Multiple Sclerosis: Just the Facts

GENERAL INFORMATION

National Multiple Sclerosis Society

Kim, diagnosed in 1986

MS Facts

What is multiple sclerosis?

MS is a disease that involves an immune system attack against the central nervous system (brain, spinal cord, and optic nerves). The disease is thought to be triggered in a genetically susceptible individual by a combination of one or more environmental factors. Although MS is thought by some scientists to be an autoimmune disease, others disagree strongly because the specific target of the immune attack in MS has not yet been identified. For this reason, MS is referred to as an immune-mediated disease.

MS can cause blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, blindness and more. These problems may be permanent or may come and go.

Most people are diagnosed between the ages of 20 and 50, although 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 MS live a normal life-span.

But the unpredictability of the disease can present many challenges, including the possibility of facing increasing limitations.

Who gets MS?

Anyone may develop MS but there are some patterns. At least two to three times more women than men have been diagnosed with MS. Studies suggest that genetic factors make certain individuals more susceptible than others, but there is no evidence that MS is directly inherited. MS occurs in most ethnic groups, including African-Americans, Asians and Hispanics/Latinos, but is more common in Caucasians of northern European ancestry.

How many people have MS?

Worldwide, MS affects about 2.1 million people. These numbers can only be estimated because the Centers for Disease Control and Prevention (CDC) do not require U.S. physicians to report new cases, MS disease activity can occur without a person being aware of it, and symptoms may be completely invisible.

What are the typical symptoms of MS?

Symptoms of MS are unpredictable; they can vary from person to person, and from time to time in the same person. For example: One person may experience abnormal fatigue and episodes of numbness and tingling. Another could have loss of balance and muscle coordination making walking difficult. Still another could have slurred speech, tremors, stiffness and bladder problems.

Sometimes major symptoms disappear completely, and the person regains lost functions. In severe MS, people have permanent symptoms that might include partial or complete paralysis and difficulties with vision, cognition, speech and elimination.

What causes the symptoms?

MS symptoms result when an immune system attack affects myelin, the protective insulation surrounding nerve fibers of the central nervous system. Myelin is often compared to insulating material around an electrical wire; loss of myelin interferes with the transmission of nerve signals.

Myelin is destroyed and replaced by scars of hardened "sclerotic" tissue. Some underlying nerve fibers are permanently damaged or severed as well. The damage appears in multiple places within the central nervous system, giving the disease its name.

Is MS fatal?

Most people living with MS have a normal or near-normal life expectancy. In rare cases, however, MS is so malignantly progressive it is terminal. Severe MS, and related complications, can shorten life.

Does MS always cause paralysis?

No. The majority of people with MS do not become severely physically disabled. Two-thirds of people living with MS remain able to walk, though many will need an aid, such as a cane or crutches, and some will use a scooter or wheelchair because of fatigue, weakness, balance problems, or to help conserve energy.

Is MS contagious or inherited?

No. MS is not contagious and is not directly inherited. Studies do indicate that genetic factors may make certain individuals susceptible to the disease.

What can be done about MS now?

There is much one can do to manage the disease and the symptoms it can cause. Medications that have been shown to "modify" or slow down the course of MS have been approved by the U.S. Food and Drug Administration (FDA). In addition, many therapeutic and technological advances are helping people manage symptoms. Advances to stop disease progression and restore lost function are made every year, and increased understanding of MS and the potential cause(s) brings us closer to the goals of stopping the disease in its tracks, restoring function, and ending MS forever.

What medications and treatments are available?

The National Multiple Sclerosis Society recommends that people consider treatment with one of the FDA-approved "disease-modifying" therapies as soon as possible following a definite diagnosis of MS with active, relapsing disease.

In many instances, starting therapy is recommended after an initial demyelinating episode ("clinically isolated syndrome") that places a person at high risk for developing clinically definite MS. These medications help to lessen the frequency and severity of MS attacks, reduce the accumulation of lesions (areas of damage) in the brain, and may slow the progression of disability.

The FDA has also approved a disease-modifying therapy for reducing disability and/or the frequency of attacks in patients with secondary-progressive, progressive-relapsing or worsening relapsing-remitting MS. This medication is a chemotherapeutic agent. The lifetime dose is limited to prevent heart damage.

In addition to therapies that address the underlying disease process, there are many medications and rehabilitation strategies to address MS symptoms such as spasticity, pain, bladder problems, fatigue, sexual dysfunction, weakness, and cognitive problems. People should consult a physician to develop a comprehensive approach to managing their MS.

Why is MS so difficult to diagnose?

