National
Multiple Sclerosis
Society
Greater
Northwest
Chapter

2013

MS Ambassador Handbook

National MS Society

Greater Northwest Chapter

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OBJECTIVES AND PROCEDURES

MS AMBASSADOR PROGRAM OBJECTIVES

MS Ambassadors educate, engage and encourage others to join the movement and help us further our mission, which is to bring about a world free of MS.

- **Educate** the public about multiple sclerosis, the programs, services and events of the National Multiple Sclerosis Society, Greater Northwest Chapter.

- **Engage** the community as a liaison of the Greater Northwest Chapter in reaching out to further inform the public of the Society's mission, programs, services and events.

- **Encourage** participation and support for programs, services and special events.

Some examples of targeted programs or events where MS Ambassador presence is requested may include:

- Heath fairs
- Employee giving campaign fairs
- Healthcare organizations
- Programs sponsored by pharmaceutical companies
- Community groups
- Civic groups
- Academic/Service Learning fairs
- Businesses
- Advocacy events
- Walk MS
- Bike MS
- On the Move Luncheon

And more! Let us know if you hear of events in your community!

AMBASSADOR EXPECTATIONS

Ambassadors will:

- Follow all Greater Northwest Chapter's volunteer policies.
- Follow Chapter Guidelines for ambassadors in public contact or speaking roles.
- Engage people encountered in daily life about the National MS Society to raise their awareness, identify community fundraising events, and seek out community engagement opportunities.
- Connect people in need with the Greater Northwest Chapter.
- Attend Volunteer Orientation and MS Ambassador-specific trainings and teleconferences.
- Participate in MS Awareness Week activities in March.
- Dress appropriately for engagements.
- Demonstrate professional demeanor before, during, and after presentation.
- E-mail is our exclusive mode of communication; if you do NOT have e-mail, please see or call Lauren or Cara.
- Make immediate phone contact with Lauren or Cara if you find you cannot attend an engagement to which you have committed.
- Be willing to do preparation work for engagements.
- Be willing to accept coaching from a more experienced MS Ambassador or staff member.

CONTACT INFORMATION

Volunteer Manager: Lauren Spero
lauren.spero@nmss.org
800-344-4867, press 2, then ext. 40241

Volunteer Coordinator: Cara Chamberlin
cara.chamberlin@nmss.org
800-344-4867, press 2, then ext. 40205

WHAT CAN I DO IN MY COMMUNITY?

1. Hang posters for an upcoming National MS Society event! Let's plaster our communities with information on Walk and Bike MS since they are the rallying point of the MS movement! Contact Lauren at lauren.spero@nmss.org to request your posters.
2. Host an informational booth at your local farmers market or grocery store! Just call the manager of your local grocery store and ask if you can have a table with information and resources on multiple sclerosis. Most local businesses will welcome and encourage your involvement! If you get the "green light", contact Lauren Spero at lauren.spero@nmss.org for more information on brochures, materials, and other table displays the Chapter can provide.
3. Re-post this great awareness video to your personal Facebook page: http://www.youtube.com/watch?v=KgaHw_6uvYU
4. Visit **Facebook.com/MSnorthwest.org** and become a fan of the Greater Northwest Chapter on Facebook. Then, share updates that interest you on your own newsfeed!
5. Share your story through the Chapter's StoryBank project. Visit **MSnorthwest.org** and select **Volunteer/The Storybank**
6. Find and connect with a Self Help Group in your area by visiting **selfhelpgroups.MSnorthwest.org**. If you are interested in visiting the Self Help Group in your area to promote the Chapter, contact Lauren at lauren.spero@nmss.org. Or, if a Self Help Group does not currently exist in your community consider starting one! Email Gregg at gregg.robinson@nmss.org for more information on starting a Self Help Group.
7. Interested in putting together your own MS education program in your community? We can provide guidance, tips and help with promotion of your event! Contact Piper at piper.reynolds@nmss.org to learn more about the possibilities!
8. Talk to your neurologist and encourage them to display National MS Society materials and to get connected with the Chapter. Contact Lauren at lauren.spero@nmss.org to request posters and other display items.
9. Reach out to your state and federal representatives and share your story to let them know how legislation affects you and others in the MS Community. Sign up for Action Alerts to stay informed of our Advocacy efforts at **MSnorthwest.org** and select **Advocacy.**
10. Invite a friend to coffee and tell them about the National MS Society and your involvement with the Chapter!
11. Bookmark the Chapter's Calendar of Events page at **calendar.MSnorthwest.org** to keep track of upcoming Chapter activities.
12. Do something to generate awareness during **MS Awareness Week** (March 11-15) or for **World MS Day** on May 29.
13. Visit **MSconnection.org** and share with others whose lives are affected by MS.
14. Join the **NOW Research Revolution** and help the National MS Society reach its goal of raising $250 million for MS research by the end of 2015. Become an MS Research Champion at **nationalMSsociety.org/research**.

Become an advocate for public policy issues affecting people living with MS. Visit MSnorthwest.org and click on Advocacy for more information.

NATIONAL MS SOCIETY CORE VALUES

As an organization whose vision is to **create a world free of multiple sclerosis**, the Society strives to live by a set of core values which guide our work and our actions on a daily basis.

- **Commitment**
  We are passionate in our commitment to people affected by MS. We strive to improve quality of life while searching for the cure.

- **Leadership**
  We are leaders in the vision of a world free of MS. Through creativity and hard work, we accelerate the pace of scientific discovery, promote quality health care, stimulate community resources and services, advocate for favorable government policies, and are the world's best source of information about multiple sclerosis.

- **Integrity**
  We are honest and straightforward in all that we do. We treat everyone with dignity and respect. We act responsibly with resources entrusted to us. We are accountable and act in accordance with these values.

- **Excellence**
  We set high standards of performance and service delivery, and work toward excellence in everything we do.

- **Teamwork**
  We advance the interests of people affected by multiple sclerosis through individual and team achievements. We recognize our ambassadors and staff as our most valued resources. We encourage collaboration across organizational boundaries.

GREATER NORTHWEST CHAPTER OF THE NATIONAL MS SOCIETY

FACT SHEET

VISION

A world free of MS.

MISSION

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

WHO WE ARE

Our Chapter serves over 12,000 people living with MS and more than 72,000 others whose lives are directly impacted (family members, friends, co-workers and caregivers) in Alaska, Montana, Western and Central Washington.

WHAT IS MS?

Multiple Sclerosis (MS) is a chronic, often disabling, unpredictable neurological disease that affects the central nervous system (brain and spinal cord). It is an elusive disease with no known cause or cure. Symptoms vary from person to person depending on where the central nervous system is affected, making it hard to diagnose. MS is considered a prime-of-life disease. Most people with MS are diagnosed between the ages of 20 and 50, with more than twice as many women as men being diagnosed with the disease. MS affects an estimated 400,000 people in the United States and every hour, someone is newly diagnosed with MS.

