

Links to a Mission



MS is a Family Disease. . .

THE NATIONAL MULTIPLE SCLEROSIS SOCIETY WAS FOUNDED IN 1946 by an extraordinarily determined young woman named Sylvia Lawry who hoped to rescue her beloved younger brother. Today, the Society is a 50-state network of 62 chapters, linked to provide programs by and for everyone who lives with MS. Linked to MS researchers around the world. Linked to comprehensive MS clinics and to health-care professionals in an array of disciplines. And linked to individuals and groups who advocate for public policies that will empower people who live with disability or chronic disease.

The National MS Society has many faces. They range from world-renowned MS clinicians and research scientists who serve on Society advisory boards to enthusiastic teenagers who collect pledges for fun fund-raising events. The Society includes major donors, corporate sponsors, and grassroots contributors. Most especially, the National



Joan Lewison folds T-shirts for one of the Society's MS 150 cycling events.

MS Society is people with MS, their family members and friends.

For pictures and stories about some of the 387,000 extraordinary people who volunteer in advocacy, fund raising, clinical services, and client programs, please visit the Volunteer Hall of Fame on the Society Web site at www.nationalmssociety.org.

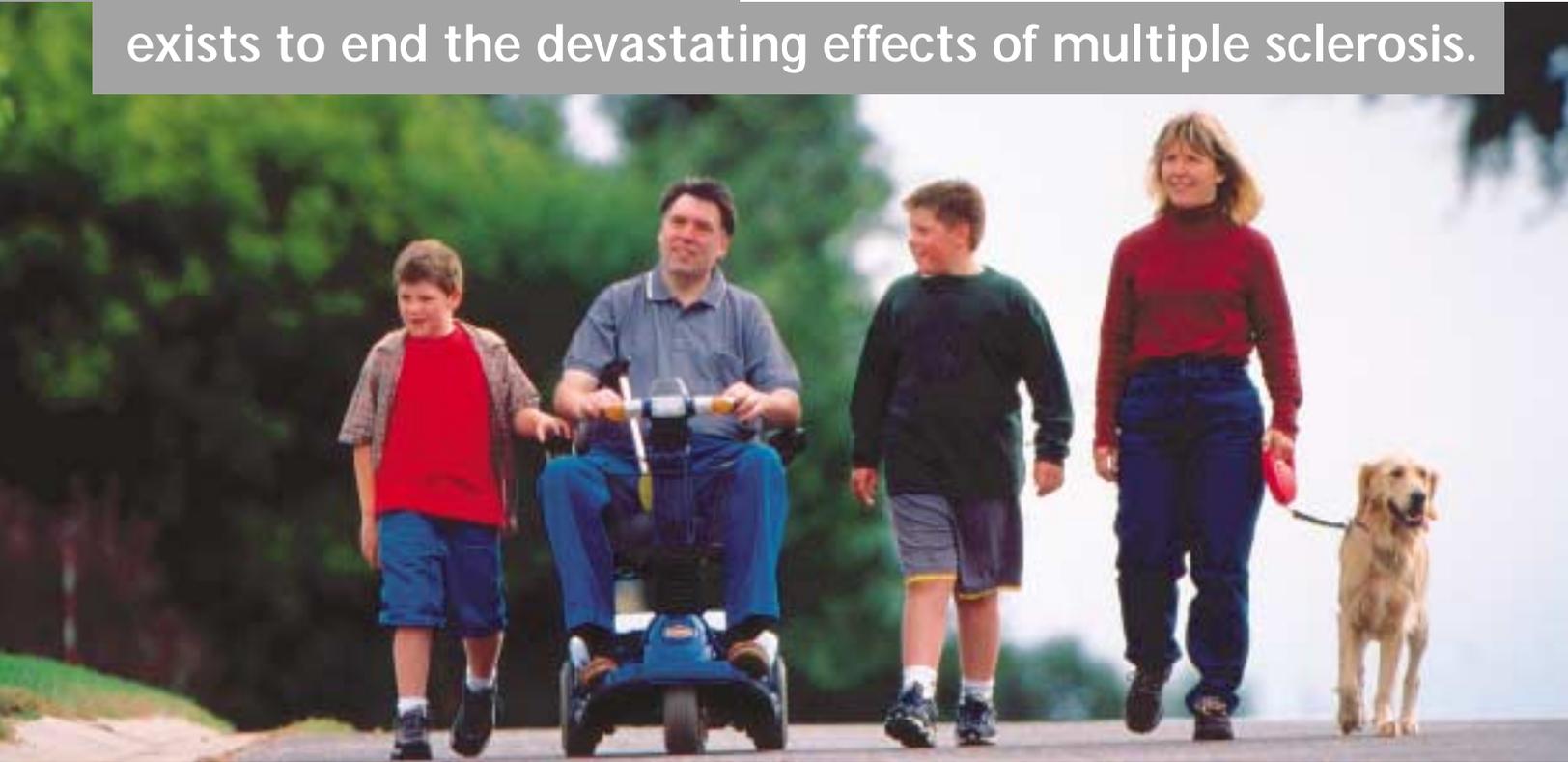


New members of the Society's Volunteer Hall of Fame at Nashville's famous Ryman Auditorium.

The National

Multiple Sclerosis Society

exists to end the devastating effects of multiple sclerosis.



The Lougee family shown on our cover looks all-American okay. They're sitting on their front porch in a suburb of Minneapolis. But as you can see in the photograph above, there is something out of the ordinary here. Something unwanted. Like 400,000 other Americans, Colin Lougee lives with MS. So do his wife, Paula, and their two boys, Christopher age 6, and Cody age 9.

MS is multiple sclerosis, a chronic often disabling disorder of the central nervous system (the brain and spinal cord). Symptoms may be mild, such as numbness in the arms or legs, or severe, including paralysis or loss of vision. These problems may be permanent or they may come and go. The progression,

severity, and specific symptoms of MS in any one person cannot be predicted, but recent advances in treatment and research are giving hope to many.

Some facts are known: MS strikes more than twice as many women as men. It is most often diagnosed in people between the ages of 20 and 50, although rare individuals as young as 2 and as old as 75 have developed it. MS is not considered a fatal disease as the vast majority of people with it live a normal lifespan. But until the disease can be stopped forever, they struggle to live as productively as possible, often with increasing limitations that medical science cannot eliminate. Not *yet*.

Progress in treatment and maintaining the quality of life



