Research Prizes

The Society has two prizes for researchers who make outstanding contributions to MS research. The *John Dystel Prize for Multiple Sclerosis Research* is a joint award by the National MS Society and the American Academy of Neurology. Each year, the prize awards \$15,000 to one researcher with an outstanding achievement.

The other prize is the *Ralph I. Straus Award for Multiple Sclerosis*. The award is a one-time award "to be given to that scientist...whose published research shall have resulted in the development of an effective and specific method of preventing or arresting multiple sclerosis in man." The Society estimates that the amount of the prize will be equivalent to or greater than the Nobel Prize in Physiology or Medicine.

Scientific Meetings

The Society also sponsors scientific meetings, *Scientific Taskforces* and *Scientific Workshops*. The meetings focus on emerging topics in MS and identifying areas that need more research. The topics are selected with the advice of the RPAC and other MS researchers.

Typically, the Society organizes two *Scientific Taskforces* per year; 22 were organized between 1997 and 2008, including a meeting that updated the diagnostic criteria for MS. A taskforce involves 12 to 15 researchers and focuses on identifying key research questions within a specific topic and developing strategies to encourage the scientific community to pursue these questions. The Society's scientific staff, with the input of the research community, selects the members of each task force.

In addition to taskforces, the Society also organizes *Scientific Workshops* to discuss broader topics of importance in MS, which engage a broader group of scientists in and out of MS research. Usually, workshops are organized every 15 to 18 months, and more than 80 scientists attend the meeting. Between 1968 and 2008 48 workshops were organized. Workshops may arise from taskforce recommendations, as was the case for stem cell research, or a taskforce may be organized to prepare for a scientific workshop. The summaries of the meetings are often published in academic journals.

Clinical Trials

In addition to providing funding for selected clinical trials, the Society also convened the International Advisory Committee on Clinical Trials to address issues related to trial design and outcome measures. The committee includes 15 to 20 members, with approximately half of the members being Americans and the other half internationals. With the development of treatment options that can slow the disease process, clinical trials became increasingly challenging and expensive, especially for placebo-controlled trials. In addition, the group also discusses topics such as outcome measures for neuroprotective and neuronal repair treatments, regulatory issues, and follow-on biologics.

The Society also seeks to encourage trial enrollment by providing information on clinical trials for MS and trials recruiting participants, along with the reasons for participation and how trials work. The Society's website also features online surveys targeting MS patients on specific research topics, as well as calls for participation for selected trials and biospecimen repository initiatives.

Support Programs

MS is a chronic disease that affects patients and their households throughout their adult lives. Therefore, support programs addressing quality of life are an integral part of the Society's mission.

Disease Information for Patients and the Public

Information dissemination tools include the Society's IRC, the website, a multimedia library, web-based learning programs, printed brochures, guidebooks, and its quarterly periodical magazine, *Momentum*. All content provided by the Society is vetted by scientific advisors.

The information content includes information such as disease description, risk factors, and treatment options; strategies for management of specific symptoms and lifestyle recommendations; employment and insurance issues, including government programs, legal rights in the workplace, and employment decisions; and updates on ongoing research. The Society also provides MS information tailored for children, through the quarterly newsletter *Keep S'myelin* and parenting materials for MS patients.

Community and Support Groups

Local chapters organize in-person self-help groups to help patients and their caregivers deal with emotional and social challenges. Also, there are groups that address specific needs based on lifecycle, for example, parents with children with MS or patients with young children. In addition to support groups, the chapters also organize social events and family programs, such as holiday parties, camps, and weekend getaways for children and families affected by MS.

In addition, since 2001, the Society has been a collaborative partner of MS World, an online community of MS patients. Other sponsors of MS World include Bayer Healthcare, EMD Serono, and Teva Neuroscience.

Direct Support

The Society's chapters also provide direct support to patients and their families. This includes support for housing modification, care management services, and medical equipments. Often, the chapters partner with other local entities to co-sponsor the assistance program. In addition, the Society has in place a college scholarship program for

families affected by MS, to help mitigate the negative effect of the disease on household economy.

Support for Healthcare Professionals

The Society also provides support for healthcare professionals such as clinicians, nurses, and other care facility staff. Major activities include information dissemination through the PRC and professional education opportunities.

Through the PRC, the Society publishes and disseminates general information on the disease targeted to healthcare professionals, treatment recommendations by experts, and information on strategic topics such as pediatric MS.¹ It also provides toolkits on strategies to discuss sensitive topics with patients and other resource material for clinicians, nurses, and administrators at assisted living facilities or at adult day programs. In addition, its MD-on-call program provides free expert consultation for clinicians.

The Society also provides multiple educational opportunities to healthcare professionals, including online programs targeting clinicians, nurses, and other healthcare professionals. It also developed a clinical training program in collaboration with the University of Texas Southwestern Medical Center. In addition to education programs, the Society has offered fellowship programs for advanced training in MS since 2003. *The Multiple Sclerosis Clinical Care Physician Fellowships Program* provides \$65,000 to support one year of training for clinicians, and *the John Dystel Fellowship in Multiple Sclerosis* seeks to develop MS nurse specialists, providing \$22,500 for three months or \$44,000 for six months.

Advocacy

The Society's policy advocacy programs focus on topics related to MS research, disability rights, access to healthcare and long-term care, and insurance. The Society publishes position papers and creates activist toolkits for outreach to elected officials. Subjects related to research include increasing funding focused on MS, encouraging stem cell research, raising awareness of the increase of MS incidence in areas affected by the Gulf War, and legislation introduced in Congress in 2008 for a National MS Disease Registry at the Centers for Disease Control and Prevention (CDC).²

The Federal MS Activism Council, which includes patients, researchers, and board members, provides input on the Society's national advocacy activities.³ The MS Action Network, with 16,000 volunteers, is an important mechanism for advocacy. Through the network, tailored e-mail messages are sent to legislators from their constituents. The Society also organizes an annual Public Policy Conference in Washington, DC, where activists from local chapters visit their legislators to voice their concerns. In addition, the Society is a founding member of the MS Coalition, a group of seven MS organizations, focusing on advocacy for quality of life of MS patients.

Major achievements in advocacy include the creation of the Congressional MS Caucus in 2007, with 116 congressmen and 20 senators as members, and the designation of MS as a disease eligible to be funded through the Department of Defense's Peer Reviewed Medical Research Program. Additionally, the Department of Defense Congressionally Directed Medical Research Program allocated \$5M for MS research in 2008.

¹ The Society currently is focusing on pediatric MS. Because MS is perceived as a disease of young adults, MS in children often is overlooked and goes undiagnosed. In addition, pediatric MS may provide a unique opportunity to study early life triggers of MS.

² The exact scope of this registry is yet to be determined.

³ The Government Relations Committees, located in each chapter, help guide the effort.

PARTNERSHIPS

With the development of the Strategic Response, collaboration with other organizations came to be an important lever for the Society. The National MS Society has long been a member of the Multiple Sclerosis International Federation, which connects MS organizations across the world. The Society's founder, Sylvia Lawry was a founding member of the Federation, and three of the Society's leaders currently serve on the Foundation's board. The Society has joint initiatives on pediatric MS with the MS Society of Canada, the Italian MS Association, and the MS Society of Argentina.

In terms of research activities, the Society collaborates closely with NIH to ensure effective use of resources in MS research. NIH and the Society often co-fund projects or jointly select projects to fund, in which case the two organizations coordinate to avoid any overlaps in funding and to maximize the resources available. Examples of such joint projects include a research project on sex differences in autoimmunity and a clinical trial on estriol based on gender differences. In addition to collaborations in research funding, a representative from NIH is present in many of the Society's meetings, including the grant review and scientific workshops.

The Society also works with the Department of Veterans Affairs' Multiple Sclerosis Center of Excellence and CDC's Agency for Toxic Substances and Disease Registry. It participates in the Integration Panel at the Department of Defense Research Program, which will define the focus of research funds available for MS from the Department. The Society also assists the Conrad N. Hilton Foundation its peer-review process.

The Society also provides input and assistance to other entities in organizing scientific meetings on MS. For example, the Society has been providing staff and logistics support to ACTRIMS (Americas Committee on Treatment and Research in Multiple Sclerosis), including organization of the 2008 scientific meeting, World Congress on Treatment and Research in Multiple Sclerosis, , which drew over 5,000 participants. It also provided inputs to the Keystone Symposia for its meeting on MS, and organized a joint conference with the Multiple Sclerosis Association of America on primary progressive MS.

In addition to research, the Society collaborates with other organizations in its advocacy and patient support activities. Partners in these areas include the Consortium of Multiple Sclerosis Centers, the Heuga Center for Multiple Sclerosis, MSFriends, and MS World. It also collaborates with organizations with a focus other than MS such as the Parkinson's Action Network, for legislation creating a patient registry for MS and Parkinson's disease.

RESEARCH STRATEGY

DEVELOPMENT OF RESEARCH PRIORITIES

The Society's research focuses on accelerating research by increasing collaboration and providing support for under researched and promising areas that could ultimately lead to a cure.

The Society has reviewed its programs every five years. It convenes a task force of leading researchers to assess the state of MS research, including progress made, key barriers, and what the Society can contribute. The task force discusses the outcome with RPAC and other

advisory committees of the Society as well as other organizations involved in MS and leaders in other disciplines. Based on the review outcome, RPAC recommends whether a specific research topic needs additional support and whether a new award category needs to be instituted. For example, the Harry Weaver Neuroscience Scholar Award was put in place after the 1980 review, to attract more scientists to MS. The 1990 review led to the introduction of pilot grants to generate preliminary data and to recruit more talent to MS research. It also led to the grant program on healthcare delivery and policy, which enables the generation of basic data to support advocacy activities. In the 1990s, targeted research programs in genetics and gender differences were launched as a result of these reviews.

While the Society's established grant programs accept proposals in a wide array of topics in MS treatment development, it also targets funding to areas where more research is needed. The Society's scientific meetings, the Task Forces and Workshops, provide an opportunity to identify these underfunded and under-investigated areas. Some topics emerge as ripe for additional investment, and in such instances, the Society puts together specific RFPs, either on its own or in collaboration with other organizations such as NIH or academic institutions. Once the topic gets traction in the research community, it is incorporated into the standard grant program.

In terms of overall reviews of the state of MS research, the Society commissioned the Institute of Medicine to conduct a strategic review of MS research in 2001. The outcome of this review was published as a report of the National Academy of Sciences. The report recommendations led to the establishment of the Collaborative Center Award and an increased focus on quality of life and rehabilitation, including the introduction of Society-funded investigator-initiated grants for these topics.

RESEARCH FOCUS

The Society's ultimate goal in funding research is to develop cures for MS. It identifies three types of cures needed by MS patients and organizes its research along these areas:

- **Cure 1 - Stopping MS attacks and disease progression:** immunology, therapy development, measurement of disease activities, infectious agents
- **Cure 2 - Repairing the damage from attacks:** glia biology, central nervous system repair, neuropathology, neurophysiology, therapy development
- **Cure 3 - Preventing onset of the disease:** genetics, epidemiology, immunology, virology
- **Beyond the three cures:** healthcare delivery and policy, therapy development and symptom management, psychosocial research, rehabilitation research

All investigators with grant proposals relevant to the areas outlined above are eligible to apply for the Society's support, and the Society does not favor any specific areas of research. Rather, support for underfunded areas that the Society sees as crucial are provided through targeted research programs with a separate RFP. Recent research areas that received funding through an RFP process include MS pathology, genetics, myelin and axonal repair, a longitudinal study of quality of life, and gender differences in MS.

Currently, the Society's major research initiatives include the following:

- **Targeted Initiatives:**
 - *Promise: 2010* is an initiative to invest \$35 million between 2005 and 2010 in four research areas in MS, which include the patterns of tissue damage in MS lesions, a longitudinal patient database on quality of life and rehabilitation,

development of research and care centers for pediatric patients, and neuroprotection and nervous system regeneration.

- Fast Forward, initiated in 2007, focuses on accelerating industry-based efforts to develop new MS treatments.
- **Collaborative MS Research Centers:** Funding for interdisciplinary teams based in specific MS research centers.
- **High-Risk Pilot Research:** Short-term grants to enable investigators to test innovative ideas and bring new investigators to MS research.

IMPACT MEASUREMENT

The Society assesses the impact of each of its grant programs on a regular basis. The reviews are conducted every year, and the Society also surveys prior grant recipients—every two years for the pilot grants, five years for collaborative center awards and most fellowships, and 10 years for the Harry Weaver Award.

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The metrics used to measure impact are defined based on the goal of individual grant programs. For example, review of pilot awards focuses on the program's success in attracting new researchers to MS and enabling researchers to secure follow-on funding on the research topic. For postdoctoral fellowships, the review focuses on whether the fellows continued a career in MS research and whether they have been successful in securing research funding afterward. In a 2008 survey of 522 past fellowship recipients, out of whom 300 were reachable and responsive, about 60 percent of the recipients were continuing to pursue research in MS.

About Fast Forward

Fast Forward is a new initiative of the Society focused on accelerating drug development for MS. While the Society has focused on funding research in academia, it realized that results from academic research are not automatically transferred to the pharmaceutical industry for commercialization. As a result, the Society has set up Fast Forward, which provides funding for pharmaceutical and biotechnology companies with projects in MS, in addition to its ongoing support for academic research.

Fast Forward operates as a venture capital model. Once a potential investment target is identified, the potential investee company submits a 10-page application. Six members of Fast Forward's science and business advisory committee (SBAC) review the application and determine whether it should move into the more detailed due diligence process.

For the formal due diligence, the company is asked to provide detailed information on its technology, clinical trial protocol, relevant publications, and intellectual property (IP) arrangements. After reviewing the material, SBAC conducts a conference call with the company, discusses the application within the committee, and votes on whether Fast Forward should pursue the investment. If two thirds or more of the reviewers support the opportunity, Fast Forward and the company discuss what would be the appropriate funding vehicle and milestones. Once this process is complete, the investment thesis is presented to the Board of Managers of Fast Forward, who makes the ultimate decision on whether to invest in the project.

Fast Forward announced its first deal in December 2008, awarding \$1M to Apitope International for a proof-of-concept trial of a therapeutic vaccine. Fast Forward aims to raise \$30M by 2012 to invest in industry-initiated projects. Initial seed funding is provided by the Society, but additional funding will be secured through fundraising efforts specifically targeting Fast Forward. One recent milestone is the collaboration with EMD Serono, announced in March 2009. According to the agreement, EMD Serono will provide up to \$19M in support for early clinical research in early biotechnology companies and academia.