SYMPTOMS

Some of the common symptoms of MS include:

- Balance and Gait Issues
- Fatigue
- Vertigo and Dizziness
- Cognitive Sensory Problems
- Tremors
- Visual Impairment

MS IN THE NORTHWEST

The Northwest has a higher incidence of MS than most anywhere on earth. Worldwide, MS occurs with much greater frequency above 40° latitude than closer to the equator. Throughout the Greater Northwest Chapter territory, approximately 180 per 100,000 people live with the disease.

WHAT WE DO

We fund MS research for better treatments and a cure. We educate and support those newly diagnosed with MS. We connect people to programs and services that improve the body, mind and spirit, social opportunities and scholarships that support families, care management to increase independence, financial assistance for help in a time of need, and advocate to improve the quality of life for people with MS. We partner with health care professionals to enhance quality of care and increase access to care for people with MS.

- Resources & Referrals
- Educational Opportunities
- Connections Programs
- Financial Assistance
- Self Advocacy & Care Management
- Local, State & Federal Political Advocacy
- National MS Research
- Local & Regional Fundraising Events
- Build MS Awareness
- Volunteer Opportunities

PROGRESS

While the cause and cure is not yet known, it is the subject of worldwide research. Currently, the National MS Society is spending nearly $40 million for 325 MS investigations.

WHERE THE DOLLARS GO

- 57% Local Programs and Services
- 18% Fundraising and Admin
- 22% Research
- 3% Reserve for future years
- It costs us 18 cents to raise $1. The industry standard is 25 cents.

CONTACT

MSnorthwest.org **800-344-4867**

LOCATIONS

Seattle Office
192 Nickerson Street
Suite 100
Seattle, WA 98109
206-284-4254

Anchorage Office
3831 Piper Street
Suite 410
Anchorage, AK 99508
907-562-7347

Billings Office
2047 Broadwater
Suite 2
Billings, MT 59102
406-252-5927

CHAPTER HISTORY

National MS Society
Sylvia Lawry founded the National Multiple Sclerosis Society in 1946 after her younger brother, Bernard, was diagnosed with the disease. In her quest for a cure for MS, she placed an ad in The New York Times stating "Multiple Sclerosis: Will anyone recovered from it please communicate with patient." When the more than 50 replies she received were from individuals as desperate as she to find encouraging news about MS, Lawry realized the need for an organized effort to stimulate and finance research into the cure, treatment, and cause of multiple sclerosis. The result was that on March 11, 1946, Lawry gathered 20 of the nation's most prominent research scientists and founded what would become the National MS Society.

National MS Society, Greater Northwest Chapter
In 1958, the first office in Western Washington opened in Tacoma and served the Pierce County community. Four years later, in 1962, another office opened in Seattle that covered ten counties throughout the Puget Sound area. In 1974, our organization expanded to cover Eastern Washington, opening an office in Yakima that covered five counties in Central Washington. In 1998, to better serve our client community, the offices were combined to form the Greater Washington Chapter, representing over 9,000 people with MS and more than 50,000 others whose lives are directly impacted in 23 counties throughout Western and Central Washington.

Building on the goal of making life better for people with MS, the Greater Washington Chapter merged in 2008 with the Multiple Sclerosis Association of King County (MSA) in a joint effort to serve this goal even more successfully. The MSA – a source of counseling and care management services for people with MS since 1956 – brought a long history of service to add to an even greater foundation of programs and services provided by the Greater Washington Chapter.

By 2010, the Greater Washington Chapter experienced even greater expansion in part to a regionalization effort across all Chapters of the National MS Society. The regionalization of Chapters has made it possible to better integrate the success of leading Chapters throughout all areas of the realigned regions, ensuring that all people living with MS have the same access to excellent programs and services.

As a result, the Greater Washington Chapter and the Alaska office of the All-America Chapter united in January of 2010 to become the Greater Northwest Chapter. Then, in October 2010 the Greater Northwest Chapter united with the Montana office of the All-America Chapter.

The newly expanded Greater Northwest Chapter is headquartered in Seattle, and has offices in Anchorage and Billings and now serves over 12,000 people living with MS and more than 72,000 others including friends, caregivers and health care professionals throughout Alaska, Montana, Western and Central Washington.

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

PROGRAMS & SERVICES

In a region where MS is more prevalent than almost anywhere else on earth, the Greater Northwest Chapter offers an extensive variety of programs, services and resources **for people living with MS, including family members, caregivers and other members of their support systems.** All of these programs and services are available across our chapter community including Alaska, Montana and 23-counties in Western and Central Washington.

The following is an overview of the programs and services provided through the Society.

MS Navigator®
Finding answers and making decisions relies on having the right information at the right time. The Society's MS Navigator® program provides people with MS answers to questions and access to information about available options. MS Navigators are partners – they can spend time problem solving, create plans for making critical decisions, deal with crises and can help people affected by MS find what they need to maintain their independence. Whatever the issue, an MS Navigator can help – just in time.

Publications
More than 60 booklets and brochures are available to people with MS and their families. Categories include General Information, Newly Diagnosed, Employment Issues, Staying Well, Managing Specific Problems, Managing Major Changes, and For Children & Teenagers. Publications, including many in Spanish, are available online or by request at 800-344-4867 or contactusnmss@nmss.org.

Connection Programs
The National MS Society helps people living with MS connect with others to share experiences and provide support. Connection programs include traditional, in-person self-help groups, peer-to-peer support, online communities and other means of bringing people together.

Education Programs
The Society provides a variety of education programs on the most up-to-date and relevant information about MS. Whether it's learning how to apply meaningful communication techniques with a loved one, gaining a better understanding of what the science is behind the latest research or simply brushing up on the latest therapies – we have something for everyone. Programs are delivered in a variety of formats – over the phone from the comfort of your home, in person, and online.

Healthy Living
Our healthy living programs help maximize physical health and general well-being, while also providing avenues for friendship, information and encouragement. We maintain a comprehensive list of community physical activity and wellness resources throughout our tri-state area, identified as fully accessible and experienced in working with chronic illness/disability. Call 800-344-4867 to find a program in your area. Wellness Grants may also be available to help with cost when needed.

Scholarships
The Society's Scholarship Program helps highly qualified students who have been diagnosed with MS, or who have a parent with MS, achieve their dreams of going to college.

Financial Assistance
The cost of living with MS can be a tremendous stress on both the person with MS, as well as their families. The financial assistance program provides short-term financial assistance that supports independence, safety, health and quality of life. MS Navigators offer guidance throughout the process by leveraging resources to help contain the financial impact of MS.

Financial Planning, Health Insurance Support, Access to Benefits
We partner with professionals to provide financial counseling and education services; guidance, understanding and evaluation of health care coverage options and rights; as well as access to professionals who can guide people living with MS who need help applying for SSDI for the first time, or appealing a denial later in the process – all free of charge!

Employment Consultation
Employment issues such as managing stress and MS symptoms at work, how to deal with discrimination on the job or seeking a reasonable accommodation are common among people living with MS. Our Employment Consultation Team consists of vocational specialists with an MS focus who provide professional guidance on employment challenges.

Care Management
Through the Chapter's Care Management programs, support is provided to individuals with MS and their families who are experiencing serious emotional, physical and/or financial challenges. MS Navigators connect individuals and families to knowledgeable and compassionate social workers who work with them to determine needs, then create and implement a personalized plan.