In early MS, symptoms that might indicate any number of possible disorders can come and go. Some people have symptoms that are very difficult for physicians to interpret, and these people must often "wait and see." While no single laboratory test is yet available to prove or rule out MS, magnetic resonance imaging (MRI) is a great help in reaching a definitive diagnosis.

What are the different types of MS?

In an effort to develop a common language for evaluating and researching MS, an international survey was conducted among scientists who specialize in MS research and patient care. Analysis of responses resulted in defining the following categories, which were introduced in 1996:

Relapsing-Remitting

Characteristics: People with this type of MS experience clearly defined flare-ups (also called relapses, attacks or exacerbations). These are episodes of acute worsening of neurologic function. They are followed by partial or complete recovery periods (remissions) that are free of disease progression.

Frequency: The most common form of MS at time of initial diagnosis. Approximately 85%.

Primary-Progressive

Characteristics: People with this type of MS experience a slow but nearly continuous worsening of their disease from the onset, with no distinct relapses or remissions. However, there are variations in rates of progression over time, occasional plateaus and temporary minor improvements.

Frequency: Relatively rare. Approximately 10%.

Secondary-Progressive

Characteristics: People with this type of MS experience an initial period of relapsing-remitting MS, followed by a steadily worsening disease course with or without occasional flare-ups, minor recoveries (remissions), or plateaus.

Frequency: According to studies in people who were not using disease-modifying MS therapies, approximately half of those whose MS begins with a relapsing-remitting course transition to this form of MS within 10 to 20 years of their initial diagnosis. Long-term data are not yet available to determine if this transition to secondary-progressive MS is significantly delayed by the available disease-modifying therapies.

Progressive-Relapsing

Characteristics: People with this type of MS experience a steadily worsening disease from the onset but subsequently have clear acute relapses (attacks or exacerbations), with or without recovery. In contrast to relapsing-remitting MS, the periods *between* relapses are characterized by continuing disease progression.

Frequency: Relatively rare. Approximately 5%.

National MS Society Facts

The National MS Society is a driving force of MS research and treatment to stop disease progression, restore function and end MS forever. The Society supports and funds a comprehensive research agenda worldwide, drives change through advocacy, facilitates professional education, and collaborates with MS organizations around the world. Through its 50-state network of chapters and the combined efforts of volunteers, donors, researchers and health care professionals, the Society provides significant outreach, education and support to individuals and families who are impacted by the disease.

How many people does the Society serve?

The Society provides assistance to over a million people every year through partnerships with the health care community, its national office and a fifty-state network of chapters.

How many volunteers does the MS Society have?

The National MS Society values every contribution of the more than 500,000 Society volunteers throughout the country who provide support for people living with MS and their families. Society volunteers lead committees, manage projects, even recruit and train other volunteers. Volunteers are moving us all closer to a world free of MS. To learn more about volunteering opportunities, go to **VolunteerMatch.org** or contact the Society directly!

Are the National MS Society's programs free?

The Society offers a variety of community-based programs to facilitate education, recreation, physical and emotional wellness, connection with others with MS, and family communication. These programs vary from one community to another; many are free or include a nominal fee.

The Society can offer guidance and resources to help contain the financial impact of MS, with a range of initiatives that support independence, safety, health, and quality of life for people living with MS, as well as their families.

In addition, through the Society's Information Resource Center (IRC), it offers an MS Navigator® program that provides a partner to every person who lives with the challenges of MS. This free service is available to anyone who calls the Society.

To learn more about any of the Society's programs, call 1-800-344-4867 or e-mail **contactusnmss@nmss.org.**

Where does the Society get its money?

The Society depends on support from members, friends, corporate partners and the public at large. The Society's total revenue in 2011 was $214 million. This sum is a combination of all revenue including individual gifts; membership dues and contributions; legacies and bequests; special events; corporate contributions and investments. Approximately 68 percent of the Society's income is generated through special events. Approximately 4 percent comes

from pharmaceuticals companies and 4 percent from corporate support and government grants.

How does the Society raise funds?

Each National MS Society chapter organizes a variety of special events and campaigns. Two key fundraising events for the Society are Bike MS and Walk MS. Key individual giving programs at chapters include Golden Circle, Circle of Distinction and Lawry Circle.