KEY ACCOMPLISHMENTS

The Society has been an integral part of MS research during the past 60 years, and it considers setting the direction of MS research as a crucial aspect of its role. The Society identifies the following as major research achievements:

- Funding research that resulted in the six disease-modifying drugs approved by FDA and research that contributed to the development of the current therapeutic pipeline;
- Funding research and organizing meetings that led to a new diagnostic criteria for MS and a standard for clinical trials design in MS;
- Supporting research on myelin and axonal repair, which demonstrated that both myelin and axonal repair are required to reverse the damage in the central nervous system;
- Supporting research that successfully leveraged human stem cells to induce myelination in mice;
- Funding the first clinical trials that demonstrated the benefits of aerobic exercise in MS;
- Funding research that led to the recognition of cognition, depression, and fatigue as major symptoms of MS and sponsoring rehabilitation trials to address them;
- Supporting research on sex differences in MS and sex hormone therapies; and
- Creating and supporting a consortium on MS genetics research, generating the first genome profile for the disease. Research results from the project led to the identification of new gene targets for treatment and understanding of the cause of the disease.

RESEARCH INFRASTRUCTURE

CLINICAL TRIALS NETWORK

In 2003, the Society provided \$220,000 in funding for the creation of the Multiple Sclerosis Cooperative Research Group (MS-CORE). MS-CORE is a clinical trial cooperative with 80 trial sites across North America, to facilitate drug development efforts by small pharmaceutical companies or academic institutions. Though MS-CORE is yet to be widely used, the Society expects the network to become more instrumental in treatment development as *Fast Forward* and *Promise: 2010* generate the need for trials beyond those conducted by the large pharmaceutical companies.

TISSUE BANKS

The Society supports the development of tissue banks for research purposes. For example, along with the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Mental Health, and the Department of Veterans Affairs' Research & Development Service, the Society sponsors the Human Brain and Spinal Fluid Resource Center at the University of California, Los Angeles, which was established in 1961. Within the Center, the Society specifically supports the MS Human Neurospecimen Bank, which collects specimens of brains, spinal cords, and cerebrospinal fluid (CSF). The most recent funding from the Society was \$2.6M for 2004-2009. As of 2008, the bank's specimens led to 893 scientific articles cumulatively.

Another tissue bank supported by the Society is the Rocky Mountain MS Center Brain & Tissue Bank in Colorado. Established in 1976, the Center has pledged from 1,100 MS

patients to donate their brain tissues and has distributed samples to 180 investigators to date. The Society's most recent grant to this tissue bank was made in 2004, a five-year grant amounting to \$806,000.

In addition, the Society has supported the development of another tissue bank, the University of Illinois at Chicago MS Tissue Repository, through a grant of \$426,000 awarded in 2007.

These tissue banks collaborate to ensure the compatibility of the tissues. When the tissue bank in Chicago applied for its grant, the Society's peer review committee specifically required the investigator to collaborate with existing banks and learn their practices.

DNA DATA

The Society supports the genetic data repository of the MS Genetics Group at the University of California, San Francisco. As part of a multi-center study to understand genetic susceptibility to MS, the repository collects DNA data of MS patients and their family members not affected by MS. As of spring 2008, the effort collected biological specimens from 3,211 MS patients and their clinical data, as well as additional samples from the patients' family members when available, in addition to unrelated controls. The genetic data was instrumental in the International Multiple Sclerosis Genetics Consortium's genome-wide screening for MS risk genes. In addition to major collaboration efforts, DNA data also is accessed by individual researchers. In 2002-2008, 26 laboratories used the data for their research.

CLINICAL TRIALS AND REHABILITATION DATA

In addition to biological data, the Society was involved in the establishment of the patient database at the Sylvia Lawry Center for MS Research in Munich, Germany. The database includes clinical and imaging data from more than 20,000 patients who received placebo in major clinical trials. Access to data is available for researchers and clinicians.

The Sonya Slifka Longitudinal Study, launched in 2000, is a targeted project launched by the Society. It is an observational study tracking over 4,500 MS patients through phone interviews. The study focuses on quality of life, rehabilitation, symptomatic therapies, employment and healthcare delivery. The first cohort of the study, including 2,000 patients, has been followed up for eight years so far, and a new cohort was added in 2006. The resulting data is used for advocacy and program development in the Society by enabling identification of problems faced by people with MS and also is made available to researchers.

RESEARCH MANAGEMENT

PROJECT SELECTION

The Society's grant selection interval varies depending on the grant type. The Society's Research Grants, which account for the majority of its grants, are issued twice a year, while the Contracts in MS Health Care Delivery and Policy Research, Collaborative MS Research Center Awards, as well as fellowships and training awards are issued once a year. In addition, pilot grants are issued on a rolling basis. The selection process takes five to six months for Research Grants, and two to three months for pilot grants. Pilot research grants are disbursed immediately after official notice. Most other grants take another two to three months until actual disbursement.

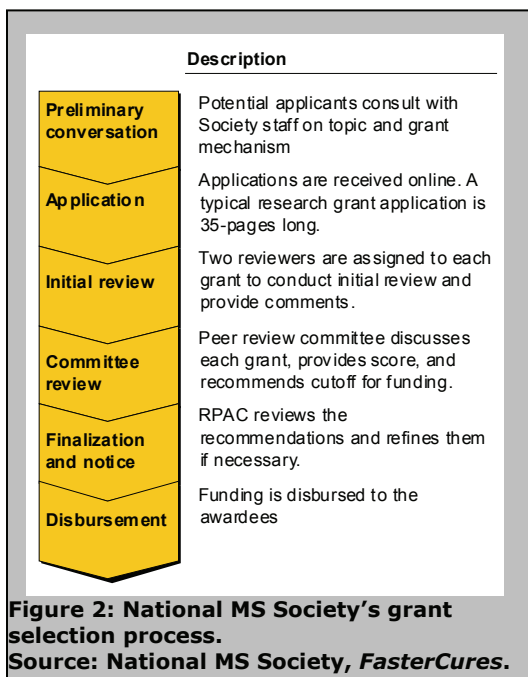


Figure 2 outlines the Society's grant selection process. Prior to grant application, the potential applicants are encouraged to consult with the Society to determine the funding program that best fits the content of the proposal and the applicant's career stage. The applications are accepted through an online grant application system. The length of the proposals varies, ranging from 2 pages for a pilot grant to 6 pages for a Collaborative MS Research Center Award to 35 pages for a typical research grant. For each proposal, two reviewers are assigned, and a critique of 2-3 pages is prepared to be shared with the applicant.

The applications recommended by the initial reviewers and those for which the two reviewers had diverging opinions are discussed during the respective advisory committee meeting, which is the next stage of the selection process. The meeting occurs in person, where each grant is discussed and scored. In the process, the committee may restructure a standard grant application into a pilot if that is appropriate, or request discussions with the applicants if necessary. Major criteria for grant selection are summarized as the following:

- Scientific merit
- Relevance to MS
- Track record of grantee as a scientist (whether in MS or outside of MS)

During the whole process, avoiding conflicts of interest and guaranteeing reviewer anonymity and confidentiality are considered crucial. In addition, the Society also collaborates with NIH to ensure the two funders do not issue overlapping grants.

Once all applications are scored, the peer-review committee arrives at a recommended cutoff score for funding. The RPAC oversees the whole process and ensures that there is no wide discrepancy among different committees' decisions. The RPAC may recommend including or excluding some of the grants if it disagrees with the peer review decision.

For pilot grants and targeted areas with a separate RFP process, the process is slightly different. Because pilot grants are issued on a rolling basis, the review is conducted by two or more ad-hoc reviewers, rather than a committee. The reviewers are selected by the Society staff from a pool of reviewers committed to the program.

Peer Review Committees

Every year, the Society organizes a total of nine grant review committees. Three committees are organized for each Research Grant review, held semi-annually, and committees also are organized once a year for fellowships and training grants, Collaborative MS Center Research Awards, and the Contracts in MS Health Care Delivery and Policy Research.

The review committee members serve for three years, with the possibility to serve additional terms, and rotate across different committees during their tenure. The Society aims to balance different expertise in each committee. Ad hoc members or outside reviewers may be invited if additional expertise is required.

The Society staff requests recommendations for reviewers throughout its routine interactions with scientists. In addition to expertise and recommendations received from the scientific community, reviewers need to have secure research funding. The Society also considers the balance of home institutions, diversity, and geography in its selection of reviewers. In addition, a representative of NINDS is present at each grant review committee.

For research areas with a separate RFP, scientists with intent to submit an application are invited to a conference call to discuss the aims of the project. Once the applications are submitted, a special panel with appropriate expertise is convened to discuss each proposal, with more conversation with investigators if necessary. The Society also may negotiate with the applicants to improve the proposal and review milestones.

PROJECT STRUCTURE

The Society has 11 different types of grant mechanisms in place to fund research in MS, which are described in Table 1.

Table 1: National MS Society's Grant Mechanisms

Grant Type	Description	Amount	Duration
Research grants			
Research Grants	<ul style="list-style-type: none"> Funds a wide array of research, including basic, pre-clinical, and clinical research, as well as patient management and rehabilitation. 	Various	1-5 years
Pilot Research	<ul style="list-style-type: none"> Funds development of preliminary data in research areas with sparse data. Applicant must be an investigator at an established research institution. 	\$40,000 maximum (10% or less in indirect cost can be added)	1 year
Career development grants			
Harry Weaver Neuroscience Scholar Awards	<ul style="list-style-type: none"> Supports young investigators to establish themselves in MS-related neuroscience. Applicant should have a doctoral degree and academic appointment as assistant professor or equivalent; at the same time, he or she should not have more than five years of independent research. 	\$550,000 maximum (10% or less in indirect costs can be added)	5 years
Daniel Haughton Senior Faculty Awards	<ul style="list-style-type: none"> Supports established investigators to acquire specialized skills that will help them conduct research in MS. The applicant should not currently be an expert in the training proposed. The award can be used for sabbatical support. 	\$118,000	Typically 1 year or less
Mentor-Based Postdoctoral Fellowship in Rehabilitation Research	<ul style="list-style-type: none"> Supports mentors to provide training on rehabilitation to postdoctoral fellows so that fellows can conduct independent research and obtain a position to do so. The mentor, the applicant, must have a faculty appointment. The fellow must have a doctoral degree or equivalent and less than three years of postdoctoral training. Mentors can train multiple fellows in the duration of the grant. 	Based on salary scale	5 years
Sylvia Lawry Physician Fellowship Award for Training in MS Clinical Trials	<ul style="list-style-type: none"> Supports M.D.s or equivalent to build skills required in MS clinical trials. Applicant must be licensed to practice medicine in the United States. 	Up to \$195,000 (\$65,000 per year)	Up to 3 years

Grant Type	Description	Amount	Duration
NMSS-AAN MS Clinician Scientist Development Awards	<ul style="list-style-type: none"> Supports research training for young clinicians committed to MS research. Applicants must be completing their residency program in the United States when the fellowship begins. 	Based on salary scale	2 years
Postdoctoral Fellowships	<ul style="list-style-type: none"> Supports postdoctoral fellows so that they can conduct independent research in MS and obtain a position to do so. Applicant must have a doctoral degree or equivalent, three years or less in postdoctoral training, and a mentor arrangement. Also eligible for the Dale McFarlin Travel Awards for NMSS Postdoctoral Fellows, which provide \$1K-1.5K for attendance at MS-related scientific meetings. 	Based on salary scale	Up to 3 years
Career Transition Fellowships	<ul style="list-style-type: none"> Funds postdoctoral trainees with commitment and potential in MS research. Supports two years as postdoctoral training and three years as new faculty. Applicant must have a doctoral degree and 2-4 years of postdoctoral research experience. 	Based on salary scale as postdoctoral fellows and \$150,000 in direct costs as faculty	5 years
Collaboration grants			
Collaborative MS Research Center Awards	<ul style="list-style-type: none"> Funds teams of researchers to encourage interaction and collaboration among members, building on ongoing individual research. Teams of three or more researchers can apply (existing individual research funding required). Teams should include one investigator that did not focus on MS research previously 	\$750,000 (10% or less in indirect cost can be added)	5 years
Healthcare delivery grants			
Patient Management, Care and Rehabilitation Research Grants	<ul style="list-style-type: none"> Funds research focusing on improvement of quality of life in people with MS, including psychosocial issues, symptom management, clinical care, and rehabilitation. Format include Research Grant, Pilot Research Awards, or fellowships, including the Mentor-Based Postdoctoral Fellowship in Rehabilitation Research Applicants can be working at a variety of organizations including academia, think tanks, or other research organizations, and a doctoral degree is not a requirement 	Various	1-3 years
Contracts in MS Health Care Delivery and Policy Research	<ul style="list-style-type: none"> Funds research that can improve government and private sector policies and benefit programs for MS patients. Applicant can be at a variety of organizations including academia, government, medical institutions, for-profit entities, nonprofits, and consortia. Invitation-based RFP process. 	Various	Multiple years

Source: National MS Society, *FasterCures*

MANAGEMENT OF RESEARCH RESULTS

Each grantee is required to provide a financial report and progress report every year, and a final financial report and progress report at the end of the award duration. Awardees are expected to include an acknowledgement of the Society's support in publications resulting from the award and also are required to provide the Society with all published reports and preprints as part of the progress reports, as well as to disclose any inventions.

Beyond the initial year, funding for subsequent years is subject to receipt and approval of annual progress reports. Failure to comply with the annual reporting requirement results in cancellation of funding after a one- to three-month grace period.

Upon receipt of annual reporting, the Society's scientific staff reviews the progress against the goals set in the original application and makes sure that the grant funds are used appropriately. For certain projects such as clinical trials, genetic studies, or healthcare delivery contracts, funding may be terminated if progress against milestones is not demonstrated. While research grants have more flexibility due to the nature of basic research, projects without adequate progress also can be terminated.

Once the award is completed, awardees are asked to provide the Society with information on publications and subsequent funding proposals on the topic. In addition, the Society conducts surveys of past grant recipients to understand the impact of its funding in the longer term.

KEY RESEARCH POLICIES

The Society's policy on IP rights defers the rights to the grantee organization, unless the grantee organization does not have appropriate policies in place. The grantee institution has the obligation to report the emergence of any IP rights and actions taken on them to the Society. The grantee institution also has the obligation to pursue commercialization of the IP and share the income derived from it with the Society. However, the Society usually does not pursue commercialization beyond the efforts made by the grantee institution. Still, the Society received some royalty income from commercialization by grantee institutions.

Major datasets derived from funding from the Society are required to be made available to the public domain. For example, the data from the International Multiple Sclerosis Genetics Consortium are made available to researchers on the Internet, subject to an application process.

The recipients of the training awards are required to attend the Tykeson Conference on MS for NMSS Fellows and Faculty Awardees, first organized in 2008. The conference, to be held every 18 months, aims to increase knowledge sharing and to build a community of MS investigators.

