



A SHARED PROMISE

2012 ANNUAL PROGRESS REPORT



National
Multiple Sclerosis
Society

NATIONAL MULTIPLE SCLEROSIS SOCIETY

We mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis, an unpredictable, often disabling disease of the central nervous system, interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50.

ABOUT THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

The National MS Society is a collective of passionate individuals who want to do something about MS now — to move together toward a world free of multiple sclerosis.

We strive to help each person address the challenges of living with MS by funding cutting-edge research, driving change through advocacy, building a nationwide network of experts in MS care, and providing programs and services that help people with MS and their families move their lives forward.

- We are a driving force of MS research and treatment to stop disease progression, restore function, and end MS forever.
- We are moving to reach out and respond to individuals, families and communities living with multiple sclerosis.

- We are inspiring politicians to champion the needs of people with MS through activism, advocacy and influence.

- We are moving to mobilize the millions of people who want to do something about MS now.

To advance our mission in 2012, we devoted \$122.1 million to programs and services that assisted more than a million people affected by MS. We also invested \$43.3 million to support more than 350 MS research projects around the world in order to stop MS in its tracks, restore what has been lost and end this disease forever. These critical investments ensure we are able to speed our progress in achieving a world free of MS. Join the movement at nationalMSSociety.org.

MS stops people from moving. We exist to make sure it doesn't.

SHARING A PROMISE

When we share a commitment, when we own our promises together, we are accountable to and for each other. You have my back, I have yours.

It's a good thing because, together, we have made one seriously big promise to the millions of people living with MS: We promise to work to create a world free of this disease. That is our vision—the promise we've shared since our organization was founded by Sylvia Lawry in March 1946.

We've come a long way in the last 66 years. Since its founding, the National Multiple Sclerosis Society has invested over \$771 million to advance MS research, paving the way for more than a dozen FDA-approved therapies. Last year the FDA fast-tracked the first-ever potential vaccine for secondary-progressive MS and the National MS Society joined MS societies around the world to launch a global effort to find solutions for progressive forms of MS.

We made significant strides last year in public policy. Thanks to the tireless efforts of MS activists nationwide, the Social Security Administration added an advanced form of MS to its list of Compassionate Allowances conditions, expediting the processing of disability claims, ensuring speedy access to resources needed to move lives forward. In addition, focused federal activism efforts helped to secure \$5 million in MS research funding through the Congressionally Directed Medical Research Program;

this is in addition to the \$43.3 million the Society invested.

We expanded access to high quality care for people living with MS in rural areas by adding 200 providers to our referral lists, training 825 health care providers and contacting nearly 360 state offices to develop partnerships for additional training, education and outreach to rural health care providers.

As leaders in the MS movement, we strive to connect people, not just with resources but with each other. Last year we brought tens of thousands of people together online through our [Facebook](#) and [Twitter](#) pages, through webcasts and the Society blog. We also launched MSconnection.org, where thousands of people support one another and together explore the issues that shape their world.

As we continue to drive the movement forward, our determination and our resolve will bring the day when no one ever hears the words, "You have MS." This is our shared promise.



Sincerely,
Cyndi Zagieboylo
Cyndi
President and Chief
Executive Officer

FUNDING RESEARCH TO CHANGE LIVES NOW AND FOREVER

I was five years old when I began fundraising to fight MS. I went door to door asking friends and neighbors to help me keep a promise. A promise I made in memory of my father and my uncle, and then later to my sister, when she was diagnosed—that I was going to do something about it.

Doing something about MS—NOW—is the shared promise we've made to the hundreds of thousands of people living with the disease in the U.S. It also directly reflects the hopes and concerns of the thousands of people affected by MS who helped us shape our 2011–2015 Strategic Response to MS. They made it clear that research is our priority. They called for:

- More funding for MS research
- Increased focus on progressive MS
- More scientists and clinicians in the field of MS

The National MS Society initiated the NOW—No Opportunity Wasted—research campaign to address these priorities by raising \$250 million for MS research, the largest MS research campaign ever undertaken.