Not so long ago, people like Andrea Heath, Michelle Ideman, and Rafael Serrano were simply told to hope. Hope is still an essential prescription, but now there are five FDA approved “disease-modifying” medications to bolster hope. One of them—Rebif—was approved for U.S. marketing in 2002. Another—Avonex—was approved for coverage by Medicare “incident to a doctor’s care” in 2002.

These drugs—Avonex, Betaseron, Copaxone, Novantrone, and Rebif—have shown in well conducted clinical trials that they can “modify” MS. They can lessen the number of devastating attacks, protect the brain from damage, and slow down the



Andrea Heath (top left) Rafael Serrano (top right) and Michelle Ideman (left) all live with severely disabling MS. They are regular participants at the MS Achievement Center of Upstate New York, a chapter-sponsored center offering rehabilitation, recreation, and respite.

expected course of the disease.

Products of the “biotechnology revolution”—and the National MS Society’s 56 years of investment in research—these drugs are far from perfect. They are expensive, require injections, control but do not cure MS, fail altogether in some

people—and demand faith and discipline from those who take them.

More than ever, knowledge and support as well as hope are essential to living well with MS. The National Multiple Sclerosis Society is rising to this challenge.

Wellness is a Society-wide focus. Chapter programs promote eating wisely, appropriate exercise, reaching out to others, and maintaining personal productivity. A wellness approach works. Research studies show that people with MS who work with their health-care professionals to control common symptoms have a better quality of life. The first step is knowledge—learning that control is possible; the second step involves finding resources.

Every Society office is a wellspring of information, referrals, assistance, and friendship. Approximately 1,836 MS self-help groups are formally affiliated with our chapters. In 2002, 38,316 members participated. Peer volunteers made almost 3,800 home visits, and 7,082 people signed up for the six-week home study program, “Knowledge is Power”, which provides basic information to those who are newly diagnosed. In 2002, the program was available both in English and in Spanish.

The Society's comprehensive Web site recorded a record 4 million “hits” from visitors seeking answers, while five live inter-

Nationwide, 135 MS clinics are affiliated with the Society. Every chapter has a referral roster of MS health-care specialists in the area. Every chapter offers an equipment loan closet, a library, an information service, and many opportunities to volunteer.

active educational Webcasts reached approximately 100,000 people.

Every Society chapter published an individualized version of **MS Connection**—a newsletter that reported on education, recreation, research, policy issues, and fund raising triumphs in regional or state areas. Nationally, 65 brochures (including 12 in Spanish) were available to supplement those friendly voices on the telephone. **InsideMS**, the Society's inspiring lifestyle magazine, brought news, information, and emotional support to some 650,000 Society members four times in 2002—garnering a Health Information gold medal for patient education.