NATIONAL MS SOCIETY: RESEARCH PORTFOLIO

OVERVIEW

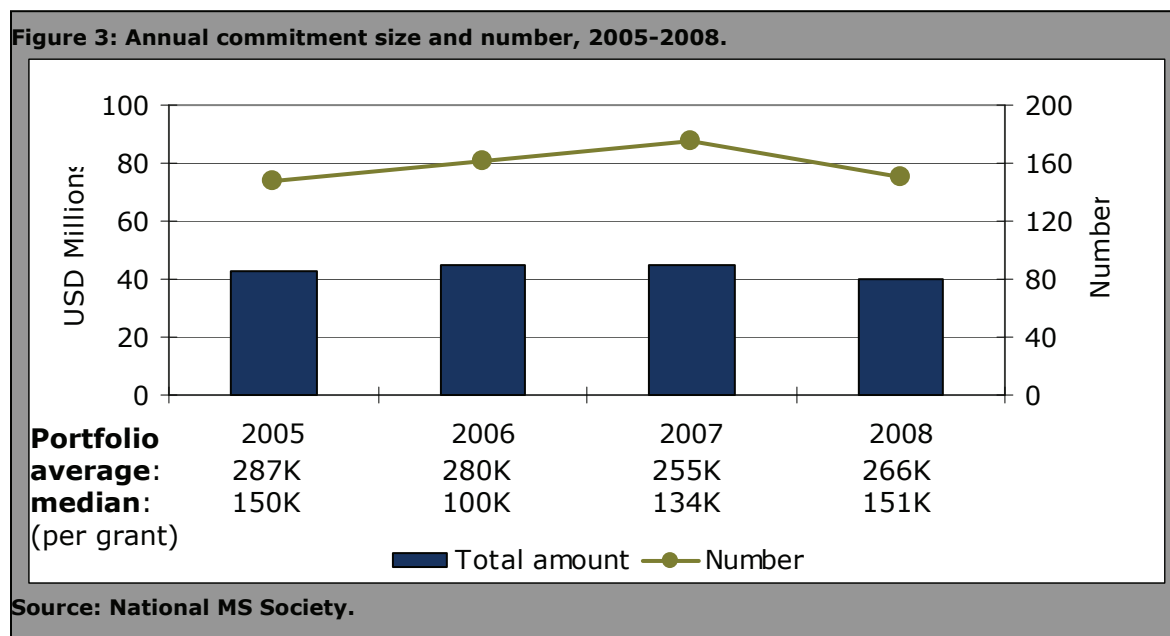
This section depicts the National MS Society's grants as of October 2008. This analysis focuses only on the new grants that were issued during the past four years, including multi-year commitments. The report analyzes the Society's active commitments issued during this period in terms of aggregate number and amount, size, duration, type, and receiving institutions.⁴ On average, the Society's active commitments, including all grant types listed in Table 1 of the Strategy Section, have durations of 2.9 years and funding of \$384,000 (the average for Research Grant category was \$485,000).

Approximately 90 percent of the Society's active commitments issued during the past four years focus on research.⁵ This also includes fellowships and career development grants that require proposals, which amount to about 10 percent of the total analyzed, as well as pilot grants that aim to test new ideas or generate data for further support, which amounted to 3 percent of the total analyzed. Research projects on etiology and treatment account for most of the portfolio, and translational research amounts to 60 percent of the research portfolio in terms of stage of research.

OVERALL PORTFOLIO

FUNDS AWARDED ANNUALLY

Figure 3 illustrates the number and amount of new grants that the Society committed each year for the past four fiscal years. For multi-year grants, the full amount is accounted for in the year in which the commitment was made.



⁴ For more information on the Society's grants, see the Strategy section or the PAS grants database online.

⁵ Note that the Society issues Research Grants as a grant category, which are part of the grants classified as research.

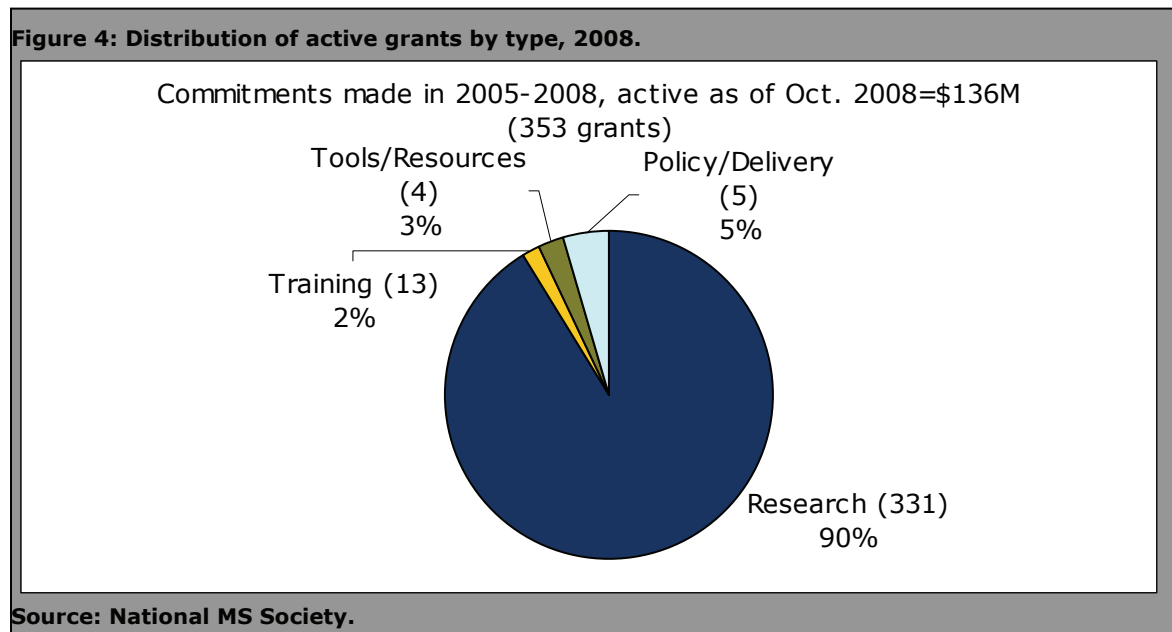
Over the past four years, the Society has made commitments for 635 grants amounting to \$172M. The level of new commitments has been relatively stable, issuing about 159 grants amounting to \$43M per year on average.

In 2005, the average and median grant size was higher than other years because more Research Grants and fewer Pilot Awards were issued. In 2006, a one-time award on neuronal repair, the Translational Research Partnerships on Nervous System Repair and Protection in MS, was issued. The program includes four grants that amounted to \$16M for five years, which contributed to the relatively high average grant size. The number of grants issued was especially high in 2007 because more pilot grants were issued that year.

GRANTS BY TYPE

Figure 4 illustrates the distribution of the Society's active grants by type: research, training, tools/resources, and policy/delivery. This analysis includes all active commitments made in 2005-2008. Multi-year commitments are also included for their full amounts.⁶

Research grants refer to funding provided to support a specific research project and include, but are not limited to, grants issued under the Society's Research Grant category. Training grants refer to funding that supports the training of individuals to build skills and expertise in a specific field, typically at the postdoctoral level, but without an individual research component. Grants that focus on providing career development opportunities to young scientists that require a specific research proposal are classified as research in this analysis. Tools/resources grants refer to funding provided to develop infrastructure required to conduct research, such as animal models, tissue banks, or equipment. Grants for policy/delivery include funding for health services research and policy studies.



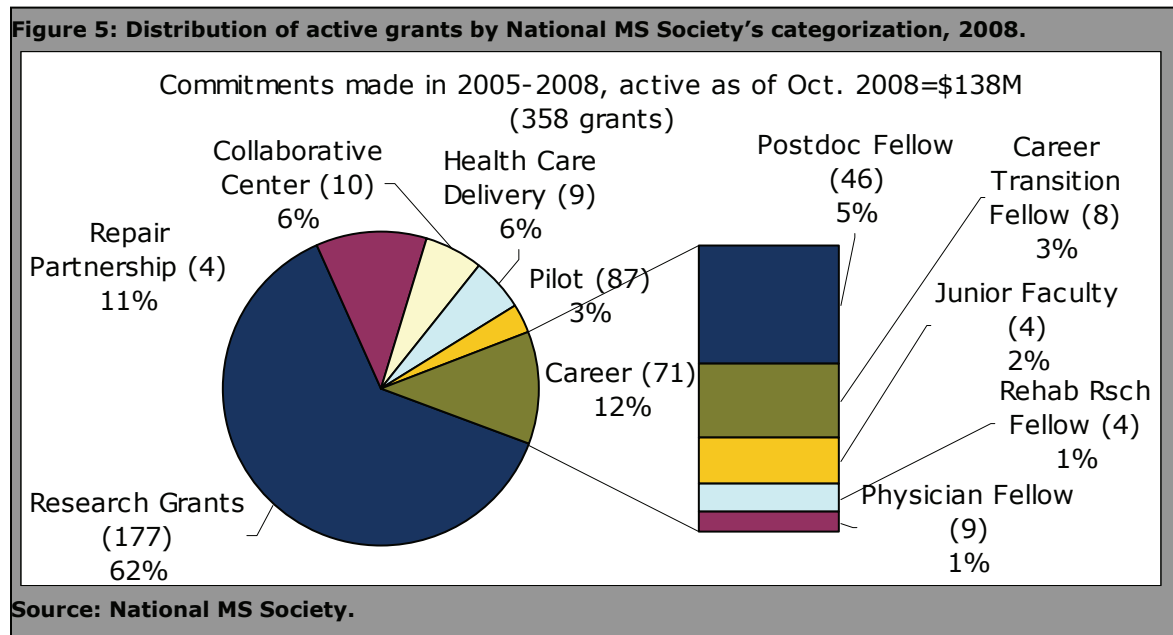
Most of the Society's grants are for research. Many of the Society's research fellowships require a research proposal, and hence are categorized as research here, as well as the Pilot

⁶ Note that Figure 4 excludes five active grants amounting to \$2M, as their summaries could not be located for analysis. However, these five grants are included in Figure 5.

Awards. Grants that are categorized as focused on training are grants that provide clinicians with the opportunity to build skills in clinical trials and those that fund mentors to develop postdoctoral fellows in rehabilitation research.

Grants for tools and resources support DNA banks, tissue repositories, and CSF repositories. Policy/delivery projects address various topics such as financial costs of MS, the Sonya Slifka study, development of indicators for quality of life, effect of mobility aids, evaluation of rehabilitation services, long-term care needs in MS, and cost effectiveness of MS treatments.

The Society’s own classification of grants provides additional information (Figure 5). Among active grants issued since fiscal year 2005, grants and fellowships aiming to assist scientists in building a career path in MS and relevant skills amount to 71 grants, or 12 percent of the active commitments, with multi-year commitments accounted for the full amount. In terms of stage of career, grants for postdoctoral fellows or equivalents amount to 59 grants or 7 percent of the portfolio analyzed. Grants specifically aiming to support young investigators, such as those transitioning from fellowship to a faculty position or junior faculty account for 12 grants amounting to 5 percent of the portfolio analyzed.

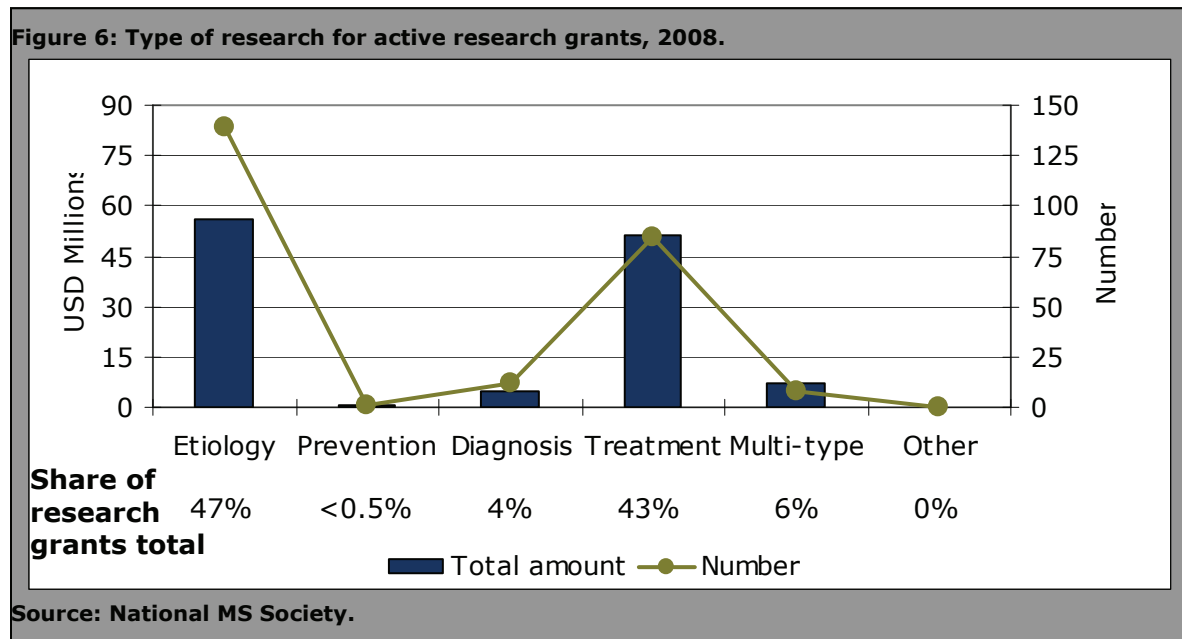


RESEARCH FOCUS

GRANTS BY RESEARCH TYPE

Figure 6 further categorizes the active research grants issued in 2005-2008 into subtypes, based on the type of research: etiology, prevention, diagnosis, treatment, and other. Grants included in Figure 6 are the grants categorized as being focused on research on Figure 4, but excluding pilot awards, which amount to 3 percent of the portfolio, as their composition changes on ongoing basis as new grants are issued. Note that the total of all grants categorized as research on Figure 4 amounted to 331 grants for \$123M, with the full amount of multi-year commitments included, and Pilot Awards, amounted to 87 grants for \$4M. Therefore, the total for Figure 6 amounts to 244 grants for \$119M.

Research on etiology focuses on building a better understanding of the disease, especially the cause of the disease. Prevention focuses on developing strategies to reduce the onset of the disease. While some research on risk factors and epidemiology may have implications to prevention, those types of research are classified as etiology unless there is a specific approach in place for the development of a prevention strategy. Developing diagnostic tools and criteria is another area of research, especially important if the disease is diagnosed only based on clinical manifestation and if disease progression cannot be clearly measured. Treatment research aims at stabilization of the disease progression or restoration of health.



Projects on disease etiology amount to 47 percent of the total analyzed, followed by treatment research, which account for 43 percent of the total. However, in terms of number of grants, projects on etiology account for 57 percent of the total, compared to 35 percent for treatment, as grants for etiology tend to be smaller than those for treatment research.