Sincerely,

Eli Rubenstein
Chair, National Board of Directors

The time is NOW to ensure that we aggressively pursue and accomplish our goals in order to STOP MS in its tracks, RESTORE what's been lost, and ultimately END the disease forever. We will:

- Better understand the scientific mechanisms that lead to disease progression and accelerate the development of new therapies.
- Pursue new avenues to discover how nerve cells are damaged and potentially repaired.
- Forge new rehabilitation techniques and symptom treatments to restore neurological function and enhance quality of life.
- Identify risk and triggering factors that cause MS, and understand the biological interactions that lead to its development so that MS can be prevented.
- Expand and strengthen the quantity and quality of MS research worldwide to accelerate new discoveries and treatments for people with MS.

Together, we will drive research progress NOW.

» [Read about Eli's history with the society](#)

» [Become a champion in the MS research revolution](#)

PUTTING PRECIOUS RESOURCES TO THE BEST POSSIBLE USE

We all know money is tight. The nonprofit health sector reported flat income in 2012, and the National MS Society felt that burden, too. But, collectively, we made good on our promise to work toward a world free of the disease. As government investment in medical research declined last year, we increased funding for MS research and ensured our programs and services were accessible for people living with MS no matter where they live. We increased the engagement of activists by 11%, growing our MS activist network from 65,000 to over 72,400, ensuring the voices of people affected by MS are heard.

As we continue to increase our commitments to people affected by MS, it only costs the Society about 17 cents to raise a dollar. The Society continues to meet or exceed the standards of all major agencies that rate non-profit groups.

Because of our responsible and conservative fiscal management, we are on track to meet our shared promise of investing \$250 million in MS research by 2016, dedicated to pursuing every promising path to stopping the disease in its tracks, restoring lost function, and ending MS forever.

Whether you are considering making a one-time gift or contributing to a Bike MS or Walk MS team or individual fundraiser, you can trust that your contribution is helping to fund cutting-edge research, drive change through advocacy, facilitate professional education, and provide programs and services to help people with MS and their families move their lives forward.

There has never been a better time to be a part of movement.



Sincerely,

Jim E. Cantalupo
Treasurer, National Board of Directors

» [Read the Society's full 2012 financial statements](#)

» [Learn about ways to change the lives of people living with MS](#)

We are a driving force of MS research and treatment to stop disease progression, restore function, and end MS forever.



DR. LILYANA AMEZCUA: GIVING BACK TO THE MS RESEARCH AND CARE COMMUNITY

Lilyana Amezcua, MD, an assistant professor of clinical neurology at the University of Southern California's MS Comprehensive Care Center in Los Angeles, says she hears a lot of "Why me?" from her Latino and Hispanic patients with MS. "They mean, 'Why me when all the data about prevalence isn't about me?'" But recent studies into genetics and MS prevalence conducted by Dr. Amezcua and others are showing an increase in the number of people throughout Latin America who have MS—a figure that is rising faster than the growth rate of the region's total population. Discovering why this is happening could shed further light on what increases risk for the disease.

Dr. Amezcua wanted to be a neurologist since she started college, inspired by a brother with a neurological and autoimmune condition. Thanks to a fellowship from the Society in 2006-08, she trained in clinical MS and neuroimmunology under Leslie P. Weiner, MD, where she learned to diagnose and treat MS and conduct clinical trials. Now she's a mentor herself—to Society Fellow Megan Langille—helping to bring the best and brightest minds into the MS research and care community. "I'll always be indebted for the financial support, wonderful mentorship and for getting to know the players," she says.

MS research continued to advance on many fronts and lives were changed with the introduction of a second oral MS therapy, the launch of new collaborative research efforts, and significant results of recent studies promising more options for people living with MS.

In 2012, we:

- Increased our research investment by 10% to \$43.3 million—more than \$3 million over 2011—to drive more than 350 important new and ongoing research projects and fellowships focusing on stopping MS in its tracks, restoring function, and ending the disease forever.
- Convened an international summit on vitamin D in MS and funded other key initiatives on risk factors and pediatric MS to better understand what triggers MS and ways to prevent it.
- Launched the International Progressive MS Collaborative, bringing the MS scientific world together to focus on treatments for progressive MS.
- Launched key partnerships and grants to advance potential therapies for spasticity and pain, and to test whether specific compounds, antioxidants and treatments approved for other disorders can protect peoples' nervous systems from MS damage.
- Launched a concerted effort to create a new measure of MS disability that will be recognized by the FDA and the European Medicines Agency to speed new therapies for progressive MS.