Progress in the struggle to cure MS

As the world's largest private supporter of MS research, the Society has been a link to all the progress to understand and cure this disease thus far. In 2002, a pioneering collaboration on MS research with the National Institutes of Health moved ahead. The first-ever joint venture with the National Institute of Allergy and Infectious Disease brought new funds to the table, adding \$4.5 million to the Society's \$3.2 million. Six projects on sex-based differences in immune disease were launched, and shortly after FY 2002 ended, the first small clinical trial of a sex hormone in women with MS issued promising preliminary results.

Altogether, the Society initiated 111 new research projects in 2002 and continued its support of 330 others, including our major initiatives: The ***MS Lesion Project***, an international effort to correlate brain lesions and the clinically observable manifestations of the

MS is a chronic disorder of the central nervous system—whose root problems are almost certainly immunologic. Symptoms of MS occur when the immune system turns against the individual's own body, attacking the insulating material called myelin which is wrapped around nerve fibers in the central nervous system. The attacks cause inflammation and swelling and, ultimately, destruction of myelin and damage to nerve fibers.

Patrizia Casaccia-Bonnet, MD, PhD, Robert Wood Johnson Medical School, University of Medicine and Dentistry of New Jersey, is just one of the hundreds of Society-funded researchers seeking keys to the puzzle of MS.

disease; the ***Sonya Slifka Longitudinal MS Study***, a nationwide effort to measure the economic, social, and health impact of MS across time in a large, widely varied population; and two groups of studies on ***genetic aspects*** and ***gender aspects*** of MS.

In 2002, Society-funded research teams made remarkable progress identifying potential biochemical targets for MS therapies. For example, Mayo Clinic researchers reported that a newly discovered myelin protein is dramatically increased in nerve fiber areas under active attack. A University of California at San Francisco team demonstrated that an immune protein called osteopontin plays a critical role in enabling an attack on myelin. And a University of Illinois at Chicago group probed “PPAR-gamma ligands”, currently used to treat diabetes, for potential in MS. The researchers are especially encouraged by animal studies showing that this compound was effective when given by mouth.

Findings by Society-supported researchers in the U.S. as well as teams in Austria and Germany showed that “statin” drugs—particularly atorvastatin, marketed in the U.S. as Lipitor, and simvastatin, marketed as Zocor—can effectively treat the experimental animal model of MS. A preliminary clinical trial in people with MS began in 2002.



Sarah Wampler, Resource Information Coordinator, opens the “front door” for the Society. Like her colleagues at every Society chapter, Sarah offers callers accurate information and local referrals.

For MS to be ***cured***, damage to nerve fibers and myelin must be repaired, and progress was made here as well. Cleveland Clinic researchers reported new data on the condition of myelin-making cells that could lead to repair therapies.

Until there is a cure, the Society has yet another research responsibility. It must develop hard data to support meaningful health-care policy. A Society-funded study at the Center for Health Economics Research documented that the health-care costs borne by people with MS are two to three times higher than normal costs. This data can be used by people developing plans for more effective health-care financing.

Progress in achieving full participation in public life

The struggle to live a productive life with MS depends critically on available accommodations and public policies. But the public can be painfully resistant. Even relatively inexpensive accommodations, mandated by the Americans with Disabilities Act—such as ramps or automatic door openers in public buildings—have to be won. More costly policies—for affordable health insurance or home health services, for example—present major challenges.

The Society is committed to supporting volunteer advocates, most of them people with MS, who can and do fight these battles. In 2002 chapter government relations committees addressed 300 issues in all the 52 states. The score? An impressive 131 successes in quality of health care, public access, long-term care services, and health insurance.

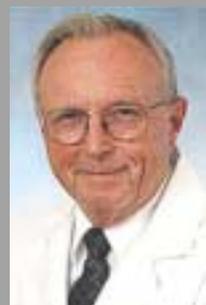
Advocacy at the federal level moves into high gear each spring, when Congress debates budget proposals. In April 2002, 210 Society advocates came to Washington and visited 300 Congressional offices. They focused on increased funding for research at the National Institutes of Health, a prescription drug benefit attached to Medicare, and federal support for respite care programs.