Multi-type grants refer to research projects that encompass multiple types of research. In the Society’s portfolio, grants that cover multiple types of research are the Collaborative Center Awards and the MS Lesion Project, which is part of *Promise: 2010*. All eight multi-type projects focus on etiology and treatment.

The Society also has a grant focused on developing a specific prevention strategy, by better understanding the role of vitamin D in disease regulation. In addition, the Society has additional projects that will have implications for prevention, such as those that focus on epidemiology or genetics, classified as part of etiology here. Within the portfolio analyzed, the Society had two epidemiology projects and nine genetics projects, which amounted to \$99,000 and \$5.8 million respectively, which amount to a total of six percent of the research grants.

GRANTS BY RESEARCH STAGE

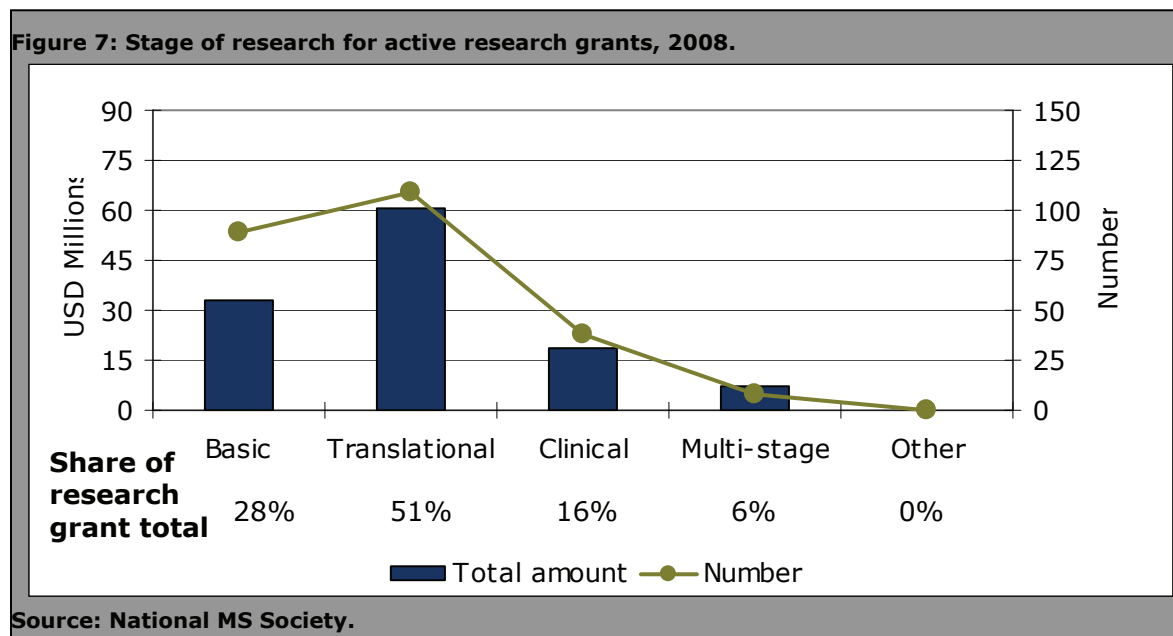
Figure 7 further categorizes the research grants by stage of research: basic, translational, clinical, and other. Grants included in Figure 7 are those categorized as focused on research

in Figure 4, but excluding pilot awards, as their composition changes on an ongoing basis as new grants are issued.

Basic research aims at deepening the knowledge about the disease, without specific application of the resulting knowledge in mind. Much of the etiological research is considered basic research.

Translational research is focused on outcomes, and seeks to fill the gap between current knowledge and a specific goal, such as developing a compound for treatment. It refers to a stage of research where the findings are yet to be applied to humans, but often uses animal models.

Clinical studies generally refer to the study of a drug, biologic, or device in human subjects with the intent to discover potential beneficial effects and/or determine safety and efficacy. They also refer to studies of human populations (e.g., epidemiology, behavior, observation). In diagnosis or treatment research, clinical studies refer to clinical trials of specific intervention strategies.



Translational research projects amount to over 50 percent of the Society’s research grants, followed by basic research and clinical research. Within translational research, 62 percent is treatment research and 35 percent is etiology research. The Society’s basic research portfolio, which accounts for 28 percent of the total research portfolio, is dominated by etiology research. In the clinical portfolio, about 60 percent are efforts to develop a treatment for MS.

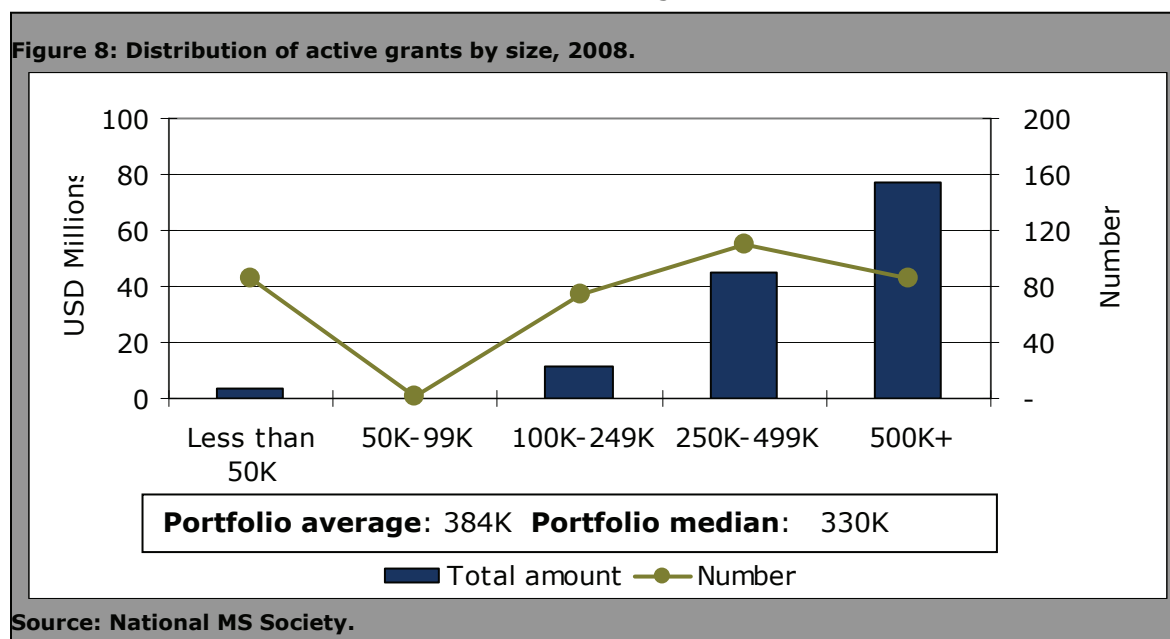
The MS Lesion Project and seven Collaborative Center Awards address multiple stages of research. Among the Collaborative Center Awards, three encompass basic and translational research, two translational and clinical research, and the other two all stages of research. The topics addressed by these grants include immunologic subjects such as leveraging T-cells to stop MS attacks, developing therapeutic vaccines and immunomodulatory agents, and developing therapies targeting specific components of an MS attack; as well as subjects in central nervous system repair such as characterizing nerve fiber damage and developing neuroprotective therapies, understanding the progressive disability in MS, and

characterizing cells involved in myelin and tissue repair. In addition, another Collaborative Center grant focuses on developing predictive markers of disease progression.

SIZE AND DURATION OF AWARDS

GRANTS BY SIZE

Figure 8 illustrates the distribution of the Society’s active grants issued between 2005 and 2008, by amount. This analysis includes all active commitments made in 2005-2008, and multi-year commitments are also included in their full amounts. The total number of grants included in this analysis is 358, amounting to \$138M, as was the case for Figure 5 The average grant amount awarded to established investigators by NIH was \$361,000 per year in 2007, or \$1.3M for the entire duration of the grant.⁷



Source: National MS Society.

The National MS Society’s grants vary widely in size. Those that are less than \$50,000 are the Pilot Awards, which aim at testing innovative ideas. Pilot Awards include seed-funding grants that seek to test new ideas and generate very preliminary data as well as grants that seek to build more substantial data from existing preliminary evidence to eventually qualify for a larger grant. The share of seed funding in the Society’s Pilot Award portfolio varies depending on years and definition, ranging from 10 percent to 70 percent.

There are 75 grants ranging \$100,000-\$249,000. Among them, 55 are fellowships for clinical training and postdoctoral fellowships, and 20 are Research Grants targeting established investigators.

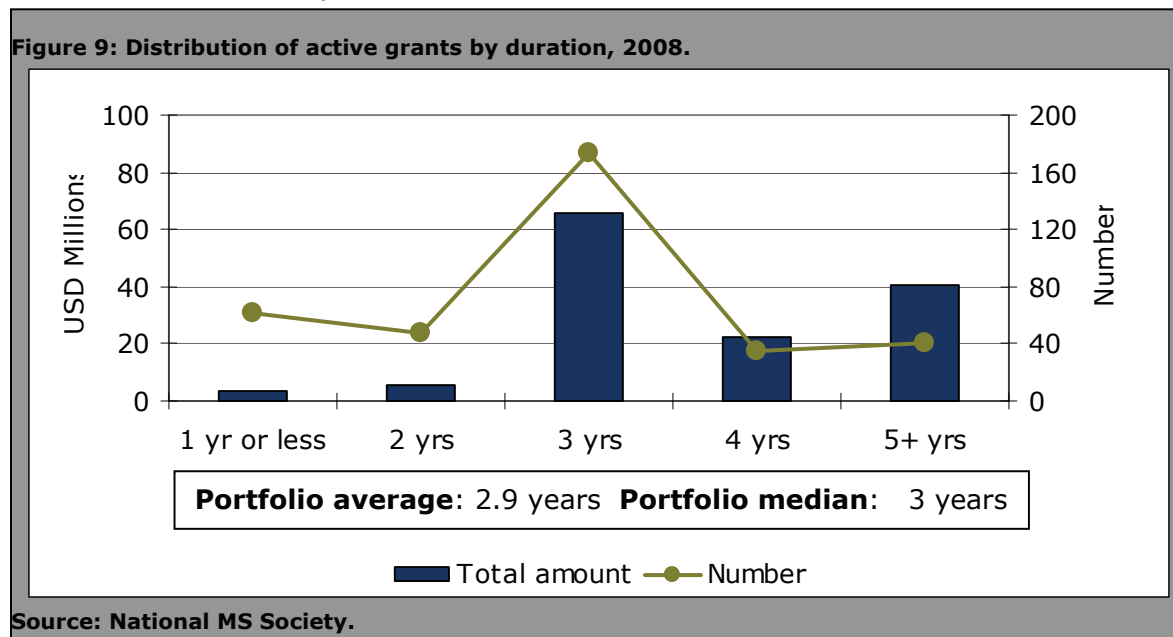
Grants of \$100,000-\$249,000 account for only 11 percent of those issued through the Research Grants mechanism, targeting 20 established investigators. Out of the 177 active grants issued as Research Grants, 94 are in the \$250,000-\$499,000 range and 62 are more than \$500,000.

⁷ Extramural R01 grants. For all extramural research grants, the average annual support was \$404K.

Research Grants, the Society’s grant mechanism that targets established investigators, account for 62 of 86 grants over \$500,000. Other grants greater than \$500,000 include the Collaborative Center Award, the Repair Partnership, Career Transition Fellowship, the Junior Faculty Award, and the Health Care Delivery Contract. Among these, ten grants were greater than \$1M, including four grants for the Repair Partnership, one Health Care Delivery Contract aiming to build a nationwide MS patient registry, and Research Grants for a clinical trial of sex hormones, genetic studies, a study on MS lesions, and a project to build a biospecimens repository.

GRANTS BY DURATION

Figure 9 illustrates the distribution by duration of the Society’s active grants issued in fiscal years 2005-2008. The total number of grants included in this analysis is 358, amounting to \$138M. The average duration of NIH’s extramural research grants was 3.7 years in 2007, and the median was 4 years.



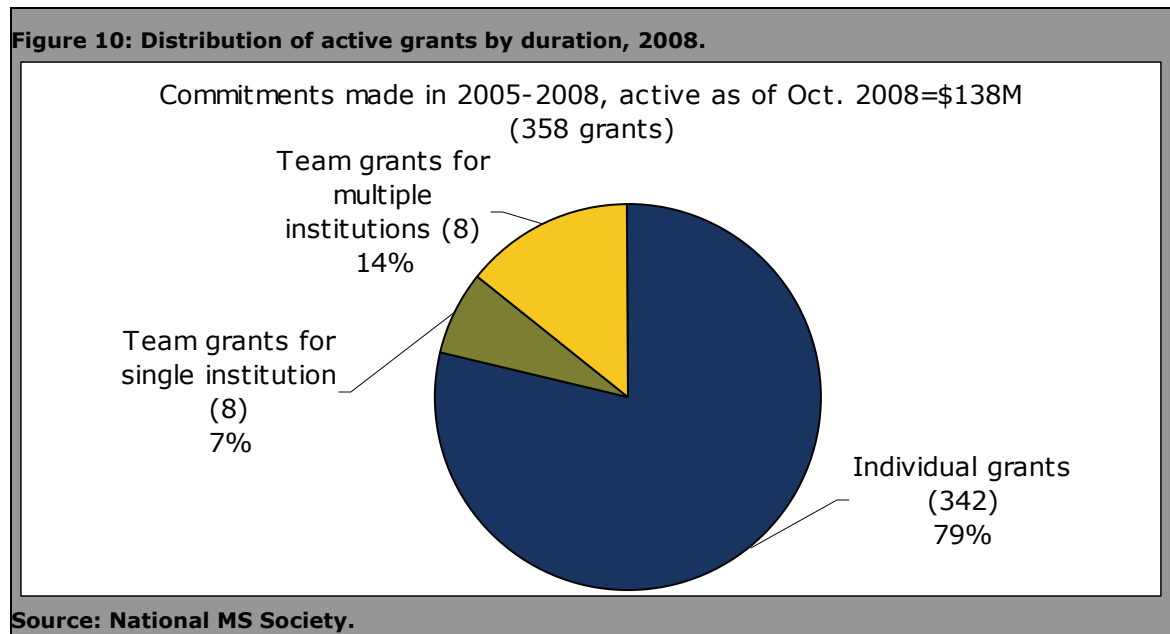
About half of the Society’s grants included in this analysis have durations of three years. Among the grants with three-year durations, 70 percent are research grants for established investigators and 22 percent are postdoctoral fellowships. Most of the grants with durations of one year or less are pilot grants, accounting for two-thirds of all pilot grants. Most of the remaining pilot grants have durations of two years, although some have even longer durations. The Society’s pilot grants include projects that aim to generate very preliminary data as well as those that already have some data but aim to accumulate more before applying for standard grants. About 10 percent of its pilot grants are without any preliminary data, providing a testing ground for new ideas.

Grants with durations of five years or more consist of large grants, including the Collaborative Center Awards, the Repair Partnership, Career Transition Fellowship, the Junior Faculty Award, and the Health Care Delivery Contract.