» [Get to know Dr. Amezcua and learn more about her research](#)

» [Read an article \(in Spanish or English\) on the Latino/Hispanic experience of MS](#)

» [Read more about the Society's comprehensive MS research strategy](#)

We develop, deliver and leverage resources to enhance care for people with MS and quality of life for those affected by the disease.



2012 SCHOLARSHIP RECIPIENT SANDRA PAOLA MEDRANO: TAUGHT TO HOPE

Sandra Paola Medrano, who just graduated from Christian Heritage School in Trumbull, Conn., is a high-achieving teen. Paola, as her friends and family call her, is also a certified nursing assistant and works in an assisted living community. Not long ago she organized the first-ever blood drive at her high school, and she's been to Haiti, the Dominican Republic and Honduras for community service projects. This summer, she will be going to India on a volunteer mission trip.

Paola's inspiration is her mom, who was diagnosed with MS eight years ago, when Paola was in 4th grade. "I got interested in science because of my mom's MS. I thought, I'm in the process of deciding my future—why shouldn't I pursue a career of research in MS?" she asks.

Paola is one of 646 students who received a total of \$1.2 million from the Society in 2012. Her Society scholarship allows her to attend Wheaton College in Illinois to pursue plans to become a physician's assistant. Her goal is to work with a cross-cultural organization such as Operation Smile or Doctors Without Borders.

"MS has taught me to hope regardless of what is in the present," she wrote in her scholarship application. "It has made me prepared for the future, with bright hopes for tomorrow. It has not defeated us, we remain unbroken. MS cannot defeat us."

Society programs change lives. In 2012, we:

- Offered more than 4,300 programs that impacted the lives of nearly 190,000 people affected by MS.
- Launched MSconnection.org, enabling a growing online community of thousands to share information and resources while supporting each other.
- Connected hundreds of thousands of people affected by MS through our social media networks: Twitter followers reached 35,000, up from 15,000 the previous year; Facebook visitors topped 250,000; and YouTube engagement rose from 1.3 million views last year to over 1.8 million views in 2012.
- Hosted research webcasts informed and engaged more than 4,500 people and our first hosted 'online' chat engaged over 400 participants.
- Connected thousands of people affected by MS with each other through the MS Friends telephone peer support program and the online peer support program.
- More than 200,000 callers and 12,000 electronic requests were addressed through the MS Navigator service, working with people to find solutions to the challenges of living with MS.
- Minimized the financial impact of MS through disbursements of over \$7.2 million to address the needs of 11,120 people with MS, including \$1.2 million in college scholarships supporting 646 families affected by MS, and \$108,000 to 94 families facing extraordinary financial obstacles through the Stepping Stones program.
- Expanded access to high-quality MS specialized care for people with MS in rural areas by adding 200 providers to our referral lists, training 825 healthcare providers and contacting 358 state offices to develop partnerships for additional training, education and outreach to rural healthcare providers.

» [Get more information on the Society's scholarship program](#)

» [Discover more about what the Society offers people affected by MS](#)

We are leaders in the worldwide
MS movement, mobilizing
millions of people to do
something about MS now.

2012 VOLUNTEER OF THE YEAR DEAN MUNGER: COMMITMENT TO DELIVERING ON OUR SHARED PROMISE



"I first became involved with the Society because of my four wonderful daughters doing research to find ways for the family to become involved to help their mother, Mary," Dean Munger recalls. His wife was diagnosed with multiple sclerosis more than 25 years ago. "As MS began to impact Mary's life, creating added stress and complications for her, I was asked to become more involved within the Society, first as a trustee, then an officer, a board chair, a task team participant, a NOW Cabinet member— you get the picture. The Society discovered the major flaw in my character: I can't say no."

Munger's amazing depth of involvement, his commitment, his positive attitude, ability to motivate others, generosity, and passion for the MS Movement were recognized recently when the Society awarded him 2012 Volunteer of the Year.