Professional Outreach & Education
It is critical that medical professionals have access to the most recent and accurate research, treatment options and data about MS. The Society makes it a priority to partner with and educate healthcare professionals, including neurologists, rehabilitation and mental health providers as well as long-term care facility staff.

Local, State and Federal Activism
Society advocacy efforts empower the MS community to be heard by their elected officials and play an integral part in shaping legislation that affects people living with MS. There are a number of easy ways to get involved, that all provide the opportunity to make a difference in the lives of those in the MS community.

To learn more or to access any of these programs and services,
call 800-344-4867 or visit www.MSnorthwest.org

FUNDRAISING

Walk MS is the rallying point of the MS movement; a community together to raise funds and celebrate hope for the future. Walk MS participants, teams, sponsors and volunteers have joined the movement with a shared determination to create a world free of MS. In 2012 alone, over **10,500** Greater Northwest Walk MS participants rallied together to raise over **$1.9 million dollars**.

Learn more at **walkMSnorthwest.org.**

Washington
4.13.13 Bainbridge Island
4.13.13 Bellingham
4.13.13 Olympia
4.13.13 Tri-Cities
4.13.13 Snohomish County
4.13.13 Kitsap County
4.13.13 South Sound
4.14.13 Seattle

Montana
5.04.13 Billings
5.05.13 Bozeman
5.11.13 Great Falls
5.11.13 Helena
5.12.13 Missoula

Alaska
5.04.13 Fairbanks
5.11.13 Anchorage
5.18.13 Copper Valley
5.18.13 Ketchikan
5.18.13 Soldotna
5.18.13 Wasilla

walk MS
walk to create a world free of MS

Bike MS is the premier cycling series in the nation for those seeking a personal challenge and a world free of MS. The Greater Northwest Chapter offers three fully-supported rides throughout the Chapter's territory, each featuring gorgeous scenic views, various route options and a weekend of fun, fitness and entertainment. Last year, approximately **2,250** cyclists and virtual riders throughout the Greater Northwest Chapter raised over **$1.9 million dollars** to help fund vital MS research, as well as essential local programs and services for those affected by MS.

bike MS
bike to create a world free of MS

Learn more at **bikeMSnorthwest.org.**

Washington
9.7-8.13 Mt. Vernon

Montana
8.17-18.13 Billings

Alaska
9.7-8.13 Girdwood

MS Rockstars train, fundraise and run a half-marathon, or half marathon relay, all in the name of creating a world free of MS. Learn more at **MSrockstars.com**.

1.20.13 Arizona (Regional Event)

MS Rockstars

Challenge Walk MS is an inspiring weekend full of fun and camaraderie , as over 200 walkers unite for 3 days and 50 miles with the unified goal of ending MS.

Date TBD Southern California (Regional Event)

challenge walk MS

THE DINNER OF CHAMPIONS is the Chapter's premier gala event honoring local philanthropists who have made a significant contribution to the fight against multiple sclerosis.

The Dinner is an elegant evening, featuring a five-course fine dining experience, entertainment, and the presentation of the prestigious **Hope Award** and **Spirit Award** to local individuals who are making a significant impact in the lives of people with MS.

Grand Hyatt Seattle – May 4, 2013

ON THE MOVE LUNCHEONS in South Sound and Seattle bring together nearly 1,000 business and community leaders to raise awareness of multiple sclerosis, educate a broad audience, and raise funds to support Chapter programs and MS research.

Seattle On the Move Luncheon:
2013 date and location TBD

South Sound On the Move Luncheon:
2013 date and location TBD

Learn more at **luncheon.MSnorthwest.org**

GOLDEN CIRCLE donors lead the way in the MS movement by providing ongoing support of Chapter initiatives through annual gifts of $1,000 or greater. Golden Circle members enjoy:

- Access to Chapter and national leadership
- Invitations to exclusive local and national special events
- Invitations to National conference calls to hear the latest progress in MS research directly from world-renowned scientists, and to pose questions directly to the scientists on the calls
- The opportunity to connect with other Golden Circle members – people who share a passion for a world free of MS

DO IT YOURSELF (DIY) FUNDRAISING is an opportunity for people with a deep commitment to the MS cause to raise awareness and critical funds for the MS movement in new and creative ways.

Separate from the Chapter's special events, DIY fundraising allows for more creativity when making your mark against MS. Some have chosen to donate proceeds from product sales, others have hosted a fundraising party or dinner, while a few have even decided to grow a Mustache for MS! There are countless possibilities – which will you choose? Learn more at **www.nationalMSsociety.org/DIYnorthwest**

RESEARCH

THE SOCIETY'S COMMITMENT TO MS RESEARCH

With cumulative research investments totaling over $760 million, the Society supports and funds research activities spanning ALL research stages, including early discovery research, translational research that brings promising ideas forward into actual therapeutic solutions for testing, and clinical trials.

Society funding has been critical in:

- Creating tools and processes to diagnose MS more quickly and accurately
- Identifying 60 genes related to MS
- Identifying a link between vitamin D and MS risk
- Facilitating collaborative MS research in more than 20 countries
- Discovering potential for neural repair; established new scientific field
- Propelling most of the approved MS disease-modifying drugs forward
- Training 800+ researchers

NOW RESEARCH CAMPAIGN

The No Opportunity Wasted (NOW) research campaign aims to raise $250 million for MS research by 2015. This campaign will move MS research forward farther and faster than ever before. No potential solutions go unexplored, and no opportunity will be wasted.

PRIORITIES

1. **Stop Disease Progression**
2. **Restore Lost Function**
3. **End MS Forever**

Strategies that will help the Society deliver on these priorities:

- Understand mechanisms that drive MS progression and find new therapies to treat it — with an increasing focus on progressive disease.
- Discover how nerve cells are damaged and how to repair them.
- Find better rehabilitation and treatment for symptoms.
- Identify what causes MS in order to find a way to prevent it.
- Expand the quantity and quality of research worldwide to drive discovery and treatments.
- Bring more physicians, scientists and researchers to the MS Movement.

SOCIETY RESEARCH (LOCAL PROJECT)

The following research project located within the Greater Northwest Chapter territory, is currently funded by the National MS Society:

Dawn Ehde, Ph.D.
University of Washington
Research Grant 7/1/2008 to 6/30/2013 $385,876

"MS rehabilitation research fellowship program"
Providing training to postdoctoral fellows in a wide variety of MS rehabilitation research areas.

NOTE: There are currently no Society funded research projects in Alaska or Montana.

LEARN MORE

www.nationalMSsociety.org/research

GENERAL MESSAGING

COMMUNICATIONS GUIDE

The consistent and respectful messaging we use in our daily interactions helps to determine the quality of relationships we are able to form within the communities we serve. There is only one chance to make a first impression – be friendly, attentive, and responsive.

MESSAGING & LANGUAGE USAGE
It is important to speak in a consistent message and tone. Refer to Fact Sheet for reference. Logo, print items, etc. all must be reviewed prior to being disseminated.