Changing public policy always involves changing public opinion. To educate the general public about MS, the Society places



Actress Teri Garr, escorted by David Lander, accepted the Society's "Shining Star" award for her service as an MS Ambassador. Ms. Garr and Mr. Lander offer the public a new image of MS. Both have lived with the disease for more than 20 years.

stories in popular magazines, produces public service announcements for print, radio, and TV, and, in 2002, welcomed celebrated actress Teri Garr and Sue Thomas, the real-life model for the heroine of cable TV's "F.B. Eye", who "went public" with their MS. They joined David Lander as Society Ambassadors. All three use humor, charm, and a positive attitude to tell their personal MS stories.



The Society recognized Dr. Stanley van den Noort, outgoing Chief Medical Officer, for his 32 years of devoted volunteer leadership at the Society—and welcomed Dr. Aaron Miller, who succeeded him as CMO.

Progress in raising the quality of professional care

MS is a complex disease, different from person to person, and different in the same person over time. MS clinical centers offer experienced care because their staff see dozens of people with MS every week. But many providers have only a few patients or clients with MS.

In 2002, the Society took a giant step toward better meeting the needs of all health-care professionals for current, evidence-based recommendations and the best professional information on complicated or unusual concerns. The former Clinical Programs Department was reinvented as the Society's Professional Resource Center.

In addition to an in-depth professional section on our Web site, the PRC established an E-mail hot line (MD_info@nmss.org, for physicians, and HealthProf_info@nmss.org, for all others) and a toll-free telephone line, 866-MS-TREAT. Hot-line inquiries are backed up with professional publications, including 11 *MS Clinical Bulletins* and two *Expert Opinion* white papers on disease management and symptom control. The new Professional Information and Library Service offers medical literature search services.

Some 1,000 nurses and pharmacists participated in the Society's interactive educational teleconference, which focused on new medications, and the PRC was proud to announce competitions for the new John



Therapist Penny Ribis provides Sarah Davidson with emotional support as well as medical expertise. When health-care professionals understand MS basics, everyone benefits.

Dystel Nursing Fellowships and Serono Multiple Sclerosis Clinical Fellowships for physicians. These are the first-ever fellowships for young professionals planning to concentrate on MS clinical care.

Perhaps the biggest impact on the professional community came via Society coordination of a joint meeting in Baltimore. Americas Committee for Treatment and Research in MS—ACTRIMS—and the European Committee for Treatment and Research in MS—ECTRIMS—met together linking over 2,000 professionals involved in MS clinical research and care. It was the largest such meeting in the history of multiple sclerosis—and it spurred new insights and new collaborations in the world-wide struggle against MS.

Progress in funding our mission

As scientists gain knowledge, research projects become more complex, and today the average MS research project requires nearly \$450,000 and three years of effort. Education, service, and recreation programs cost more too. Even the price of a postage stamp soared in 2002.

Our chapters met this challenge with challenges of their own. In addition to the income every chapter is required to share for national programs, 56 of our 62 chapters joined the Research Honor Roll by contributing an **additional** \$6.3 million for research. A special Research Challenge—spurring chapters to raise an additional \$20 million over five years—is now 100% committed and over 60% funded in its third year.

The chapter-based Dinner of Champions, which honors area celebrities, increased income by 7%. The National MS Walk, which every chapter hosts in April or May—and which now includes an accessible route at every venue—grew by 4%. And the Society's world-famous bike rides, the MS 150 Bike Tours, and the many special rides featuring regional attractions from coast to coast, increased income by 10%.

The most exciting fund raising event was held in seven markets in 2002: The MS Challenge Walk. The event bonded its 2,500 participants as they struggled to accomplish a

daunting 50-mile walk. The group included an amazing 200 walkers who themselves have MS. They trained and strained with the others to demonstrate the strength of their hope. The MS Challenge Walk will be offered in 11 markets in 2003.

Not all fund raising is accomplished through events. Annual giving, the volunteer Helping Hands campaign, and direct marketing appeals by mail, all made gains. Gifts made through estates and charitable gift annuities more than doubled over 2001, and significant outright gifts increased by 19%.

In the last five years, the Society has begun to develop important financial support by seeking to involve major donors who are capable of giving five, six, even seven figure gifts. Financial support at this level is essential for the stability and continued growth of the Society's efforts. The Society has received three gifts of \$1 million or more, nearly a dozen in the \$500,000 range, and hundreds of gifts of \$10,000 or more. We are a country of unprecedented affluence, and we look forward to adding new partners to this special roster of distinguished philanthropists.

Design: Lai Mei Tong.