RECIPIENTS

RECIPIENT TYPE

Figure 10 illustrates the composition of the Society's grants in terms of recipient type. This analysis includes all active grants that the Society issued between 2005 and 2008, including the full amount of multi-year commitments. Grants are categorized as individual grants provided to a single investigator, team grants within a single institution, and team grants for multiple institutions. This analysis aims to understand the extent to which the organization issues grants that require collaboration.



The Society's portfolio primarily is composed of grants for individual researchers, with 21 percent of the portfolio, or 16 projects, being grants that explicitly require collaboration. These grants include the Collaborative MS Research Center Awards, the very type of grant mechanism the Society created to foster collaboration in MS research, as well as the MS Lesion Project and the Nervous System Repair and Protection Initiative, both part of the *Promise 2010* initiative. Among these 16 awards, eight involve collaboration within a single institution, while the other eight involve collaboration across multiple institutions.

TOP RECIPIENTS

Table 2 shows the organizations to which the Society pledged the most funding during the past four fiscal years. Total commitments made by the Society during this period amount to 635 grants, for \$172M, as shown in Figure 3.

Table 2: Organizations Receiving Most Funds from the National MS Society

Institution	Total amount (\$ in millions)	Number of grants	Average (\$ in thousands)
University of California, San Francisco	9.6	24	400
Brigham and Women's Hospital	9.3	31	300

Cleveland Clinic Foundation	9.2	32	289
University of California, Los Angeles	6.7	17	395
University of Wisconsin-Madison	5.9	8	735
Share of top 5 out of the total	24%	18%	N/A

Source: National MS Society.

Over the past four years, the Society provided research funding to 210 different institutions. Among them, the University of California, San Francisco, received the most funds, while the Cleveland Clinic Foundation received the highest number of grants. The largest grant was made to the Johns Hopkins Hospital as part of the Repair Partnership Initiative, which amounted to \$4.8M.

Although the top recipient institutions are all based in the United States, the Society's research funding is not restricted to domestic institutions. During the past four years, the Society has issued 41 grants to institutions overseas, including Australia, Canada, Israel, Italy, and the United Kingdom.

NATIONAL MS SOCIETY: MANAGEMENT

OVERVIEW

The Board of Directors is the ultimate decision-making body of the Society. Because of its structure as an organization with multiple chapters, the Society has mechanisms in place to make sure that the activities of the national office and the chapters are aligned and that the chapters' perspectives are reflected in the national office's operations.

In addition to the Board of Directors, the Society has multiple bodies that provide advice on its activities, including the NCAB and the RPAC. In addition, Fast Forward, a wholly-owned subsidiary, has its own Board of Managers and Science and Business Advisory Board (SBAC).

The Society's Board of Directors, RPAC, and its leadership bring connections from other organizations that the Society is able to leverage. Such connections are focused in nonprofit and clinical research institutions and nonprofit research funders and advocacy groups.

The Society makes its annual report and financials available online. It also provides a list of its current grants and newly issued grants.

MANAGEMENT AND GOVERNANCE

MANAGEMENT STAFF

The Society has a staff of 1,400 employees, out of which 200 work in the home office, including over 40 employees in the Informational Resource Center. The Society's leadership includes the following:

- **Joyce Nelson:** President and Chief Executive Officer
- **Duane Brown:** General Counsel
- **Julie Butcher:** Executive Vice President, Information Technology
- **David Chatel:** Executive Vice President, Advocacy Programs
- **Lisa Goldfarb:** Executive Vice President, Human Resources
- **Nancy Law:** Executive Vice President, Programs and Services
- **Graham McReynolds:** Executive Vice President, Marketing and Development
- **Mary Milgrom:** Executive Vice President, Strategic Philanthropy
- **John Richert:** Executive Vice President, Research and Clinical Programs
- **Lisa Risi:** Chief Financial Officer
- **Paul Weiss:** Chief Operating Officer
- **Cyndi Zagieboylo:** Executive Vice President, Field Operations

The Society's CEO reports the Society's activities to the Board of Directors on a quarterly basis. The update is organized around the five areas of focus from the strategic response. Each staff member is evaluated annually based on individualized objectives tied back to the strategic goals, core competencies, and professional development.

Many leaders of the Society have worked for the Society for more than a decade or have backgrounds in nonprofit management. The Society also has scientific expertise in-house. The head of Research and Clinical Programs is a research clinician in MS, and other staff members in the research operation have scientific backgrounds.

The Society has more than 20 full-time staff for its research operations. A sizeable number of professional staff is required as the Society's staff reviews the annual progress reports for each grant, organizes scientific meetings, and is involved in communication with donors, chapters, and public officials.

LOCAL CHAPTERS

The Society's 53 chapters have their own boards and conduct their own programs to meet the needs of the constituents in their area. The chapters share a common set of bylaws and undergo an annual certification process to ensure that chapters meet minimum standards established by the Society for their governance, resource development, programs, and financial management. Chapters are required to contribute a set percentage of funds raised to the home office for research funding purposes, and they often contribute more than what is required to fund additional research grants and targeted programs such as *Promise: 2010*.

The chapters also provide input to the national office, through a quarterly call in which the chapter chairs participate. In addition, the home office organizes opportunities for cross-chapter networking and sharing best practices.

BOARD OF DIRECTORS

The Society's National Board of Directors sets the strategic direction of the organization. The board meets four times a year to have strategic discussions about new initiatives, the Society's role in coalitions, and policy, such as the Society's position on embryonic stem cell research or its National Health Care Reform Principles. The Board also reviews the Society's progress against its strategy.

The Society's board is composed of 35 directors with one-year terms and the potential to serve for nine consecutive years. The nominating committee, composed of three or four board members and two or three chapter chairs, selects the board candidates, and the Delegate Assembly, composed of representatives from each chapter and all members of the National Board of Directors, elects the directors through votes.

The Society constructs its board so that a majority of the board members (51 percent) also serve as local chapter trustees. While these members are expected to provide chapter perspectives, they do not represent individual chapters. The Society aims to create a balanced board in terms of demographics and experience. It also seeks to ensure that most board members have a personal connection to MS. Board members often come from business backgrounds and have been leaders in their fields. Some also have backgrounds in policy advocacy and healthcare regulations, as well as expertise in social work and assisted living facilities.

During the first board meeting of each year, the Society leadership conducts a new board orientation. Each new member is assigned to an existing board member who serves as a mentor.

Multiple committees within the board help the Society conduct its mission. These include committees on finance, chapter relations, and governance. Additional committees focusing on management include the audit and investment committees.

The governance committee reviews the board's nominating process and its policies. It also assesses the performance of the overall board and individual board members based on the

fundraising requirement, active participation in board meetings, and committee activities. In addition, board members are asked to submit an assessment of each meeting.

In addition to regular board meetings, the Executive Committee meets as needed for the Society's operation. The Executive Committee comprises the following directors:

- **Ron Boire:** Toys "R" Us
- **Carol M. Houghtby:** Securico, Inc.
- **Weyman T. Johnson, Jr:** Paul, Hastings, Janofsky & Walker LLP; Chairman
- **Craig T. Lynch:** Parker, Poe, Adams & Bernstein LLP; Secretary
- **Linda J. McAleer:** Melior Group
- **Richard J. Mengel:** Mengel, Metzger, Barr & Co LLP; Treasurer
- **Joyce Nelson:** President and CEO of National MS Society
- **Kevin O'Sullivan:** MIRATECH Corporation
- **Eli Rubenstein:** Goulston Storrs

In addition to its board, the Society also has 15 honorary life directors and seven National Advisory Council members who provide additional input and contribute resources to the Society.

RESEARCH PROGRAMS ADVISORY COMMITTEE (RPAC)

RPAC sets the general direction of research funding at the Society. The committee oversees all research initiatives, provides input on topics for scientific meetings, serves as advisors on research policy, oversees the grant review process, and provides input. RPAC must approve all special initiatives of the Society. It meets twice a year, following the grant review meetings.

RPAC is comprised of senior scientists who are leaders in MS research. The Society aims to create an RPAC reflecting major areas of scientific expertise in MS as well as major institutions involved in MS research, such as NIH or the Department of Veterans Affairs. RPAC members serve for a term of three years, with the possibility to serve another term. Current RPAC members include the following:

- **Etty (Tika) Benveniste, Ph.D.:** University of Alabama at Birmingham
- **Anne H. Cross, M.D.:** Washington University at St. Louis
- **Marie Filbin, Ph.D.:** Hunter College
- **Gary M. Franklin, M.D.:** University of Washington
- **William Hickey, M.D.:** Dartmouth Medical School
- **Weyman T. Johnson:** Paul, Hastings, Janofsky & Walker LLP; Chairman of the Board
- **Edward A. Kangas:** Deloitte Touche Tohmatsu International, retired
- **Steven Lipstein:** BJC Healthcare
- **Aaron E. Miller, M.D.:** Mount Sinai School of Medicine
- **Frederick Munschauer, M.D.:** Buffalo General Hospital
- **Joyce Nelson:** President and CEO of National MS Society
- **Paul O'Connor:** St. Michael's Hospital
- **Raymond P. Roos, M.D.:** University of Chicago
- **John W. Rose, M.D.:** VA Salt Lake City Health Care System
- **Richard Rudick, M.D.:** Cleveland Clinic
- **Madeleine Sherak:** Calabasas, CA
- **Dinah Singer, Ph.D.:** National Cancer Institute

- **Richard B. Slifka:** Global Petroleum Corporation
- **Stephen G. Waxman, M.D., Ph.D.:** Yale University
- **Howard L. Weiner, M.D.:** Brigham and Women's Hospital

NATIONAL CLINICAL ADVISORY BOARD (NCAB)

NCAB provides advice on educational and clinical programs at the Society. It also identifies areas where information on MS is not sufficient and produces expert opinion papers to address the void. The board comprises over 80 members who serve as clinical speakers for the Society and experts on the MD-on-call program on a weekly basis.

NCAB members must have a national reputation as MS clinicians. The nominating committee selects new members, who serve a three-year term, without renewal limitation.

The Executive Committee of the NCAB meets once a year as well as through conference calls several times a year to review specific material or discuss specific topics. In addition, there are 10 subcommittees to provide advice on specific areas, such as various aspects of care, education for the public and healthcare professionals, and specific patient groups. The subcommittees also meet once a year through conference calls.

MANAGEMENT OF FAST FORWARD

MANAGEMENT TEAM

Fast Forward, a wholly-owned subsidiary of the Society, draws its management team from the Society. The Society's president and CEO serves at Fast Forward in the same capacity, and the executive director, Timothy Coetzee, Ph.D., has a background in MS research and molecular biology and was part of the Society's research program staff prior to assuming his current role. Fast Forward contracts fundraising, marketing, and operations with the Society. In addition, Fast Forward has an external consultant serving as a portfolio advisor.

BOARD OF MANAGERS

Fast Forward's Board of Managers has 13 members. Nine members also serve on the Society's national Board of Directors to ensure that Fast Forward is a controlled entity of the Society. The remaining four members are individuals with financial expertise. The Board of Managers includes people with MS, physicians, and individuals with business backgrounds such as consulting and risk management. The board reviews the investment thesis and makes the final decisions on Fast Forward's funding.

SCIENTIFIC AND BUSINESS ADVISORY COMMITTEE (SBAC)

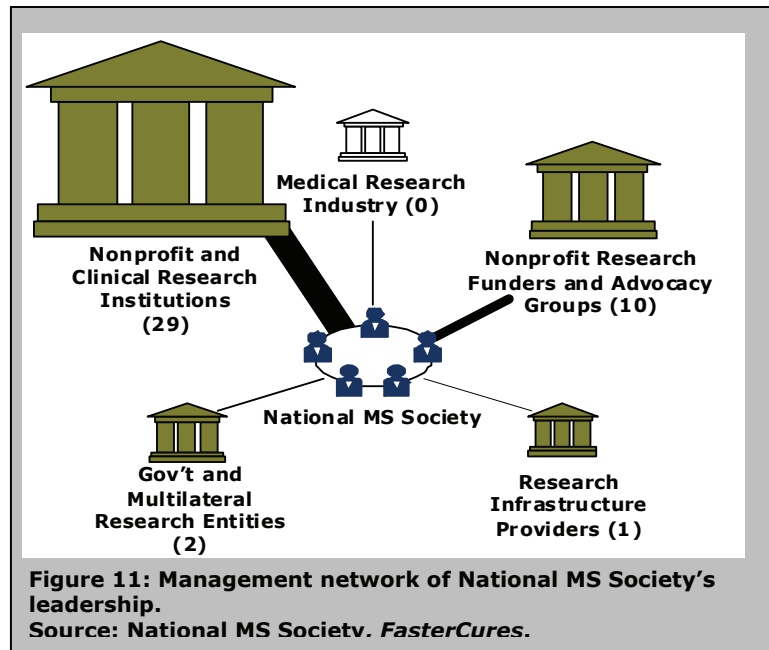
SBAC is the reviewing body for Fast Forward's funding to industry players. It assesses the investment opportunities presented to Fast Forward and makes recommendations to the Board of Managers. Half of the committee members have scientific expertise and the other half have business backgrounds.

TRANSPARENCY

The Society posts its annual report, IRS tax forms, and financial statements of the national office and consolidated financial statements on its website. It also provides a list of its active grants and new grants on its website.

MANAGEMENT NETWORK

This section seeks to identify the informal network that the National MS Society's leadership has with other organizations that could be leveraged in advancing the Society's research mission, in addition to existing collaborative relations described in the Strategy section. The analysis focuses on for-profit organizations in the medical industry, nonprofit and clinical research institutions—including academic medical centers and research laboratories—government and multilateral research entities, nonprofit research funders across various diseases and advocacy groups focusing on MS, and organizations that provide research infrastructure. In this analysis, a connection is defined as when a member of the staff leadership, National Board of Directors, or RPAC also holds leadership positions, such as board membership or management leadership, at organizations that are in the categories of interest.⁸



The organization's network is focused on nonprofit and clinical research institutions, primarily due to members of RPAC and the Board of Directors, who often have leadership positions at clinical or academic institutions (Figure 11). These connections include domestic and international research centers. The organization's leadership also connects the organization with other nonprofits focusing on MS or medical research in other diseases, as well as a research infrastructure provider. The Society has proactively developed connections with organizations focusing on MS by ensuring their presence on its board and vice versa. MSAC also provides links to the Department of Veterans Affairs and NIH. Table 3 summarizes major institutions to which the Society is connected.

In addition, the Society leadership is connected to various businesses, for example, Microsoft. The Society is one of the beneficiaries of Microsoft's *i'm Initiative*, which donates part of its advertisement revenue to nine nonprofit organizations across the world based on user's designation and traffic. For 2007, the initiative contributed \$100,000 to the Society.