Be consistent in name and language usage:

DO	DON'T
National Multiple Sclerosis Society, National MS Society	MS Society, NMSS
People with MS / People living with MS (our "clients")	Afflicted with MS
People with disabilities	Crippled by MS
People with a chronic illness	Victim or sufferer of MS
Those who are affected (family members, friends, employers)	MS client, MS person
Those who have the potential to help (donors, volunteers, community members, event participants)	MSer

CONFIDENTIALITY: GUIDELINES OF THE NATIONAL MS SOCIETY
Do everything you can to safeguard the confidentiality of personal information. Never disclose any information without permission, and always get signed permission to share someone's story.

DISSEMINATING MEDICAL INFORMATION
Use Society approved literature (booklets, brochures, Web site, etc.), or reiterate the Society's position. *"We recommend talking to your personal physician about what treatment is right for you. Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional or contacting the National MS Society at nationalMSsociety.org or 1-800-344-4867."*

FIELDING QUESTIONS – OUTSIDE AREA OF EXPERTISE
Regardless of role with the Chapter, it is important to respond warmly and efficiently. If you do not know the answer, it is okay to say "I'm not sure of the answer, but let me find out and get back to you."

- Convey that their interest is welcomed and appreciated.
- Provide with basic information – Walk MS, Bike MS, Chapter programs, etc.
- Connect with the staff member who can best answer their questions.

HANDLING COMPLAINTS

- Listen, empathize, get the facts, restate the situation, act, thank…
- Share with Chapter staff or a Supervisor.
- Field questions to the Information Resource Center (IRC) at 1-800-344-4867.
- It is important for each of us to make every effort to "make someone's day." Do what you can to remedy a situation – all our customers want is to receive personal attention, a positive response, and to be understood and helped.

INFORMATION AND REFERRAL

Information and Referral (I & R) refers to the role of any staff person or volunteer working within a chapter's Programs Department whose role is to provide the following to clients and other customers:

- Information and education about multiple sclerosis
- Referrals to National MS Society-sponsored programs and services
- Referrals to programs and resources in the community
- Referrals to national resources and programs
- Linkages to other chapter events or activities
- Emotional support
- Crisis-intervention
- Support for self-advocacy

The Role of the Information and Referral Process

The Information Resource Center (IRC), chapter staff, and volunteers are supporting people's efforts to manage the impact of the illness on their daily lives. National MS Society staff and volunteers are providing people with the tools, information, education, support, and resources to meet the physical, social and emotional challenges they may face.

People with MS have consistently identified information and referral as the most important client program of the National MS Society. They look to the Society to provide the most accurate, up-to-date information about the disease as well as access to vital community resources.

The National MS Society's I&R process is designed to help our clients and other customers:

- **Today:** by providing access to the information and services they need
- **Tomorrow:** by helping chapters (and the organization as a whole) to recognize gaps or weaknesses in today's programs and services so that they can be fine-tuned and expanded for the future

It is important to remember that contact with an I&R provider or volunteer may well be the community member's first impression of the National MS Society. This is a critical opportunity for initiating a positive relationship between the community member and the National MS Society and forging a lasting and mutually beneficial connection. In meeting the needs of our clients and other customers for quality information and referral services, we are also cultivating potential volunteers, donors, and event participants who are so essential to our mission.

Providing Information: Policies of the National Multiple Sclerosis Society

Provision of information about scientific and medical matters is central to the mission of the organization. In 1985 and 1986, the policies and procedures of the National MS Society concerning provision of medical and scientific information were reviewed by a task force of the National Board of Directors. The recommendations made by the task force, and approved by the board, serve as guidelines for the provision of medical or scientific information. These guidelines, as listed below, apply whether the information is provided verbally or by email, telephone, letter, published articles, media contact, or any other form of communication.

- Information produced by the National MS Society is accurate and up-to-date.
- All information that is relevant to disease management or the treatment of people with multiple sclerosis has been reviewed by members of the National MS Society Medical Advisory Board (MAB), a national committee of medical professionals that sets organizational standards.
- All customers of the National MS Society have access to the same information, provided in a standardized, verbal or printed format.
- High standards for accuracy, completeness, fairness, and objectivity in the production and publication of information and opinion protect the national MS Society and its individual staff and volunteers from the possibility of liability.

The National MS Society policy on the provision of medical information is as follows:

1. Staff and volunteers must be aware at all times of the risks of legal liability of the National MS Society. Adhering to the Society's policies and procedures on provision of medical information will reduce the risk of litigation against the National MS Society or any of our staff and volunteers.
2. The National MS Society provides information and evaluation of scientific and medical matters for its customers as soon as such information and evaluation is supported by publically available data and reviewed by appropriate staff and medical and scientific advisors.
3. While acting in the role of National MS Society staff or volunteer, no person, regardless of qualifications or personal experience, should provide information that could be interpreted as medical advice. This is true whether the staff person or volunteer is giving that information to a person with multiple sclerosis, family members of a person who has multiple sclerosis, or a member of the general public. Any information provided to a person with MS, family member or the general public should:
    a. Come directly from MSIR or the Society's website (www.nationalmssociety.org)
    b. Be made available in printed form as well as orally
    c. Include the request that it be discussed with his or her physician
    d. Be mailed only to the person who has requested it. For reasons of privacy and confidentiality, no printed materials should be sent to another person (individual with MS or family member) at the request of the caller
4. National MS Society staff and volunteers do not give personal interpretations or elaboration of information presented, and must always request that individuals consult their own physicians regarding their medical care and treatment. It is particularly important that staff members and volunteers with MS refrain from giving personal opinions based on their own history, symptoms, or treatments.
5. The medical information given to customers should be limited to that which has been provided to chapters by the home office or in MSIR. When confronted with a question that cannot be answered using this search engine, the I&R provider should consult the Information Resource Center (IRC) by e-mail (generalmailbox@nmss.org) or by phone at 1-800-344-4867.

6. Staff and volunteers must be careful to obtain professional opinion and advice—from the chapter's CAC or the home office—on all matters to be brought to the attention of the public. For example, the following materials/resources need to be reviewed by the CAC before being given to the public:

    a. Chapter newsletter articles pertaining to MS, prior to mailing
    b. Publications and videos in the lending library
    c. Educational materials that have not been reviewed by the home office
    d. Medical resources in the Community Resource File

7. For any controversial issues concerning therapeutic intervention or the clinical management of people with multiple sclerosis, National MS Society staff and volunteers must either contact the IRC or solicit the advice of the Professional Resource Center (1-866-MS-TREAT or healthprof_infor@nmss.org). In matters concerning the significance of new scientific findings, contact the IRC or the Research and Clinical Programs Department at (212-986-3240).
8. When staff members and volunteers convey information orally (e.g. by telephone call, public presentation, or press interview) rather than in written form, they run an increased risk of being misunderstood/misquoted. It is essential that particular care be taken in the methods used to present oral information.
9. Any printed information that is given to people with MS, family members, health professionals, or the general public must include the National MS Society's Disclaimer Statement. This is particularly important for materials pertaining to medical or research information.