Our volunteers keep us all connected. In 2012:

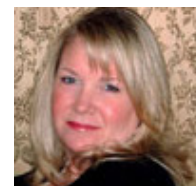
- More than 500,000 volunteers gave their all to help change the lives of everyone living with MS. These volunteers commit precious time and talent to ensure that Society programs and services impact more than a million people affected by this disease.
- Pro-bono expertise was offered by more than 14,000 volunteers in leadership positions, including self-help leaders, trustees and members of board, programs and government relations committees. The Society engaged more than 1,000 healthcare professionals who helped shape strategies to improve access to care and spoke at educational programs.
- More than 450,000 people, including corporate and friends and family teams, participated in hundreds of Walk MS, Bike MS and other events across the country, engaging more people and raising more awareness through fundraising and media coverage than in previous years.
- Thousands of volunteers served as ambassadors, champions and community leaders to change the lives of people living with MS by donating computers, building wheelchair ramps, painting houses, delivering meals and visiting people with MS experiencing isolation.
- Volunteers from the MS community, including healthcare professionals and people living with the disease, provided critical guidance in shaping the Society's communication and awareness efforts including brochures, webcasts and our magazine, Momentum.

» [Meet all of the Society's
2012 Volunteer Honorees](#)

» [Learn about the many ways
to Join the Movement](#)

» [Become a
volunteer](#)

We are
activists.



2012 ADVOCACY HALL OF FAME INDUCTEE ROBIN D'ANDREA

"I was diagnosed with MS in 1997 and after a few rough years, I started volunteering with the Society," Robin D'Andrea says. Before her diagnosis, D'Andrea was a social worker with a background in advocacy and mental health. "I had always been an advocate for my patients," she explains, "so MS advocacy sounded kind of fun." Though she says she was nervous on her first visit to Capitol Hill, "when this influential and intelligent politician confused MS with muscular dystrophy, I realized 'hey, this isn't so hard.'" She realized how much she could do to educate and raise awareness about MS.

D'Andrea joined the Long Island's Government Relations Committee more than 10 years ago and has co-chaired the committee for the last eight years. She also co-leads the Society's We Are Activists Goal Steering and Implementation teams. In 2012, she was inducted into the Advocacy Hall of Fame.

"We've come a long way," D'Andrea says, "thanks to the many MS activists around the country. The more of us there are, the more powerful our voice will be. The Society makes it easy to take action, sending electronic notices that people affected by MS can forward on to their elected officials." People living with MS or who care about someone with the disease can help change legislation, and thus the lives of many others like them, she says. "Their stories resonate and our legislators will remember. These stories will garner the support we need to change policies."

» **Meet all seven of the Society's 2012 Advocacy Hall of Fame Inductees**

» **Become an MS Activist now**

MS activists are driving change nationwide. In 2012, we:

- Collaborated with the Social Security Administration to add progressive forms of MS to a list of conditions that get expedited review for disability benefits.
- Secured \$5 million for MS research through the Congressionally Directed Medical Research Programs and increased overall funding at the National Institutes of Health by \$71 million — adding to the Society's investment of \$43.3 million.
- Protected Medicaid, Medicare beneficiaries and Social Security benefits from significant cuts within the federal budget.
- Secured nearly \$2.5 million for the Lifespan Respite Care Program that helps improve family caregivers' access to respite care.
- Sent over 27,000 emails to Capitol Hill urging support on several federal issues important to people with MS including ratification of the UN Convention on the Rights of Persons with Disabilities.
- Added members to the bipartisan Congressional MS Caucus, bringing the total of the 112th Congress to 161 U.S. Representatives and 31 U.S. Senators.
- Visited more than 365 offices on Capitol Hill during the Society's Public Policy Conference and met in more than 80 Congressional in-district offices.
- Worked toward effective implementation of the Affordable Care Act at federal and state levels.
- Converged at more than 35 state capitals across the country to advance state policies and programs that positively impact the lives of people with MS.
- Pursued legislative and regulatory solutions in 35 states to address access to care for people with MS and in 20 states to address accessible transportation and housing.
- Released a YouTube video featuring MS activists discussing the importance of activism that has over 6,500 views.

We develop and align human, business and financial resources to achieve breakthrough results.



2012 PHILANTHROPISTS OF THE YEAR DOLLY AND MERWYN DAN: AT THE FOREFRONT OF DRIVING MS RESEARCH

Dolly and Merwyn Dan insist they are like anyone else in the MS movement. But when their youngest daughter was diagnosed with MS in 1998, it changed the Dan family's life forever, spurring them to inspire, engage and challenge fellow volunteers to increase the research funds needed to speed new and better therapies to people living with MS.