⁸ The connections were identified using the biographies provided by the Society. We focus on leadership position as this would indicate the potential to mobilize the connected organization.

Table 3: Major Organizations to Which the National MS Society’s Management Is Connected

Organization type	Organization name
Nonprofit and Clinical Research Institutions	BJC Healthcare
	Boston Medical Center
	Brigham and Women's Hospital
	Cleveland Clinic
	Dartmouth Medical School
	Hunter College of the City University of New York
	LMU Munich
	Maimonides Medical Center
	Marine Biology Laboratory
	Max-Planck Institute of Neurobiology
	MCG Health
	Mount Sinai School of Medicine
	Our Lady of Mercy Medical Center
	Rutgers University
	Scripps Research Institute
	St. Michael's Hospital
	State University of New York at Buffalo
	Tenet Healthcare Corporation
	University College London
	University of Alabama at Birmingham
	University of Chicago
	University of Heidelberg
	University of Nebraska Medical Center
	University of Puerto Rico School of Medicine
VA Connecticut Healthcare Center	
VA Medical Center, White River Junction, VT	
VA Salt Lake City Health Care System	
Washington University at St. Louis School of Medicine	
Yale Medical School	
Government and Multilateral Research Entities	Department of Veterans Affairs
	NIH - National Cancer Institute
Nonprofit Research Funders and Advocacy Groups	ALS Association
	Coalition for the Advancement of Medical Research
	Institute of Medicine
	International Brain Research Organization
	MS Coalition
	Multiple Sclerosis International Federation
	Multiple Sclerosis Society of Canada
	Myasthenia Gravis Foundation of America
	National Polycystic Kidney Disease Research Foundation
	Neuropathy Association
Research Infrastructure Providers	Consortium of MS Centers

Source: National MS Society; *FasterCures* analysis.

NATIONAL MS SOCIETY: FINANCIALS

OVERVIEW

This section focuses on the financial aspects of the National MS Society as a consolidated entity, including its chapters. The Society's annual budget is close to \$250M and its asset base is \$180M. Research activities account for 21 percent of the Society's total expenses, out of which 18 percent is for research grants, 34 percent for service to people affected by MS, and 22 percent for administrative and fundraising costs.

In 2005-2006, the Society reviewed its strategy and has refocused its activities around five major goals. Since then, it has seen a period of financial expansion, and its investment in research has increased both in terms of absolute amount and share of program expenses.

Special events have been the traditional source of fundraising and still are the most important fundraising mechanism for the Society. At the same time, the organization is diversifying its fundraising activities to include major donor cultivation, direct marketing, and corporate sponsorship. While the Society has a broad mission, donors have the option to direct their giving to a specific area of interest or specific type of expense, in which case the full amount is allocated to the designated program.

FINANCIALS

HISTORICAL TRENDS

As an organization over 60 years old, the National MS Society is a large organization with annual revenue and expenses approaching \$250M. During 2004-2007, the Society's revenue and expenses have grown at 9 percent and 10 percent compound annual growth rates, respectively. During the same period, assets grew by 6 percent per annum (Figure 12).

Biomedical research grants, including research and training, amount to over \$40M and have been growing at a compound annual growth rate of fourteen percent during 2004-2007. This growth rate is higher than that of total expenses, which explains the slight growth in the share of grants out of total expenses, from 17 to 18 percent (Figure 13).

While research has always been part of the Society's mission, several large research initiatives were

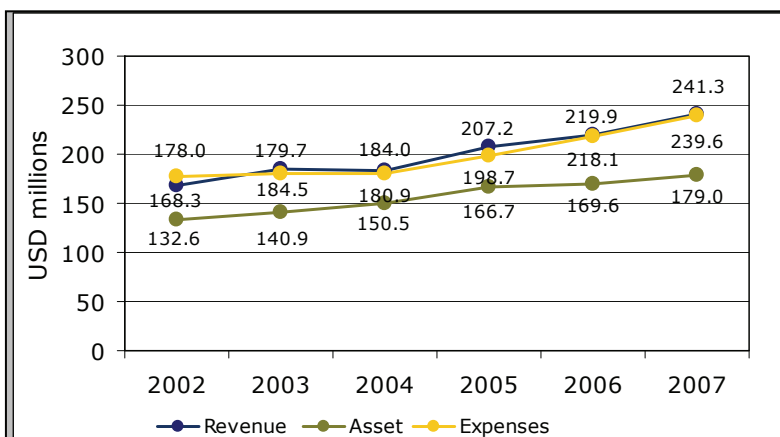


Figure 12: Financial activity, 2004-2007.
Source: National MS Society.

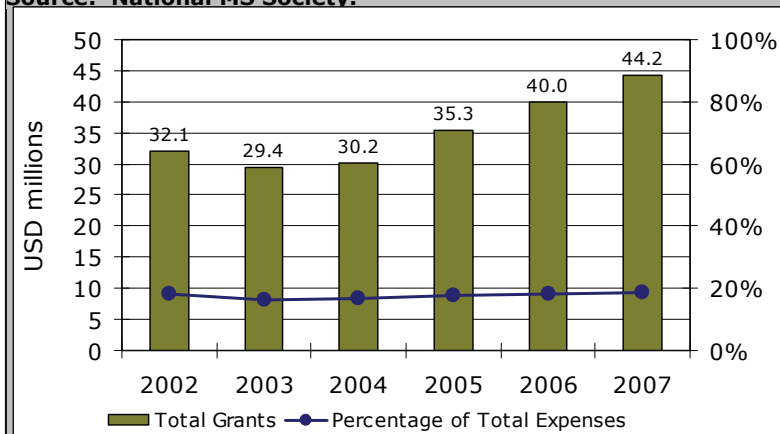
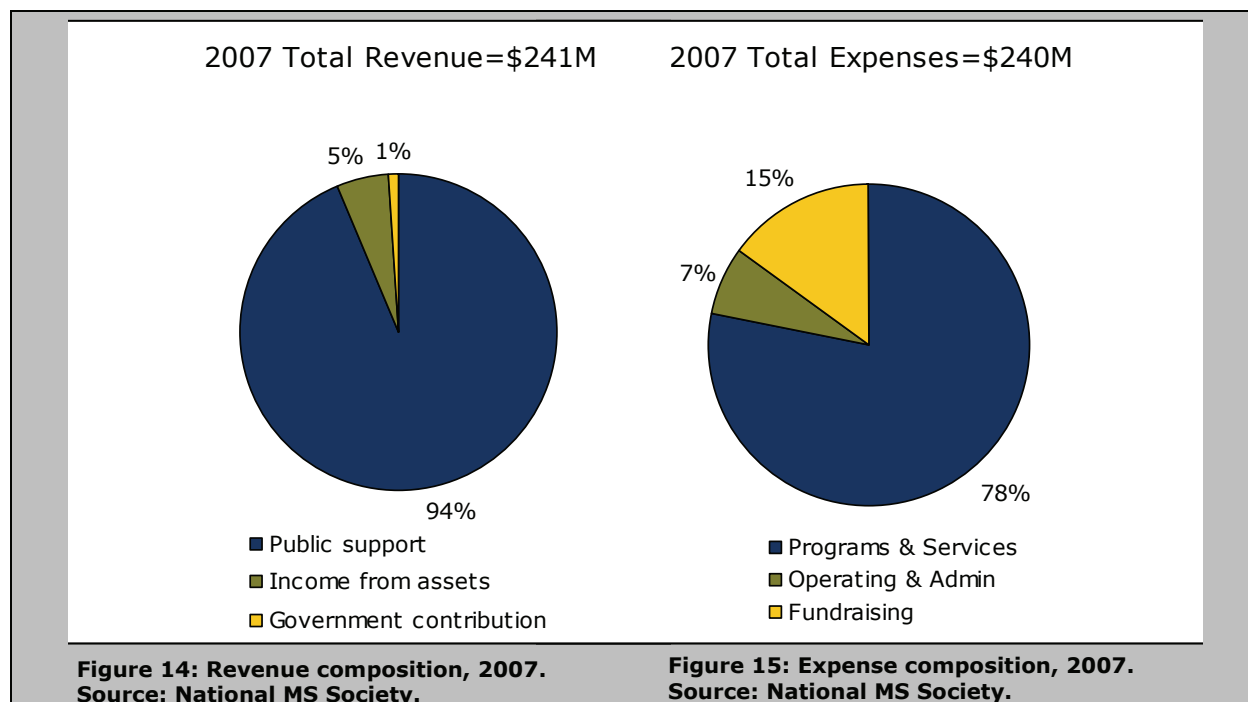


Figure 13: Grant activity, 2004-2007.
Source: National MS Society.

launched during this period, including the *Promise: 2010* Initiative. As a result, large research commitments were put in place, which is reflected in the growth of grant disbursement. Examples of large commitments initiated during this period include the Rehabilitation Research Fellowship, the Translational Research Partnerships on Nervous System Repair and Protection in MS, and a large-scale genome screening project.

REVENUE AND EXPENSES



The overall composition of the Society’s revenue has been fairly constant, with over 90 percent of revenue being generated from public support. Other sources of income include income from assets and government support for joint research programs (Figure 14).

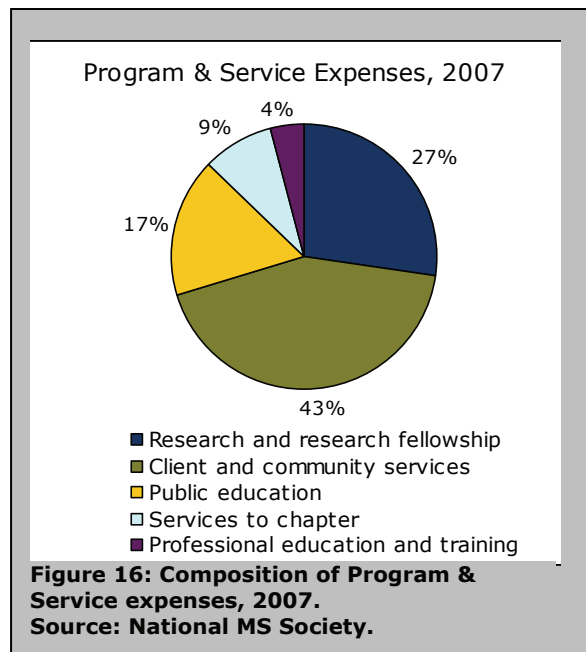
Within public support, special events are the largest source of income, accounting for 62 percent of total revenue. These events, Bike MS and Walk MS, are organized by the Society’s chapters across the country, and have enjoyed a growth of 10 percent per year over the last three years.

Close to 80 percent of the Society’s expenses are attributed to programs and services. Operational expenses and fundraising costs account for 7 and 15 percent of total expenses respectively. The respective shares of these two expense categories have been fairly constant over the past four years, and within the Society’s guideline to maintain these combined expenses to less than 25 percent of total expenses (Figure 15).

Within programs and services, client and community services—which include programs that target the population affected by MS—account for the largest share of the total, reflecting the fact that the Society has a broad mission. This also includes the costs associated with the Society’s Information Resource Center.

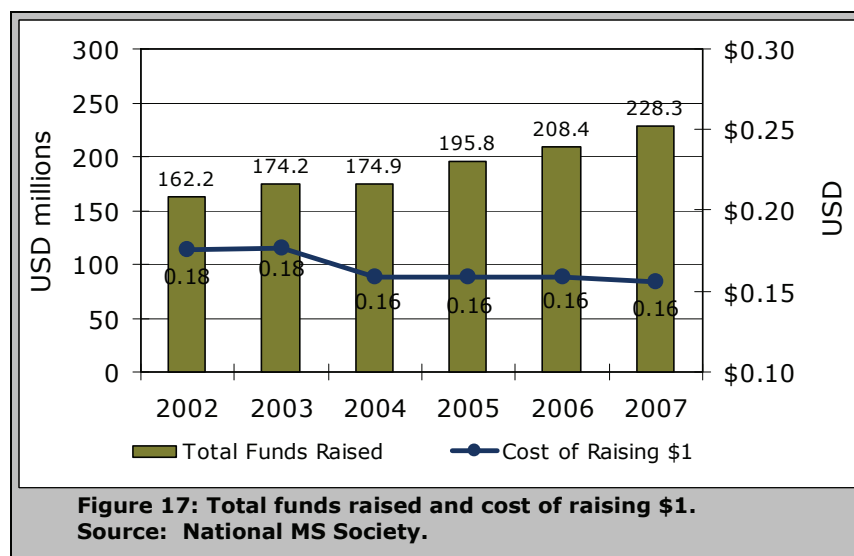
Research programs account for a little less than 30 percent of total program and service expenses in 2007. This includes research grants and fellowships, conferences, and any contract or costs associated with the research operation. Research and research fellowships have been the fastest growing program area during the past four years, with a compound annual growth rate of 13 percent.

Professional education and training includes programs that target medical professionals. The Society also incurs expenses from its efforts to support and strengthen the chapters, reflecting its organizational structure. These include expenses associated with staff training, information technology, and human resources, much of which are centrally managed by the national office (Figure 16).



FUNDRAISING

In 2007, the Society raised \$228M in total, excluding the costs associated with special events. Total funds raised grew by a nine percent compound annual growth rate over 2004-2007, which is in line with revenue growth. At the same time, the cost of raising \$1 has remained level at 16 cents, with a slightly decreasing trend compared to 2002. This reduction in cost is attributed to the use of the Internet in fundraising, which took place between 2003 and 2005 (Figure 17).



With the goal of raising \$1.25B between 2006 and 2010, the Society employs multiple fundraising strategies. The Society targets a broad range of donors, ranging from corporate donors providing financial and in-kind support to small individual donors based on direct marketing and online donations. Among the diverse areas of the Society's missions, donors can direct their contributions to specific program areas or specific

research projects approved through the peer-review process.

Chapters play a crucial role in the Society's fundraising activities, contributing over 80 percent of total income. The chapters organize special events, including Bike MS and Walk

MS. In the course of these events, the Society ensures that the participants form bonds with the MS community.

Bike MS and Walk MS

Bike MS and Walk MS are key fundraising and awareness-raising events that the Society organizes across the nation with the participation of the regional chapters. Participants, whether participating as individuals or as a team, are asked to raise funds for the Society, and the Society provides toolkits to facilitate the effort—including brochures, Web-based management tools, and any financial forms required. These events raise about \$150M a year.

The chapters also have been instrumental in increasing funding available for research. During the annual financial planning process, chapters commit to provide specific levels of funding for national programs, out of which half is allocated to research and the other half to other programs.⁹ However, in addition to the set amount allocated to research, chapters have been contributing more funds to the national office to support research, and the Society estimates that chapters contribute 90 percent of discretionary funds available at the end of the fiscal year to research.