THE INFORMATION AND REFERRAL PROVIDER WHO HAS MS

How Your MS Affects Your Role as an I&R Provider

Your personal experience with MS gives you a special empathy for our clients. You share with them some feelings and challenges that the rest of us can never completely understand. At the same time, your own experiences can sometimes interfere with your ability to be objective about the clients' situation and needs. It is critically important that you, as an I&R provider, be able to establish and maintain appropriate boundaries between yourself and the clients you serve. These boundaries will help to ensure that the information and referrals you provide address the clients' needs and priorities rather than your own.

Since no two people with MS are exactly alike, and no two cases of MS are exactly the same, your symptoms, treatments, and coping mechanisms are your own—and perhaps very different from those of the clients who call you. Therefore, your task as an I&R provider is to use the designated resources available to you to provide accurate, up-to-date information about MS and appropriate referrals. Sharing information about your own MS is not necessary, and may not even be beneficial to your clients. In any given situation, you will need to decide whether it is appropriate or helpful to disclose your own diagnosis.

The Question of Disclosure

In most situations, there is no need to volunteer the information that you have MS. In the event that someone you are speaking with asks whether you have MS, you are free to decide how you want to answer the question. The important thing to remember is that your role is not to talk about you, but to talk about whatever the person's questions or concerns might be. If the person you are talking to tries to find out what kinds of symptoms or treatments you have had, you will need to remind him or her that everyone's MS is different and then offer to give the person information from MSIR about the specific symptoms and/or treatments in question.

For example, someone may approach your outreach booth and want to know if you are on one of the disease-modifying agents and, if so, which one. If you, as an I&R provider representing the National MS Society, tell the person which medication you are taking, that information may be seen as an endorsement by the Society of that particular drug. You should therefore refrain from giving any information about your own treatment that might be taken to be a recommendation, endorsement, or advertisement. You should respond to this kind of question by saying, "It really doesn't matter whether I am taking one of the drugs or which one since your MS and mine may be very different. You need to make this decision with your physician. I would be happy to tell you about the treatments that have been approved in MS and send you information about them if you would like."

Compensating When MS Symptoms Interfere with Your Activities

As a result of MS, you may experience one or another kind of physical or cognitive challenge that interferes with your work and/or comfort in the chapter office. You might find, for example, that it is difficult for you to maneuver your way around the office, hold on to a telephone, handle printed materials, or manipulate a pen or keyboard. Or, you may have difficulty remembering what a potential client has said to you, navigating through MSIR, or making referral selections for a particular client. You may find that all of these become more difficult when you are tired or upset.

Your role as an information and referral provider for the National MS Society is a significant one. Here are some suggestions for ways to enhance your comfort and effectiveness in that role:

- Self-monitor; don't wait for someone else to identify a problem.
- Discuss any problems you are having with your mentor or supervisor. He or she can problem-solve with you to find solutions.
- If you experience significant fatigue as a result of your MS, arrange a work schedule that allows for rest periods. You will be more effective in your job if you don't try to push yourself beyond your limits.

TOP TEN TALKING POINTS

1. **The cause of multiple sclerosis (MS) is unknown and there is no cure.**
2. Approximately 2.1 million people worldwide are estimated to be living with MS, including more than 12,000 people served by the Greater Northwest Chapter in Alaska, Montana, Central and Western Washington.
3. MS is a chronic disease that attacks the central nervous system, which is made up of the brain, spinal cord, and optic nerves. The progress, severity and symptoms of MS are unpredictable and vary from one person to another.
4. Effective strategies for some are available to modify the disease course, treat exacerbations, manage symptoms, improve function and safety, and provide emotional support. There are also currently nine FDA-approved disease modifying therapies, including two oral medications, on the market.
5. The Society's vision is a world free of MS. The Society's mission is to mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS.
6. The Society addresses the challenges of each person affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, collaborating with MS organizations around the world, and providing programs and services designed to help people with MS and their families move forward with their lives.
7. The Society's bold NOW (No Opportunity Wasted) research initiative aims to STOP disease progression, RESTORE function that has already been lost, and END MS forever.
8. Volunteers are the cornerstone of the MS Movement. In 2012 alone, over 1,400 committed volunteers throughout the Greater Northwest Chapter territory logged an impressive 17,000 volunteer hours to help fulfill the mission of the Society.
9. The Greater Northwest Chapter hosts four signature fundraising events throughout the year; Walk MS and Dinner of Champions in the spring, Bike MS in late summer and the On the Move Luncheon during the fall. These events bring thousands of people together to have fun, celebrate successes large and small, build a caring community and raise money for programs, services and research.
10. As efficient, effective stewards of our donors' contributions, the Greater Northwest Chapter makes sure that 78 cents of every dollar raised goes directly to support Society programs, services and research.

GENERAL TIPS FOR PUBLIC SPEAKING

1. Arrive early to your event, so that you can set up any equipment or handouts that you are using and learn how the microphone works. Getting used to the space will allow you to relax. It is also important to use this time to meet some of the people you will be speaking to and glean information. It will both allow you feel more at ease and it will allow you to make the talk more specific to that group.

2. You may make mistakes, but don't let it get you down! No one but you knows that you had three points to make, not just two. Remember that you will know much more about your topic than most of the audience and often they will not even realize when you've made a mistake.

3. Be yourself. You'll feel more comfortable if you share your personality and perspective with the audience. They will respond to your sincerity.

4. Your talk is more than what you say. It's how you say it, and what your body reveals about your feelings about the topic. Consider practicing your delivery to a chair and in front of a mirror. This may give you ideas about how to emphasize important points in your speech or to minimize fidgeting or other habits that can distract from your message.

5. Your audience will begin forming its impression of you from the moment they realize that you are there to speak to them. Carry yourself the way you want to be perceived, even before you begin to speak.

6. You have a right to be comfortable as you speak and have every possible opportunity for the audience to absorb your message. Don't be afraid to adjust microphones or other equipment for your comfort, or to have blinds or doors closed, etc., if it will enhance your effectiveness.

7. Speak as clearly as possible.

8. Make eye contact with one person at a time and move around the room to include everyone in the remarks you are making.

9. Large audiences may intimidate even the most experienced speakers. It is natural to feel nervousness. Use the skills you learn in training to manage the nervous energy so does not detract from your message.

TIPS FOR EFFECTIVE COMMUNICATION

Communication skills are essential in the helping process. They enable the helper not only to hear the words the client is saying, but to understand the client's perspective. Communication skills also make it possible for the helper to respond in ways that the client can understand and utilize. In other words, it takes practice to listen in a way that allows the client to talk, and to talk in a way that makes it easier for the client to listen.

Active Listening

Active listening involves listening to and gaining an understanding of. . .

a. the thoughts behind the words people use
b. the relationship between people's feelings and actions; and
c. the person in the context of his or her unique situation. The following six principles are essential to this kind of listening:

1. **Empathy vs. Sympathy**
   Sympathy implies a "put down" or silently saying to yourself, "Thank goodness it isn't me." Empathy implies that you understand the client and can say to yourself, "I understand this person's perspective."