Photography: Kevin Berne, p. 11;

Forest McMullin, pp. 4, 9;

John Noltner, cover, pp. 2 (top), 3, 7;

John Russell, pp. 2 (bottom), 8 (top);

Photo on p. 6 courtesy of the Robert Wood Johnson Medical School.



“Three days. 50 miles. Closer to the cure.”

The MS Challenge Walk in California.

Progress in governance and leadership



ED KANGAS
*Chairman, National
Board of Directors*

This was a good year for the National MS Society. We have much to be proud of. For people living with MS, we now hold up a single standard for Society efforts in every chapter and branch. The standard is a simple one: excellence.

But our accomplishments are not good enough. I don't believe any of you will feel truly satisfied until we can say multiple sclerosis is no more. That means we must be able to stop it in its tracks. We must be able to repair the damage it has caused. And we must be able to prevent it from taking another day of freedom from the beautiful people it attacks.

How will we get there?

We will get there by not being satisfied with the status quo. The new treatments for MS tell us clearly that we need to push research by providing as much funding support as we can muster. This is job one. The current treatments quiet MS, but they don't cure it. There are better possibilities out there, waiting to be developed.

Even with research proceeding at breakneck speed, people with disabilities—and their family members—need to live productive lives in the here and now. That means they need access to transportation, public facilities, employment opportunities, appropriate equipment and therapy, and to home care or long-term care services that maximize independence and productivity. Our nation can't afford to waste the capacities of the talented people who are being sidelined by limitations imposed by MS.

This second job is two-fold: We need to teach the public about the accomplishments and contributions people with disabilities can make. We need to advocate for public policies that empower people to participate to whatever extent their abilities permit.

Please join me in pressing forward.

A handwritten signature in black ink, appearing to read 'Ed Kangas', written in a cursive style.

We made substantial progress on all major fronts this year. Society-funded researchers created new knowledge. New medications and techniques for symptom management were approved and disseminated. Every Society chapter linking our nation improved the programs offered to people affected by MS. Our national and chapter Web sites grew in depth and ease of use. Our publications informed people with MS and the professionals who care for them. And we forged new links to funding sources. Most visible of these is the Society's collaboration with the National Institute of Allergy and Infectious Diseases through which a \$3.2 million investment by the Society becomes \$7.7 million in total funds for new MS-related research.

Vigorous advocacy by Society volunteers and leadership helped ensure that funding for the National Institutes of Health continued its upward curve.

In response to a strategic review of our activities undertaken in 2000 by the prestigious Institute of Medicine, we developed new programs to fill needs identified through this rigorous process. The Society has traditionally been instrumental in setting research directions through national and international meetings. In 2002, the Society took on the new responsibility of developing the social policy data so badly needed by legislators and regulators.

But the most fundamental accomplishment of 2002 will drive the Society forward on all fronts. With broad support from our chapters, and leadership from the National Board of Directors, the Society recreated itself. We are now more nationwide, more diverse, more democratic, and more chapter-driven. These changes bring new energy to our long struggle against the devastating effects of multiple sclerosis.

Thank you all for your support and determination!



MIKE DUGAN
General, USAF, Ret.
President and CEO

A handwritten signature in black ink that reads "Mike Dugan". The signature is written in a cursive, flowing style.

Report from the treasurer



DICK MENGEL
*Treasurer, National
Board of Directors*

We are stewards of contributions that stem in large portion from grassroots funding by chapters, but whatever the source, we regard contributions as a form of trust. We invite you to contact the nearest Society office to learn more about the activities, programs, and research your support makes possible.

In FY 02, most chapter financial reserves were maintained in a second year of uncertain economic times. Home office income increased over the previous year by \$5 million—or 6.5%—but funds spent on vital programs increased faster—by 19%. The situation is sobering.

Prudent action has been taken to trim expenses in FY 03 while pressing forward to work smarter. We will steer a course between too much risk and too much comfort, always mindful of the pressing need to end the devastating effects of multiple sclerosis as soon as possible.

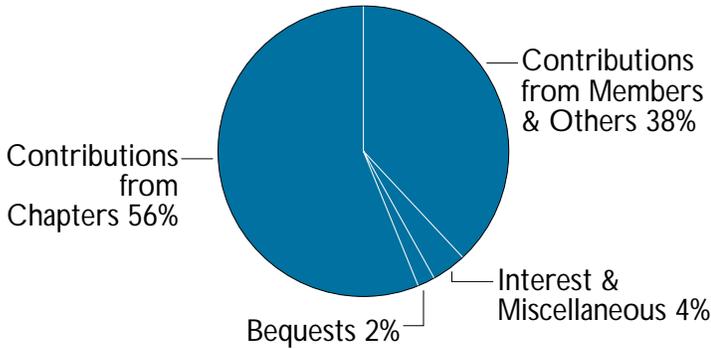
A long awaited Society-wide data management system, enabling more effective management of resources, has already proven its value as cobwebs and duplications are cleared from our records. Fifty-six of our 62 chapters are now in this database, sharing information and financial reports which are transparent across the whole Society.