In addition to special events, corporate sponsorship, direct marketing, and major gifts are the major sources of funds for the Society. Among corporate sponsors, pharmaceutical companies contribute about four percent of total income; however, the

Society ensures that such sponsors do not influence its programs. Other corporate sponsors include “Corporate Stars” participating in the special events, which contribute \$500,000 in revenue; companies involved in cause-related marketing, such as Christopher & Banks, Pure Protein, Care-a-lot, and Crocs; and corporations providing pro-bono services. The Society has 38 national corporate supporters, in addition to various corporate supporters at the chapter level.

Direct marketing brings in about 10 percent of the Society’s income. With a database containing information on a million individuals, the Society’s direct mail generates about \$25M, with an average donation of \$43. It also initiated online fundraising efforts in 2007, which generated \$1M. The effort is combined with the Society’s monthly national e-newsletter, and the Society sees it as a definite growth area. Finally, Helping Hands is an initiative supporting volunteers raising funds in their communities by providing fundraising toolkits; it contributes \$4-5M a year.

Major gifts are an area of increasing importance. Initiatives such as *Promise: 2010* and *Fast Forward* provide an impetus for additional fundraising and also motivate donors to contribute. Major gifts have been the fastest growing area of growth, with a growth rate of 24 percent. The Society has a team in the national office focused on major giving and has developed individualized plans for its 400 largest donors and individuals with potential. It also is building capacity in its chapters, including 23 existing major gift officers across the country.

The Society maintains a recognition program, the Discovery Circle, for its donors, organized into nine tiers based on annual contributions ranging from \$250-\$499 to more than \$75,000. Those who make a gift through bequest or gift annuity are recognized as Pillars of Society. In addition, the Society organizes calls to update major donors of its research progress, such as the Monthly National Research Call, and provides quarterly updates on the Society’s activities through the newsletter *On the Move*.

⁹ This general rule does not apply for cases where the donor designated specific programs for which to use the funds.

The Society's strategic goals guide the Society's funding priorities through 2010. Among those, research areas defined in *Promise: 2010* and Fast Forward are areas where funding is most needed.

NATIONAL MS SOCIETY: ASSESSMENT

OVERVIEW

This section provides an assessment of the Society's operations and research portfolio. It is based on a set of metrics developed by *FasterCures* to assess practices and attributes of nonprofit disease research groups that contribute to the acceleration of high-impact biomedical research. While these areas of assessment are believed to contribute to accelerating research, it should not be assumed that all organizations will exhibit all of these practices and attributes. Each organization's assessment is made within the context of its stated strategies and mission as well as the research needs within the specific disease. In addition, this section also highlights how the Society's efforts respond to the needs of the research community as identified in the PAS disease report on MS.

ASSESSMENT RESULTS

The metrics used for the assessment are organized into four primary groups:

- **Accountability:** The degree to which an organization engages in planning, demonstrates transparency, and upholds stakeholder responsibility
- **Collaboration:** The degree to which an organization can engage and nurture relationships that accelerate the overall funding and research cycle
- **Research Effectiveness:** The degree to which the organization's research portfolio yields sufficient data and deliverables in alignment with its stated mission
- **Resource Building:** The degree to which the organization contributes critical resources and infrastructure to the greater scientific community

Several metrics are included in each assessment category. The *assessment* reflects *FasterCures'* evaluation of the organization's performance for that metric and the *results* color indicates the quality of performance.

- **OUTSTANDING** performance
- **STRONG** performance
- **ACCEPTABLE** performance
- Performance **NEEDS IMPROVEMENT**

Accountability: Accountability refers to the degree to which an organization engages in planning, demonstrates transparency, and upholds stakeholder responsibility.

Metric	Results	Assessment
Strategic Planning and Monitoring	Strong	The Society formulates its organizational strategy every three years, through a rigorous process that incorporates input from a large group of constituents, which helps to ensure they are addressing their needs. The Society also regularly reviews its grant programs using metrics tailored to the goal of each program, a good practice given that some of its grant mechanisms have very specific goals. In addition, the Society is upgrading to a more effective mechanism for tracking the progress of its activities against its goals.
Milestones	Strong	The grants funded by the Society are subject to an annual interim review, and grants that do not make reasonable progress may be terminated. Some clinical research grants and healthcare delivery and policy grants are subject to additional pre-determined milestones. Given that most of the Society's grants are investigator-

Metric	Results	Assessment
		initiated, it is difficult to directly tie the achievement of the specific aims of individual grants to the organization's strategy, beyond research advancement and career development. However, the Society also invests a sizeable share of its research budget in Targeted Initiatives, in which case the achievement of aims can be linked directly to the achievement of a larger goal.
Advisory Boards	Strong	In addition to the National Board of Directors, the Society convenes multiple advisory boards to solicit expert input. The RPAC is the main standing advisory body that provides input on its overall research operation, and additional ad hoc committees and taskforces are established for specific issues or initiatives. In addition to RPAC, the National Clinical Advisory Board provides input on clinical issues.
Intellectual Property (IP)	Acceptable	The Society relies on the IP policies of the grantee organizations, but requires them to report on IP right creation and to pursue commercialization. This policy is generally aligned with the Society's programs, similar to policies of peer organizations, and easily operationalized within the existing challenges of the university technology transfer environment. The Society is commended for their enforcement of the policy to ensure their rights are protected as defined in their policy. Opportunities exist for the Society to better understand the potential for policy and procedural changes to more effectively share IP with the broader MS community.

Collaboration: Collaboration refers to the degree to which an organization can engage and nurture relationships that accelerate the overall funding and research cycle.

Metric	Results	Assessment
Industry Partnerships	Outstanding	Fast Forward, launched in 2007, actively seeks opportunities to fund industry-based drug development efforts. Fast Forward aims to accelerate MS drug development by providing funding to drug development projects in academia and early-stage biomedical companies. In addition to announcing its first deal in December 2008, Fast Forward also entered into a collaborative agreement with EMD Serono, to which the company has contributed up to \$19 million. At the same time, PAS' scientific advisors expressed concern that a focus on commercialization could hinder the Society's capability to fund basic science research, so maintaining strength in both areas will be an important measure of success for the Society.
Knowledge-sharing	Strong	The Society contributes to knowledge sharing in MS research by organizing Task Forces and Workshops on specific issues, which has been very effective in bringing MS researchers together, as well as in providing support for scientific meetings organized by other entities. In addition, the Society launched its Tykeson Fellowship Conference in 2008, which all training award recipients are required to attend to increase knowledge sharing, build a community of MS researchers, and interact with patients. Such efforts could be expanded across its research programs.
Team Science	Strong	The Society's Collaborative MS Research Center Award was specifically put in place as a strategy to increase collaboration in MS research, based on a recommendation of an IOM review of MS research. In addition, many of the organization's Targeted Initiatives are large-scale projects structured as team grants with multiple collaborators. In total, about 20 percent of the Society's active portfolio is composed of team grants, reflecting the Society's emphasis in this area, although additional resources could be invested in this area.

Metric	Results	Assessment
Global Research	Outstanding	The Society's grant programs are open to researchers in the United States and overseas, and approximately 10 percent of active grants are disbursed to researchers in other countries, including grants for targeted initiatives. In addition, the Society engages international scientists in various aspects of its research operations, including its Scientific Workshops, study groups, and advisory committees. One notable international effort is the Atlas of MS, an international survey done in conjunction with the WHO to collect data on disease prevalence for over 88 percent of the world's population.

Research Effectiveness: Research effectiveness refers to the degree to which the organization's research portfolio yields sufficient data and deliverables in alignment with its stated mission.

Metric	Results	Assessment
Scientific Advancement	Strong	PAS's scientific advisors point out that the Society has been the single organization serving as a catalyst for new research in MS. This contribution to science is made through the Society's research funding as well as its Scientific Workshops, which raise awareness in the scientific community about new research areas. The organization could further track the outcomes of the research projects against a research plan to demonstrate how the funded research is advancing the Society's strategic goals.
Portfolio Congruence	Strong	The Society's research strategy focuses on accelerating research toward a cure by increasing collaboration and providing support for under researched and promising areas. The Collaborative Center Awards, the Pilot Awards, and the targeted RFPs are mechanisms specifically designed to address these focus areas, which amount to over 20 percent of the active portfolio. The Society's research portfolio is balanced between etiology and treatment research, and the PAS SAB believes that the Society's portfolio is consistent with what is required given the status of research, with additional focus on psychosocial aspect of the disease.
Knowledge Production	Strong	The Society is a key source of new knowledge about MS. Internal tracking of publications of its grantees indicates that a typical grant results in 4-6 publications, and that in 2008, research grants resulted in 240 publications. The Society has also calculated that in 2006 – 2008, 67 percent of the applications reviewed were from investigators who had written their proposals based on data produced from previous Society grants indicating contribution of new knowledge to the field. The Society could benefit from tracking publications electronically and systematically tracking the quality of its publications.

Resource Building: Resource building refers to the degree to which the organization contributes critical resources and infrastructure to the greater scientific community.

Metric	Results	Assessment
Tools/ Resources Development	Strong	The Society has provided support for multiple tissue banks in MS, an important resource for research on the pathology of the disease. In addition to providing financial support, the Society also ensures the compatibility of sample collection procedures by requiring all banks to use the same collection methodology, which is important for research using biospecimens. In addition, the Society contributes to generating research data accessible to the research community, including its support of the genetic data repository of the MS Genetics Group at the

Metric	Results	Assessment
		University of California, San Francisco and its collection of quality of life data through its Sonya Slifka Longitudinal Study in the United States. At the same time, the Society is at a unique position to contribute to the field in this area, calling for additional responsibility.
Research Training	Outstanding	Providing funding to build the next generation of MS researchers is an important mission of the Society, and among the active grants issued since 2005, 12 percent focus on providing career development opportunities to postdoctoral fellows or equivalent and to young investigators. The PAS SAB notes that the Society's support for young investigators has been crucial in research training and that the majority of leading researchers today were past recipients of the Society's career development grants.
Patient Organization	Strong	The Society is advocating for passage of the National MS Disease Registry Act in Congress, which aims to create a National MS Registry at CDC. The registry is expected to contribute to better understanding of the epidemiology and causes of MS, and also complement the existing patient registry maintained by the Consortium of MS Centers. However, given the unique position that the Society has in terms of patient access, the Society can make an important contribution in executing such efforts, so it will be interesting to see the role it will play in building the registry.
Clinical Trials Networks	Strong	The Society has funded the establishment of MS-CORE, a clinical trial network of 80 sites. Although the network is yet to be widely used, it will help facilitate clinical trials, especially those sponsored by agents other than the pharmaceutical industry.

The National MS Society was not assessed against the following metrics as they are not aligned with the organization's stated strategy:

1. Pipeline Profile

SCIENTIFIC CONTRIBUTION

This section highlights the National MS Society's scientific contributions to the research community, focusing on how it is contributing to addressing the challenges facing the research community. The Society's specific ongoing contributions are summarized below:

Spectrum	Scientific Contribution
Care Continuum	
Disease Understanding	Limited understanding of the causes of the disease is an underlying challenge in MS research, and the Society's research funding, with <i>almost half of it directed to etiology research</i> , contributes to progress in this area. In addition, the Society's MS Lesion project focuses on understanding the difference in clinical disease by researching the patterns of MS lesions in different patients. This project is likely to contribute to better understanding of the drivers of disease progression as well as the differences among disease subtypes . Additional areas are identified as major areas requiring investment, and this project has the potential to greatly advance science in MS.
Prevention	Better understanding the role of vitamin D and its potential in prevention approaches requires research attention. The Society has <i>an investigator-initiated grant directly addressing this issue</i> . In addition, the Society's research on risk factors and epidemiology will contribute to the development of treatment measures in the long run.
Diagnostics	Major challenges to development of diagnostics and disease markers for MS include the lack of tools to monitor disease activities as well as tools to

Spectrum	Scientific Contribution
	<p>measure disease progress and treatment effectiveness, including neurodegeneration and neuronal repair. The Society has issued a number of investigator-initiated grants focused on disease markers. In addition, the <i>Nervous System Repair and Protection Initiative</i>, described more in detail in the treatment section, includes research to develop markers to measure treatment effectiveness, including improved imaging technology to detect myelin and nerve fiber damage and repair, which could contribute to direct observation of myelin.</p>
Treatment	<p>Treatment research focusing on neuronal repair and neuroprotection, in addition to strategies focusing on inflammation, were identified by PAS's scientific advisors as areas needing more investment. The Society's <i>Nervous System Repair and Protection Initiative</i>, an investment of more than \$15M plans to enable clinical trials by 2010. Scientists have highlighted the potential impact of this project to the MS research field overall. In addition, another area needing research investment is more effective symptomatic treatment. The Society's research strategy calls for focus on all aspects of treatment, <i>including stopping MS attacks and disease progression, repairing the damage from the attacks, preventing the onset of the disease, as well as quality of life issues such as policy and delivery, rehabilitation, symptom management, and psychosocial research.</i> As such, the research projects funded by Society span these areas.</p>
Delivery	<p>The high cost of treatments and access to specialists is a major issue for MS patients, though not an issue directly linked to research. Through the <i>Sonya Slifka Longitudinal Study</i>, the Society collects data on quality of life, rehabilitation, symptomatic therapies, employment, and healthcare delivery. These data will be leveraged to develop strategies for the Society's own advocacy efforts, and will be made available for use by researchers. In addition, the Society's <i>advocacy and patient support activities</i> directly help address this challenge.</p>
Research Tools	
Biospecimens and Data	<p>The small number of samples, limiting the power of analyses, and difficulties caused by differences in collection protocols are some of the major challenges facing the use of biospecimens in MS research. The Society has <i>funded three biospecimen repositories for MS research</i>, including the Human Neurospecimen Bank at the University of California, Los Angeles; the Rocky Mountain MS Tissue Bank; and the recently established University of Illinois at Chicago MS Tissue Repository. In addition, the Society specifically required the biospecimens repository at the University of Illinois to collaborate with the existing repositories to <i>ensure that the tissues are collected in a compatible manner.</i></p>
Clinical Trials	<p>As treatment options have been introduced in MS, placebo-controlled trials have become increasingly difficult to conduct. The <i>International Advisory Committee on Clinical Trials</i>, convened by the Society, discusses and seeks solutions to issues related to trial design and outcome measures.</p>
Animal Models	<p>The EAE model, the dominant animal model in MS research, focuses only on the immunologic aspects of the disease, and therefore is not adequate for research focused on other aspects of the disease. Through its investigator-initiated grant mechanism, the Society has funded <i>grants aiming to validate animal models that allow investigations beyond immunology, such as axon degeneration.</i></p>
Research Training	<p>The limitations in multidisciplinary talent and lack of young investigators with an interest in a career in MS research are major challenges for MS research community. The Society addresses these by establishing grant programs designed to meet these needs, including its <i>Collaborative Center Awards and Pilot Awards</i> that seek to attract scientists from other fields as well as its <i>Career Development Awards.</i></p>

NATIONAL MS SOCIETY: ACRONYMS

ACTRIMS: Americas Committee on Treatment and Research in Multiple Sclerosis

CDC: Centers for Disease Control and Prevention

CSF: Cerebrospinal fluid

IP: Intellectual property

IRC: Information Resource Center

MS: Multiple sclerosis

MS-CORE: Multiple Sclerosis Cooperative Research Group

NCAB: National Clinical Advisory Board

NIH: National Institutes of Health

NINDS: National Institute of Neurological Disorders and Stroke

PRC: Professional Resource Center

RFP: Request for Proposal

RPAC: Research Programs Advisory Committee

SBAC: Science and Business Advisory Board

NATIONAL MS SOCIETY: GLOSSARY

RESEARCH PORTFOLIO

GRANT OR PROJECT TYPE

- ♦ **Research:** The systematic process of collecting and analyzing information to increase our understanding of the phenomenon under study. It can be hypothesis-driven, problem-oriented, or discovery-based. It can be conducted by a single investigator or multiple investigators, and at single or multiple sites. A project should be defined with an expected goal.
- ♦ **Training:** The systematic process of developing knowledge, skills, and attitudes for current or future jobs. Sometimes used interchangeably with “education.” In the sciences it typically occurs at the postdoctoral level, or as part of career advancement. Predoctoral education is sometimes called training. Training grants can be made to individuals or institutions. The funds are supporting the training, not any research that might be conducted as part of the training. For example, someone might have a postdoctoral fellowship, which is training, but be working on a research project funded by a grant submitted by the principal investigator. Excludes K-12 science education.
- ♦ **Tools/resources:** Support for infrastructure, sometimes called “cores.” It can include databases, tissue banks, information technology, statistical centers, equipment, technology, support staff (administrators, librarians). In most cases they will be resources or tools that are shared but can sometimes be needed for a specific project. Not to be confused with the purchase of equipment as part of a research grant.
- ♦ **Policy/delivery:** Includes health services research, policy studies, and can include surveys (e.g., attitudinal, delivery related).