2. **Universality of Feelings**
   We all have felt pain, fear, anger, etc. at some time in our lives. Even if we cannot readily identify with the caller's specific problem, the specifics of the problem are often less important than the feelings about the problem.

3. **Problem Ownership**
   Remember that the client "owns" the problem, not you. It is not your job to solve the problem, but rather to offer the client tools with which to solve it him- or herself.

4. **Listening for Feelings**
   In order to build trust with a client, you must convey that you understand what he or she might be feeling. Statements like, "I know you're scared right now..." or "I'm sure this is very frustrating for you..." let the client know you have some understanding of the situation and encourage further clarification.

5. **Listening for Values**
   When listening to the client, try to figure out what is of value to him or her. People usually worry about things that are important to them—which they feel threatened about losing. Paying attention to these values can help you identify helpful options and resources for them to pursue.

6. **Non-judgmental Attitude**
   Try to remember that feelings expressed by clients are neither right nor wrong—they are just feelings.

TIPS FOR ANSWERING QUESTIONS

- Listen. Make sure that you understand the question before you begin answering it. Ask for clarification if you need it.
- Focus on the questioner when listening, but when you respond speak to the whole group.
- Begin your response with a paraphrasing of the question, so that others who may not have heard understand the context of your remarks.
- Consider your response before "jumping in" with the answer. If you don't know the answer to all or part of the question, it is best to say so. If you do this, tell the questioner what steps you will take to give them the answer (e.g., refer them to the chapter or the Information and Referral Center (IRC), get their phone number to call them at a later time).
- Be as direct as possible. Begin with the bottom line when possible (e.g., "No. And here's why:"). Avoid giving more detail than was requested.
- Don't promise anything you can't deliver.
- Check to see if questioner understands the answer you have given.

POLICIES FOR VOLUNTEERS IN COMMUNITY OUTREACH ROLES

Remember that you're representing the National MS Society.

Opinions that you express can be interpreted as the stance of the agency. Your choice of words, the way you dress and your demeanor will influence the community's view of the Society.

Provide a balanced view of the realities of multiple sclerosis.

We don't want members of the public to believe that people with MS have nothing left to contribute; on the other hand, you don't want to downplay the effects of the disease to the point that the importance of the Society's mission is lost.

Do not give medical opinions.

Unless you have the required medical credentials, you are not qualified to recommend treatments. Be open about this if you are asked a question that you should not answer. "That's a very good question and the answer may be different for each person. That type of thing is best discussed with your personal physician."

Be careful what you say about non-FDA approved or "alternative" therapies.

If you are asked about anything from bee venom to bone marrow transplant, the best answer is something like, "Many treatments are being studied but presently lack data to support therapeutic claims. Again, it's best to consult a personal physician before exploring treatment options."

Make sure that you do not violate anyone's right to confidentiality.

If you are going to draw from a particular person's experience, make sure that you have their permission to do this. If you do not obtain the person's permission, change their name and obscure the facts enough to ensure privacy. (Mary who is 35 with 3 children can just as easily be introduced as Lucy, aged 37, with 4 children.)

LIKELY SCENARIOS FOR MS AMBASSADORS

In this section you'll see how to use the Top Ten talking points, facts and ideas for talking about MS and the MS Society. Plus, you'll find tips for how to be a good ambassador for the organization while you're at events held in the community.

These are the scenarios you may run into as a volunteer working at a booth at community events. Consider these as suggestions for how to handle the scenario. In each case you may be able to provide unique stories or suggestions to the visitor.

Scenario 1: (connection to MS and participant)

- YOU: Hi, How are you? Are you familiar with MS or the MS Society?
- VISITOR: Yes, my sister-in-law has MS.
- YOU: Is she connected with the MS Society? We have a lot of programs and services for people with MS.
- VISITOR: I'm not sure. I think maybe she is.
- YOU: Well, if you're interested in learning more about the programs we offer people with MS. She might be interested in learning more about them as well.
- VISITOR: Thanks.
- YOU: You're welcome. Do you have any questions about the disease?
- VISITOR: I don't think so. I do the Walk every year and am on your e-mail list.
- YOU: Oh, that's great! Thanks for doing the walk. We have our date set for next year. Here, take one of our brochures on Walk MS. It has information if you're interested in participating in or volunteering for one.
- VISITOR: Great! Thanks.
- YOU: Thank YOU for all you do to bring us closer to a world free of MS. And thanks for stopping by!

Scenario 2: (no connection or knowledge of MS)

- YOU: Hi! Are you familiar with MS or know anyone who has it?
- VISITOR: No. What is it?
- YOU: MS is a disease that affects the central nervous system, which is the brain, spinal cord and optic nerve. It interrupts the flow of information from the brain to the rest of the body.
- VISITOR: Oh is that the disease where people can't walk?
- YOU: Yeah, sometimes. Symptoms are different for everyone depending on where the damage is in the nervous system and how progressed the disease is. They can range from numbness and tingling to paralysis and blindness.
- VISITOR: Why does this happen? Is there a cure?
- YOU: We don't know for sure what causes it and there is no cure. There is a lot of research going on right now looking at what causes MS, how we can prevent it from happening and how we can slow down some of the damage that has already occurred.
- VISITOR: Cool.
- YOU: Here is a brochure that will help you understand a little more about MS. Oh, and here is a list of all the fun events that we hold to raise money for research and programs to help people. You should check them out!
- VISITOR: Alright.
- YOU: Oh, and here! Have a pencil!
- VISITOR: Cool thanks.
- YOU: Thanks for stopping by!

Scenario 3: (person with MS)

- YOU: Hi!
- VISITOR: Hi, I just wanted to stop by to say I have MS and thank you for being here.
- YOU: Oh, it's our pleasure.
- VISITOR: I was diagnosed 8 years ago and I do the Walk and also volunteer for the bike ride.
- YOU: Well we are glad you've been so involved with us. We have lots of other great ways you can get involved and share your story.
- VISITOR: What do you mean share my story?
- YOU: Well everyone affected by MS has a unique story that is important. The MS Society has opportunities for you to use your personal story to raise awareness in your community, help create change at the Capitol and lots more.
- VISITOR: Oh, I don't think I'd be good at that.
- YOU: Well I think you should consider it. Here – this is our volunteer brochure with lots of simple ways to make changes in your community. Also, here is some information about our Speakers Bureau program. This is a great way to get the inside scoop on stuff that's happening at the MS Society, tips for telling your story and fun ways to get more involved with the chapter.
- VISITOR: Ok thanks. I'll think about it.
- YOU: You definitely should. And if you have questions, you can call the National MS Society. Tell her you stopped by the Society booth.
- VISITOR: Ok. Well thanks.
- YOU: Thank YOU! Have a wonderful day

Scenario 4: (person interested in research)

- YOU: Hi. Are you familiar with MS or know anyone with the disease?
- VISITOR: I'm familiar with it, but I don't think I know anyone with it. MS is the one that affects the nervous system, right?
- YOU: Yes you're correct. It damages the insulation around the nerves and makes it difficult for the brain to send messages to the body.
- VISITOR: Yeah, so what's the status on research? Have they found a cure yet?
- YOU: They haven't found a cure yet, but there is some exciting research happening that is leading to new treatments and a better understanding of how to prevent damage to the nervous system.
- VISITOR: What kind of treatments?
- YOU: Currently there are six treatments to slow the progression of the disease. And all of them are injections. Right now there is a pill that looks promising. The FDA approved it in the fall of 2010.
- VISITOR: Well that's great!
- YOU: Yes, there is so much exciting research happening to investigate the cause of and cure for MS. Here – these are a couple of the latest research studies if you're interested in learning more. Plus, the MS Connection newsletter has some great research news in it.
- VISITOR: Great!
- YOU: Do you have any other questions about MS?
- VISITOR: Nope. I don't think so. Keep up the great work you're doing. This is a great cause.
- YOU: Thanks for stopping by!