I invite you to examine the financial charts on these pages and to visit our Web site at www.nationalmssociety.org where our audited annual report figures are displayed in detail.

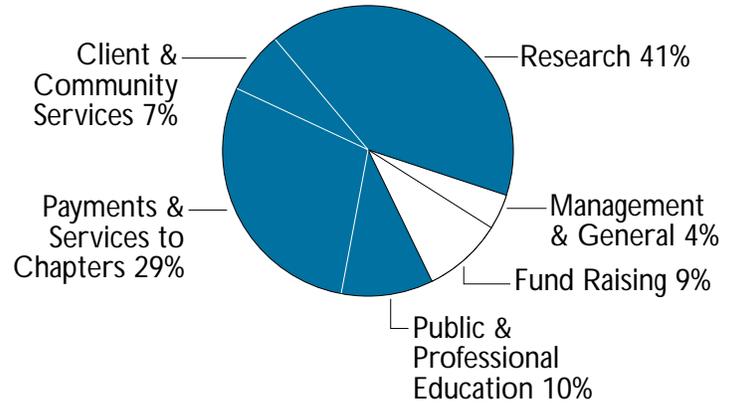
Richard J. Mengel

Home Office

INCOME

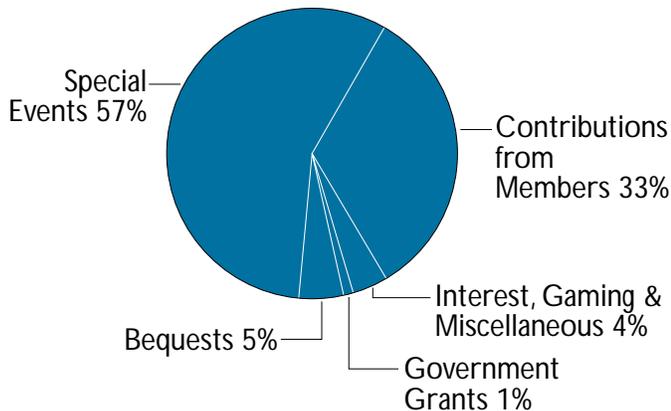


EXPENSES

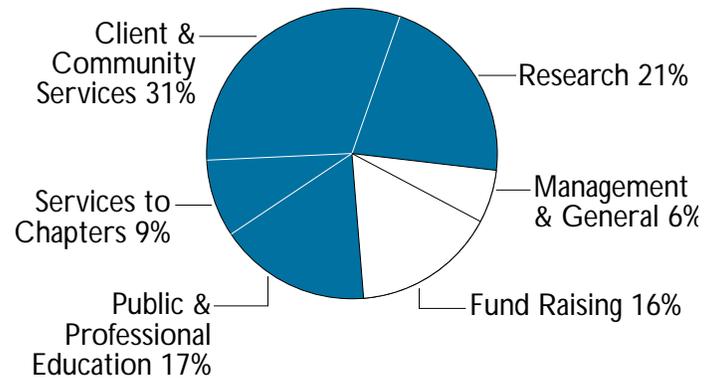


Home Office & Chapters

INCOME



EXPENSES



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**• Member,
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The number of voting members of the Society as of October 2002 was 35 board members and 62 chapter chairs. The number of members known to the Society as of October 2002 was approximately 616,305.

National Board of Directors as of December 2002

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Northwestern Ohio
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Ohio Valley Chapter
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West Virginia Division

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Oregon Chapter

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Chapter

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Rhode Island Chapter

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Mid Atlantic Chapter

South Dakota

Dakota Chapter

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Mid South Chapter

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Lone Star Chapter
North Central Texas
Chapter
All America Chapter,
Panhandle Division
All America Chapter,
West Texas Division
All America Chapter,
Rio Grande Division

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Utah State Chapter

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Vermont Division

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West Virginia Division

Wisconsin

Wisconsin Chapter
Minnesota Chapter

Wyoming

All America Chapter,
Wyoming Division



The National Multiple Sclerosis Society

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