Bike MS®

With more than 100 unique rides across the nation, cyclists can find the ride that's right for them. These fully supported rides not only connect cyclists to more than 100,000 other cyclists, but also to a growing movement to create a world free of MS. Proceeds benefit the Society's national research programs and fund programs that help people living with MS and their families. For information about Bike MS, call 1-800-FIGHT-MS (1-800-344-4867) or visit **bikeMS.org.**

Walk MS®

Each year over 300,000 people unite across the country to participate in Walk MS. All walks have an accessible route so people of all abilities can participate. Funds raised support the Society's research and services programs. For more information about Walk MS, call 1-800-FIGHT-MS (1-800-344-4867) or visit **walkMS.org.**

Challenge Walk MS℠

Accept the challenge to walk 30–50 miles over 2 to 3 days at any of our nine Challenge Walks across the nation. For more information about the Challenge Walk, call 1-800-FIGHT-MS (1-800-344-4867) or visit **challengewalkMS.org.**

Golden Circle and Circle of Distinction

Golden Circle is an annual membership program that engages donors in securing resources to help those living with MS move their lives forward through support for services, advocacy and research. Circle of Distinction honors the leadership of donors giving $1 million to the Society throughout their lifetime. For information about Golden Circle and Circle of Distinction call 1-800-FIGHT-MS (1-800-344-4867) or visit **nationalMSsociety.org/donate/Golden_Circle/index.aspx.**

Lawry Circle

Lawry Circle recognizes donors who have informed their chapter of their intention to help create a better future for people with MS through a gift from their will, trust or estate plan. These forward thinking people have linked their own legacy with the MS Society mission and have embraced the quest for a world free of MS beyond their lifetime. For information about Lawry Circle and planned giving call 1-800-FIGHT-MS (1-800-344-4867) or visit **nationalMSsociety.org/donate/lawry-circle/index.aspx.**

How does the National MS Society spend its money?

The Society's nationwide network of chapters is the lifeblood of MS research, providing major support for research programs. No less than half of all the unrestricted income that the chapters share with the national office goes to MS research.

- Approximately 76% of Society total revenue is devoted to research and service programs that enhance the lives of people with MS and their families, while the remainder is invested in support services such as fundraising and Society management.
- It costs the Society approximately 17 cents to raise a dollar.
- On average, at least sixty cents of every dollar stays in the chapter for local program use.

What do donations to the Society mean to you?

Research

The National MS Society is committed to a world free of MS, advancing a comprehensive strategy of promising research aimed at stopping the progression

of the disease and restoring function for all those living with the disease; and ultimately ending MS forever. Since its founding in 1946, the Society has propelled research forward into many of the currently available therapies and treatments by allocating more than $761 million.

We support a unique, comprehensive approach that funds research activities spanning all types and stages of research ensuring that promising paths are not overlooked. Whether it's academic and early discovery research, translational research tests ideas for use in people, or the commercial development that results in therapeutic solutions for testing, and clinical trials, we drive promising research that can impact those living with multiple sclerosis.

The Society's Strategic Response to MS for 2011–2015 focuses on achieving these objectives:

- Better understanding the scientific mechanisms that lead to disease progression and accelerating the development of new therapies;
- Pursuing new avenues to discover how nerve cells are damaged and potentially repaired;
- Fostering new rehabilitation techniques and symptomatic treatments to restore neurological function and enhance quality of life;
- Identifying risk and triggering factors that cause MS, and understanding the biological interactions that lead to its development so that MS can be prevented; and
- Expanding and strengthening the quantity and quality of MS research worldwide to accelerate new discoveries and treatments for people with MS.

Programs and Services

While research progresses toward stopping the disease, restoring function, and ending MS forever, the Society helps families manage the challenges of dealing with chronic illness. The Society committed $164 million in 2011 to client programs to educate, empower, support, and inform people with MS and their families. The Society offers over 60 educational brochures, more than 1,600 support groups, and 3,000 programs to over 75,000 participants.

The Society offers several publications, including *Momentum,* a lifestyle magazine, and *MSConnection,* a newsletter featuring local news and information, as well as a monthly national e-newsletter.

Professional Education

Through its clinical programs, the Society offers a full complement of literature and educational training to assist primary care physicians, neurologists, nurse practitioners and other health professionals stay current with new therapies and continuing MS research.

The Professional Resource Center offers library services, publications and MS specialist consultations for physicians as well as MS information for allied health care providers and a hotline for health care personnel.