Scenario 5: (someone facing a new diagnosis)

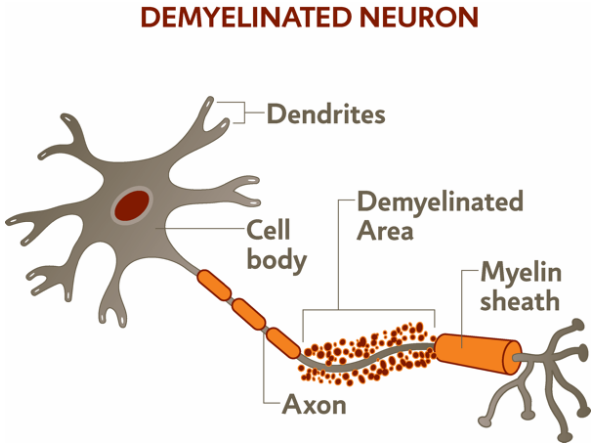
- YOU: Hi. How are you? Are you familiar with MS?
- VISITOR: Yeah I am actually. I was just diagnosed a couple months ago.
- YOU: I'm sorry to hear that. Have you reached out to the MS Society yet?
- VISITOR: No, I've kinda not wanted to deal with it.

- YOU: Well one of the best things you can do it get connected with us. We have tons of programs, support and activities. We have MS Navigators that can help people with MS find resources and answer questions. If you'd like to write down your contact information we can have one of them call you.
- VISITOR: That would be great, actually.
- YOU: Plus, they can tell you about other great things that our chapter offers like newsletters, special events, activism, volunteer opportunities, and much more!
- VISITOR: Well I don't know how much I want to be involved yet.
- YOU: I definitely understand. If you'd like, I can offer some materials at the booth that might be interesting to you.
- VISITOR: Sure, I'd like that.
- YOU: Great! (Give the visitor materials the most pertain to his/her situation including an IRC card.) Please let us know if you have any questions or need anything. I will give your contact information to our MS Navigators and they will be in touch.
- VISITOR: I appreciate your help.
- YOU: My pleasure. Thanks so much for stopping by. It's such an important step to make.

MS 101

What is Multiple Sclerosis?

- Multiple sclerosis is a chronic, unpredictable disease of the central nervous system, which is made up of the brain, spinal cord, and optic nerves.
- Multiple sclerosis is thought to be an autoimmune disorder.
- Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision.
- The progress, severity, and symptoms of MS are unpredictable and vary from one person to another. Today, new treatments and advances in research are giving new hope to people affected by the disease.



Who Gets MS?

- As in other autoimmune diseases, MS is significantly more common (at least 2-3 times) in women than men
- Studies suggest that genetic factors make certain individuals more susceptible than others, but there is no evidence that MS is directly inherited
- MS is more common in Caucasians of northern European ancestry, but occurs in most ethnic groups, including African-Americans, Asians and Hispanics/Latinos
- Most people are diagnosed between the ages of 20 and 50, however MS can appear in young children and teens as well as older adults
- Approximately 400,000 Americans have MS, and every hour someone is newly diagnosed

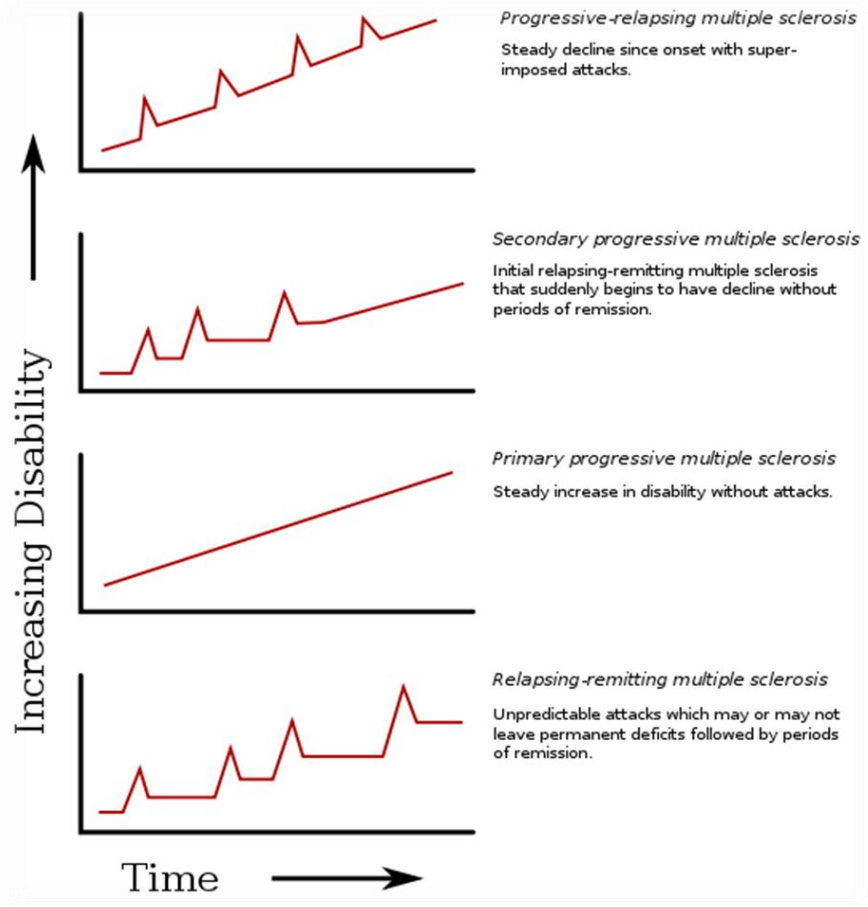
Types of MS:

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%.



Symptoms of MS:

Symptoms of MS are unpredictable; they can vary from person to person, and from time to time in the same person. Some of the most common symptoms of MS include:

- Fatigue
- Numbness
- Walking, balance and coordination problems
- Bladder and bowel dysfunction
- Vision problems
- Dizziness and vertigo
- Sexual dysfunction
- Pain
- Cognitive dysfunction
- Emotional changes
- Depression
- Spasticity

Diagnosis:

At this time, there are no symptoms, physical findings or laboratory tests that can, by themselves, determine if a person has MS. The doctor uses several strategies to determine if a person meets the long-established criteria for a diagnosis of MS and to rule out other possible causes of whatever symptoms the person is experiencing. These strategies include a careful medical history, a neurologic exam and various tests, including magnetic resonance imaging (MRI), evoked potentials (EP) and spinal fluid analysis.