As longtime volunteers for the Society, the Dans are passionate about getting other families to give to research, and see an opportunity in the NOW—No Opportunity Wasted—campaign. "The more that people contribute to this effort, the more partnerships we'll be able to make—and the more grants the Society will be able to award," Merwyn says. The Dans recently made their own \$1 million long-term pledge to research, focusing on accelerated commercial development of new treatments for MS. The Dans' gift helped develop a targeted program in nervous system repair, which the couple believes one day will stop their daughter's disease progression and restore the function she has lost. "This is the key opportunity for her," Merwyn says.

He and Dolly see NOW's \$250 million commitment to research as critical, and with their pledge they challenge others to make the most meaningful gift they can.

In recognition of their extraordinary commitment to the MS movement, the Society honored Merwyn as a member of the Volunteer Hall of Fame, and both Dolly and Merwyn are members of the Circle of Distinction and 2012 Philanthropists of the Year.

Fundraisers and donors change lives. In 2012 we:

- Engaged 452,000 participants in our Walk MS, Bike MS, Challenge Walk and other special events raising nearly \$163 million.
- Launched Do It Yourself (DIY) online fundraising, resulting in 15% DIY revenue increase from more than 1,000 new unique events.
- Engaged dozens of corporate partners including receiving \$3.2 million in new revenue from relationships with Sam's Club, Sara Lee and Bimbo Bakeries.
- Increased corporate giving with a \$1.3 million Walk MS sponsorship from Novartis and a \$1.2 million partnership with Genzyme for the 'EveryDay Matters' Program. Significantly increased awareness of MS and the Society with media placements valued at \$3 million in the first three months of our awareness campaign, an increase of more than 30% over last year. Ninety-two percent of all stories on MS in the media mentioned the Society, up from 84% in 2011.
- Received \$9.4 million in research gifts from individuals, an increase of more than \$3.5 million over 2011.

» [Read more about the Dan family](#)

» [Join Dolly and Merwyn Dan and help propel MS research through The Golden Circle](#)

» [Become a Champion in the MS Research Revolution](#)

2012 FINANCIALS



2012 HOME OFFICE

Total Income: \$106,138, 910

- Contributions from Chapters: \$75, 339, 647
- Contributions from Members & Others: \$26, 356, 013
- Interest & Miscellaneous Income: \$4, 443, 250



2012 HOME OFFICE

Total Expenses: \$105,460,508

- Research: \$42,255,235
- Client & Community Services: \$9,083,351
- Public & Professional Education: \$10,504,918
- Payments & Services to Chapters: \$27,396,780
- Fundraising: \$7,745,953
- Management & General: \$7,474,271

[» LINK TO COMPLETE FINANCIALS](#)

All statistics from Fiscal Year 2012 (October 1, 2011 to September 20, 2012)



2012 HOME OFFICE & LOCAL OFFICES COMBINED

Total Income: \$216,363,554

- Special Events: \$143,543,399
- Contributions from Members & Others: \$54,990,377
- Legacies & Bequests: \$6,465,545
- Interest & Miscellaneous Income: \$8,926,780
- Government Grants: \$691,321
- Federal Service Campaign & Fundraising Organization: \$1,746,132

[» LINK TO COMPLETE FINANCIALS](#)

All statistics from Fiscal Year 2012 (October 1, 2011 to September 20, 2012)



2012 HOME OFFICE & LOCAL OFFICES COMBINED

Total Expenses: \$218,943,020

- Research: \$43,255,235
- Client & Community Services: \$65,425,784
- Public & Professional Education: \$33,260,861
- Payments & Services to Chapters: \$23,566,071
- Fundraising: \$37,553,242
- Management & General: \$15,881,827

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Montana

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Greater Delaware Valley Chapter

New Jersey Metro Chapter

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Central North Carolina Chapter