TYPE OF RESEARCH

- ♦ **Etiology:** The study or theory of the factors that cause disease.
- ♦ **Prevention:** The study of factors that can thwart the onset of disease (e.g., diet, behavior change, dietary replacements or supplements).
- ♦ **Diagnosis:** The development of tools that can be used to detect and/or diagnose disease (e.g., blood tests, biomarkers, imaging techniques).
- ♦ **Treatment:** Research aimed at the deliberate alteration of the chemical and/or physical aspects of the biological system. Treatment studies can be aimed at stabilization and/or restoration of health.
- ♦ **Other:** Any research not included in previous categories.

STAGE OF RESEARCH

- ♦ **Basic:** Systematic study directed toward fuller knowledge or understanding of the fundamental aspects of phenomena and of observable facts without specific applications towards processes or products in mind.
- ♦ **Translational:** Outcome-focused research where a problem or obstacle has been identified. Translational research takes what is known and calculates what studies still must be done to answer a question or solve a problem. It can include basic studies that are focused on a well defined problem, but it does not include clinical studies involving interventions in human populations. In some cases, it can involve the analysis of human biological materials (e.g., blood, tissue, tumors)
- ♦ **Clinical:** Clinical research generally refers to the study of a drug, biologic, device, or other intervention in human subjects with the intent to discover potential beneficial effects and/or determine safety and efficacy. It also refers to studies of human populations (e.g., epidemiology, behavior, observation). Also called clinical study and

clinical investigation. It is not necessarily synonymous with the regulatory definition of human subjects research. (See 45 CFR 46.102(f).)

- ♦ **Other:** Any research not included in previous stages.

MANAGEMENT

- **Medical research industry:** Pharmaceutical, biotechnology, or medical device companies that may serve as an industry partner to the organization. This category does not include payors or providers.
- **Nonprofit research funders and advocacy groups:** Nonprofit organizations funding research in any diseases and organizations focusing on advocacy activities in the given disease.
- **Nonprofit and clinical research institutions:** Institutions where research is conducted, including academia, independent research centers, and hospitals, including Veterans' Affairs medical centers.
- **Government and multilateral research entities:** Initiatives or sub-units within government entities on the national and international levels pertinent to the focus disease; examples include the Food and Drug Administration, units under the National Institutes of Health, and the World Health Organization.
- **Research infrastructure providers:** Entities that provide tools and resources for research. Examples include biospecimen repositories, clinical trial networks, or data repositories, but exclude hospitals.

FINANCIALS

- ♦ **Direct public support:** Contributions, gifts, and similar amounts received directly from the public. Can be cash or in-kind and be raised by the organization itself or by a third party (except federated agencies). If the latter, the full amount raised (not the amount the organization actually received) should be included. Membership dues and assessments that are more of public contribution than payment for benefits received or payment from affiliated organizations should be included in public support. Contributions by a commercial co-venture and contributions raised through special events are also included here.
- ♦ **Funds raised:** Sum of public support, government contributions, and income from special events and activities.
- ♦ **Gross profit or loss from sales of inventory:** Gross profit or loss from the sale of inventory items, excluding those sold at special events. Sales of investments on which the organization expected to profit by appreciation and sale are not reported here.
- ♦ **Indirect public support:** Contributions received indirectly from the public through solicitation campaigns conducted by federated organizations (e.g., United Way). Contributions by closely associated organizations (e.g., parent organization, affiliate) are also included here.
- ♦ **Income from assets:** Income derived from financial and nonfinancial assets. This includes interest income, net rental income, dividends, other investment income, and net gain or loss from sales of assets other than inventory.
- ♦ **Income from program services and sales:** Income from "Program service revenue including government fees and contracts" and "Gross profit or loss from sales of inventory."
- ♦ **Program service revenue including government fees and contracts:** Income from activities that form the basis of an organization's exemption from tax. Income from program-related investments (e.g., scholarship loans) should also be included in this category.

- ♦ **Public support:** Comprised of IRS Form 990 line items “Donor advised funds,” “Direct public support,” and “Indirect public support.”
- ♦ **Other income:** Income from special events and activities and any other sources not covered. Special events and activities include dinners, dances, carnivals, raffles, bingo games, other gaming activities, and door-to-door sales of merchandise.

METRICS DEFINITION

Accountability: The degree to which an organization engages in planning, demonstrates transparency, and upholds stakeholder responsibility.

Metric	Definition	Sample Metric	Importance
Strategic Planning and Monitoring	Establishes a research strategic plan for managing a portfolio of research projects and evaluates itself against the goals and objectives outlined in the plan	<ul style="list-style-type: none"> • Existence of a strategic plan that responds to the needs of the field and incorporates measurable goals • Evidence of monitoring efforts at regular intervals using a performance management system 	Organizations taking a proactive approach to understanding their position in the disease landscape, to developing a research strategic plan, and to monitoring research portfolios are better able to target the research “investments” where they will have the most impact in understanding and curing disease. Those that incorporate a feedback loop from the patients and key constituencies ensures the plan is relevant to its stakeholders and responsive to the needs of the field.
Milestones	Utilizes milestones to measure and manage scientific advancement against its research plan and project goals	<ul style="list-style-type: none"> • Alignment of project milestones to overall research plan • Demonstrated use of milestones to secure future funding • Evidence of terminating underperforming projects 	Organizations that require achievement of milestones for funding, as appropriate for the duration of the grant, ensure that focus is maintained on key activities and vital resources are appropriately distributed to efforts and researchers demonstrating progress.
Advisory Boards	Has established active advisory boards, with appropriate composition, that provide external, objective guidance at regular intervals	<ul style="list-style-type: none"> • Effective use of advisory boards that have balanced membership, adequate turnover, and whose decisions are key inputs to leadership and Board decisions 	Organizations can convene scientific, clinical, business, and other advisory boards to validate research excellence as well as to provide guidance in developing and executing their organizational strategy. These boards should have the relevant skill and experience mix for the organization’s mission and membership should turnover to ensure the benefit of new perspectives.
Intellectual Property (IP)	Has established an actionable IP policy aligned with the organizational mission	<ul style="list-style-type: none"> • Existence of IP policy consistent with mission • Demonstration that efforts to commercialize appropriate technologies are pursued 	IP is an important consideration when sharing knowledge among researchers as well as when enticing industry for drug development. An IP policy should be documented, enforced, and aligned with the organization’s mission, strategy, and goals.
Access and Delivery Strategy	Provides a strategy for ensuring candidate interventions can be made available to the target population, particularly in endemic countries	<ul style="list-style-type: none"> • Existence of a robust strategy that engages and has been vetted by product constituencies, addresses affordability, and is timed appropriately to the product development timeline 	Candidate therapies are not effective if they cannot reach the target patient population. There are several obstacles that impede access to interventions in the developing world including lack of healthcare facilities, skilled professionals to administer care, and political will. Organizations with missions of delivering novel therapies to these regions will need to implement strategies for ensuring the access and delivery obstacles can be overcome in a timely manner.

Collaboration: The degree to which an organization can engage and nurture relationships that accelerate the overall funding and research cycle.

Metric	Definition	Sample Measure	Importance
Industry Partnerships	Has formed arrangements to engage with industry towards product development or has a mechanism and strategy for moving research towards commercialization	<ul style="list-style-type: none"> Existence of industry relationships and/ or drug development subsidiaries Existence of a commercialization plan if no industry partnerships Demonstration of feedback loop from partners 	Organizations engaging in partnerships, particularly with industry, will help to accelerate the translation of basic science at the bench into clinical application in the market. Partnership arrangements may differ and include instances of nonprofit venture funding of for-profit research.
Knowledge-sharing	Employs policies and practices to facilitate sharing of data (both internally and externally) from projects funded by the organization	<ul style="list-style-type: none"> Existence and execution of policy Demonstration that the knowledge shared has made a relevant contribution to the field 	Sharing knowledge from studies helps to accelerate the research process by equipping scientists with data to identify studies with potential impact as well as to further inform their own scientific questions. In-person sessions such as annual scientific retreats as well as open access publishing can expedite the knowledge-sharing process and reduce the information dissemination cycle.
Team Science	Funds / conducts goal-oriented, team-based science with a translational endpoint	<ul style="list-style-type: none"> Existence of multi-investigator projects to target large, complex scientific questions 	Organizations funding team science help to facilitate collaboration among leading research stakeholders, to focus innovation that benefits patients, and to shorten the cycle of discovery and development.
Global Research	Funds or collaborates on international research initiatives	<ul style="list-style-type: none"> Existence of international funding or collaborations 	In an ever-increasing global environment, it is important for organizations to acknowledge a geographic position within a global research environment and build international relationships among top researchers, industry partners, and funders, etc. around the world, as appropriate.

Research Effectiveness: The degree to which the organization’s research portfolio yields sufficient data and deliverables in alignment with its stated strategy.

Metric	Definition	Sample Measure	Importance
Scientific Advancement	Results in generation of scientific deliverables (e.g., assays, targets, pathways, biomarkers) that are aligned with the needs of the field	<ul style="list-style-type: none"> Number of scientific deliverables as portion of those planned Rate of projects moving through the R&D pipeline as compared to the planned rate 	Research projects that produce deliverables and advance candidates through the R&D pipeline per their project plans demonstrate the ability of the organization to identify capable investigators and to bring together the necessary resources to achieve the desired outcomes of the organization and the field.
Portfolio Congruence	Achieves a research portfolio aligned with the organization’s mission and stated goals as well as those needs of the field	<ul style="list-style-type: none"> Distribution of research funding across types and stages as compared to organizational objectives and field needs 	Organizations that demonstrate research portfolios that are congruent with their goals and objectives are appropriately stewarding their research funding in efforts to achieve desired outcomes. This validates their planning and resource management efforts to focus on outcomes.

Pipeline Profile	Funds a portfolio of projects that ensures sufficient volume of candidates to move into later-stage testing	<ul style="list-style-type: none"> Proportion of early-stage to late-stage research projects 	Organizations with missions to deliver novel therapeutic products to the market need to ensure they are funding a sufficient number of early-stage projects that will feed later-stage development. If outside of one's mission, there must be a strategy for ensuring that early-stage inputs can be added to the pipeline.
Knowledge Production	Results in annual generation of new data and knowledge for the field	Annual measurement of: <ul style="list-style-type: none"> Number of presentations Number of publications Number of citations 	Research that is presented, published in peer-reviewed publications, and then subsequently cited, especially by those in varying disciplines, demonstrates the ability of the organization to identify high-quality, high-impact research and thus to efficiently allocate funding to these research efforts. Knowledge that drives the advancement of ideas through drug development is particularly valuable to the field.

Resource Building: The degree to which the organization contributes critical resources and infrastructure to the greater scientific community.

Metric	Definition	Sample Measure	Importance
Tools/ Resources Development	Funds the creation, maintenance, and expansion of infrastructure and resources to meet the needs of the field	<ul style="list-style-type: none"> Percentage of total grant funding dedicated to tools/resources Congruency of tool development with their plan Contribution of tool to the field 	More resources must be readily available to the research community, including predictive animal models, interoperable clinical and research databases and systems, comprehensive biobanks, information technology platforms, and data standards and protocols. Effective research resources are essential to expand available datasets and analytical capabilities that are necessary to accelerate and drive research from discovery to the clinic.
Research Training	Funds training programs to develop a new cadre of translational researchers to meet training needs in the field	<ul style="list-style-type: none"> Percentage of total funding dedicated to translational research training Congruency of training with organization's plan Contribution of training to the field 	Training is required to develop a cadre of researchers who have the multidisciplinary skills necessary for a R&D environment focused on translational and clinical research.
Patient Organization	Dedicates resources to understanding and organizing their target patient population	<ul style="list-style-type: none"> Number of patients organized in a patient registry as proportion of disease burden Understanding of the patient profile as evidenced by the segmentation of patient population (e.g., by geography, subtype, ethnicity) 	Understanding and engaging patient populations is essential to developing effective treatments. Patient enrollment to clinical trials is one of the most significant hurdles for conducting clinical research for new therapies. Therefore, efforts like registries that organize patients and potential research participants enable expedited study enrollment and overall acceleration of the research process. These registries also provide data to better understand the patient population and thus design effective intervention trials.
Clinical Trials Networks	Organizes or develops a group of sites that are trained in administering clinical trials for a particular disease	<ul style="list-style-type: none"> Number of sites organized in a clinical trials network 	Clinical trials networks create a group of research sites that are connected through common informatics systems to share data, employ consistently trained clinical trials coordinators and staff, are attractive for industry partnerships, and thus are able to more quickly advance the clinical development of promising compounds. Clinical trial network development that incorporates business and project management training is particularly valuable.

NATIONAL MS SOCIETY: REFERENCES

- Organization website (www.nationalmssociety.org)
- Organization interview
- Annual report, research updates, white papers, press releases from the organization
- IRS Tax Filings (Form 990), financial statements