For information and other services, please go to: **nationalMSsociety.org/PRC.** Physicians can e-mail **MD_Info@nmss.org;** other health professionals can e-mail **HealthProf_info@nmss.org.**

Advocacy

MS activists raise their collective voice to encourage legislative progress on a wide range of issues that benefit the lives of people with MS and their families, spread awareness, cultivate positive change, and achieve real-world results. MS activists have helped secure a new federal funding stream that provides millions of dollars for MS research and creates more awareness about MS among elected officials at all levels of government. Activists have many different mechanisms for participating in these efforts including collaborating with the Society's Public Policy Office, participating in chapter Government Relations Committees, joining coalitions with like-minded groups, and attending the annual MS Public Policy Conference in Washington D.C. To become an MS activist, please go to **nationalMSsociety.org/MSActivist.**

The Society in People Terms

Life Situation:

My wife was just diagnosed with MS, and we have many unanswered questions. Where can we go for information?

The National MS Society offers accurate information and empowering programs. *Knowledge is Power* — a free six-week educational series is a good way to begin. Sign up on our Web site or contact an MS Navigator®. Your chapter has a face-to-face educational program specifically for people who have just been diagnosed. You can also request a packet of literature. If you ask, they will help you find another person with MS to talk to.

Life Situation:

I'm so depressed. I'm at home with a newborn baby, and I just had an exacerbation. My symptoms are odd and nobody can explain them. Can you help?

The National MS Society offers referrals to physicians and allied health professionals, MS treatment centers, phone groups and peer support. Chapters have access to our national Information Resource Center, where MS Navigators are available to research difficult questions. Professionals in MS care can access our Professional Resource Center by e-mail.

Life Situation:

My MS has worsened, and I'm finding it increasingly difficult to get around the office.

The National MS Society offers information about your rights in the workplace under the Americans with Disabilities Act, information for employers, and strategies for managing symptoms and asking for accommodations.

Life Situation:

I am unable to see an appropriate specialist quickly in my managed care health group.

Call us. A Society MS Navigator® can help you determine the best course of action to advocate for your needs with your health care provider. In addition, organized volunteer advocates are working with state and federal legislators to achieve quality health care. You are invited to join.

Life Situation:

I can't cross the street in my neighborhood because there are no curb cuts.

National MS Society volunteers work to secure accessibility in our communities. Talk to your chapter's Government Relations Committee.

Life Situation:

My mother is having some memory problems, and I'm afraid that she is going to get worse..

The National MS Society offers reassuring information, self-help groups, and referrals to experts familiar with these problems.

Life Situation:

Help! My scooter is being repaired and I have no way of getting around until it's fixed.

The National MS Society offers emergency equipment loans and equipment assistance.

Life Situation:

I am so tired, and my husband doesn't understand that I'm fighting fatigue. He wonders why I don't try harder.

The National MS Society offers education about MS, referral to family counselors and community resources, and to occupational or physical therapists who may help. Many chapters have family programs that combine recreation and education.

Life Situation:

I want to start an exercise program, but I'm not sure what to do or not do.

The National MS Society offers referrals to area medical and physical therapy resources. Some chapters sponsor exercise classes and aquatics programs, or make referrals to MS-friendly programs.

Life Situation:

I want to keep up-to-date on advances in MS research and treatments.

The National MS Society supplies information on the telephone, in chapter newsletters, in brochures and pamphlets, and in the national magazine, *Momentum.* The Society's Web site is available 24/7. It carries breaking news, background facts, and live and recorded webcasts, including regular "MS Learn Online" segments, all presenting experts who help to explain MS research strategies and directions for treatment.

Life Situation:

My dad is in a wheelchair, and the kids at school think that's weird.

The National MS Society offers family programs that combine education, disability awareness, counseling and fun. Some chapters have special programs for children or teens. Our award-winning children's newsletter, *Keep S'myelin®* is available free on our Web site. The children's newsletter is also available in print from chapter offices. *When a Parent Has MS*, a publication for teens is also available online or in print.

Life Situation:

My best friend saw an MS cure on the Internet. Why don't you tell people about this?

We rely on an international board of scientific and medical experts in MS for advice about safe and effective treatments. The home page on our Web site always lists breaking news and an MS Navigator® will be able to answer questions.

Life Situation:

I am in search of an understanding neurologist who knows MS.

The National MS Society offers physician referrals and information about MS centers and clinics.

Life Situation:

Sometimes I feel so alone and would like to talk to other people who have MS.

National MS Society chapters offer more than 1,600 support groups, peer support programs and 3,000 programs to people with MS and their families annually, many of whom stay connected via the internet. We can help you connect with others. Just let us know.

MS STOPS PEOPLE FROM MOVING.

WE EXIST TO MAKE SURE IT DOESN'T.

JOIN THE MOVEMENT®.

National
Multiple Sclerosis
Society

nationalMSsociety.org

For Information:
1 800 FIGHT MS (1 800 344 4867)

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