Eastern North Carolina Chapter

Hampton Roads Chapter

Mid Atlantic Chapter

North Dakota

North Central States Chapter

Ohio

Northwestern Ohio Chapter

Ohio Buckeye Chapter

Ohio Valley Chapter

Oklahoma

South Central Chapter

Oregon

Oregon Chapter

Pennsylvania

Central Pennsylvania Chapter

Greater Delaware Valley Chapter

Western Pennsylvania Chapter

Rhode Island

Rhode Island Chapter

South Carolina

Mid Atlantic Chapter

South Dakota

North Central States Chapter

Tennessee

Mid South Chapter

Texas

South Central Chapter

Utah

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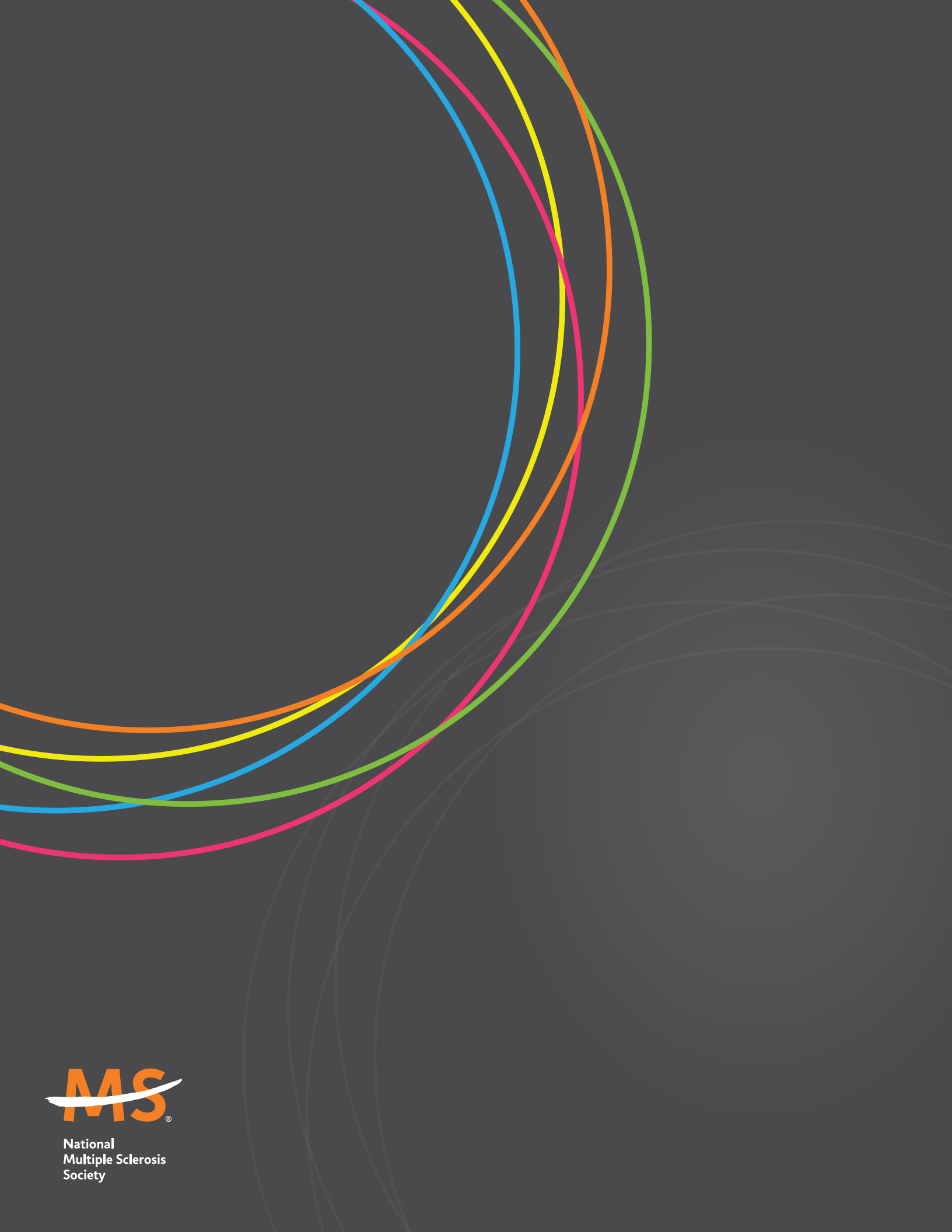
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