In order to make a diagnosis of MS, the physician must:

a) Find evidence of damage in at least **two** areas of the central nervous system
   -AND -
b) Find evidence that the damage occurred at least one month apart
   - AND -
c) Rule out all other possible diagnoses.

Treatment:

Although there is still no cure for MS, effective strategies are available to modify the disease course, treat exacerbations, manage symptoms, improve function and safety, and provide emotional support. Some of the FDA-approved disease modifying therapies include:

- Aubagio
- Avonex
- Betaseron
- Copaxone
- Extavia
- Gilenya
- Novantrone
- Rebif
- Tysabri

MYTHS ABOUT MS

MYTH #1 **MS is fatal.**
MS is not fatal. Statistics show that most people with MS have a near normal life span. Most deaths associated with MS are due to complications in advanced, progressive stages of the disease. Effective early treatment of MS should help to prevent those complications. In very rare cases, MS is malignantly progressive and may be fatal.

MYTH #2 **Everyone with MS will be in a wheelchair sooner or later.**
This is untrue. Many people with MS remain able to walk without help. However, the likelihood of needing a mobility device increases the longer someone has MS. In addition, people who are still able to walk may use a wheelchair, cane, scooter or other device to conserve energy or prevent injury from falls. Only 25 percent of people with MS use a wheelchair or stay in bed because they are unable to walk, according to a well-designed survey completed before the new disease-modifying drugs became available.

MYTH #3 **Because there is no cure for MS, nothing can be done for those with the disease.**
Currently there is no cure for MS, but there are now FDA-approved medications that have been shown to modify or slow down the underlying course of MS. Additionally, many therapeutic and technological advances are helping people manage symptoms and lead productive lives. Advances in treating and understanding MS are made every year and progress in research to find a cure is very encouraging.

MYTH #4 **People with MS should stop working because stress will aggravate the disease.**
There is no scientific evidence that the normal stress of working has any effect on MS. But symptoms such as fatigue can cause problems on the job. Approximately 30 percent of people with MS are working full-time after 20 years. The National MS Society thinks that number could be higher and works to change the attitudes of employers and employees alike.

MYTH #5 **People with MS shouldn't have children.**
Most women with MS find their symptoms lessen during pregnancy. Then the risk of an attack rises somewhat in the first six months after delivery. Overall, pregnancy and childbirth have no long-term effect on MS.

MYTH #6 **Natural treatments are safer than prescription medications.**
Controversy continues regarding the value of alternative approaches. Advocates of alternative therapies sometimes claim that conventional medicine is ignoring or suppressing treatments that can alleviate symptoms and even cure some diseases. Conventional medicine adopts therapies that can be proven safe and effective.

MYTH #7 **Scientists aren't making much progress in the fight against MS**.
There has never been a more exciting time in MS research. Until 1992 there were no medicines that could alter the underlying disease and now there are nine approved drugs for different forms of MS. The National MS Society, the largest private funder of MS research in the world, is spending nearly $40 million on MS research each year and currently supports 325 MS research projects worldwide.

MS IN THE NORTHWEST

SUMMARY NORTHWEST

The Northwest has a higher incidence of MS than most anywhere on earth. Based on self-identifying information, our Chapter estimates there are more than 12,000 people living with multiple sclerosis in the greater Northwest area (Alaska, Montana, Western and Central Washington) and more than 72,000 people are affected by the disease (family members, caregivers, friends, health care professionals, etc.).

For unknown reasons, MS occurs with much greater frequency in higher latitudes (above 40° latitude) away from the equator, than in lower latitudes, closer to the equator. In particular, much of the Greater Northwest Chapter territory lies between the 46° and 49° parallel, therefore, has an estimated prevalence rate of 180/100,000 persons. This is in comparison to states closer to the equator such as Florida and Texas who have an estimated prevalence rate of 68/100,000 persons. (See the map "Estimated U.S. Prevalence rates", provided by the Research Dept. at the National MS Society, New York)

EPIDEMEOLOGY

Currently, a national coordinated system does not exist to collect and analyze data on MS in the United States. In order to have a more accurate account for the prevalence of MS, the Society is urging Congress to support the National Neurological Diseases Surveillance System Act (S.425/H.R. 2595). This legislation would create a centralized data collection system at the Centers for Disease Control and Prevention (CDC) that will track and collect data on the epidemiology of neurological diseases, including MS. Accurate knowledge and information about incidence and prevalence is critical to gain a better understanding of this disease. The data system could help uncover and inform promising areas of MS and other neurological disease research such as, genetic and environmental risk factors, and support the discovery of disease therapies, treatments, and one day—a cure. Additionally, because the CDC does not require U.S. physicians to report new cases, and because symptoms can be completely invisible, the numbers can only be estimated.

The last national study of incidence and prevalence of MS was conducted in 1975. That lack of core knowledge inhibits MS research, programs, and services from progressing further. The information collected through the centralized data system will provide a foundation for evaluating and understanding many MS factors such as geographic clusters of MS diagnoses, variances in the gender ratio, disease burden, and changes in health care practices. The resulting data could be used to provide consistency and coordination in addressing the disease nationwide.

CLUSTERS

Research is being conducted across the country where there are higher than average rates of MS but so far, cluster studies have not produced clear evidence for the existence of any causative or triggering factor or factors in MS. For more information on clusters, visit:

LEARN MORE

Epidemiology:
http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/who-gets-ms/epidemiology-of-ms/index.aspx

Clusters:
http://www.nationalmssociety.org/about-multiple-sclerosis/who-gets-ms/clusters/index.aspx

General:
www.MSnorthwest.org
800-344-4867

Additional Materials

National
Multiple Sclerosis
Society
Greater
Northwest
Chapter

Volunteer Job Description

TITLE: MS Ambassador
DEPARTMENT: Community Relations
REPORTS TO: Lauren Spero, Volunteer Manager

JOB SUMMARY:

Our mission at the National MS Society is to mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS. We keep our communities moving forward by breaking down barriers and providing opportunities so that everyone who wants to do something about MS can contribute.

MS Ambassadors expertly represent the Society's movement for a world free of MS by mobilizing the community and increasing public understanding, awareness and education of MS.

More specifically, MS Ambassadors will be responsible for:

- Educating the general public and internal audiences about MS, the Society and Chapter activities by participating in local health fairs, visiting community/civic groups, public speaking opportunities, and media appearances
- Attending Chapter programs, fundraising events, and team fundraisers/kick-offs to talk about the Society and Greater Northwest Chapter
- Advocating locally and nationally for issues that impact the MS community
- Recruit new volunteers, clients, and participants for Chapter activities

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IMPACT:

As spokespeople for the Chapter and Society, MS Ambassadors are grassroots volunteers that spread the word about MS in their community. Their knowledge about the Chapter's advocacy, support, research, and fundraising gives MS Ambassadors the chance to increase the capacity of the Chapter, thus moving us closer to achieving our mission of a world free of MS.

TRAINING AND SUPPORT:

Ambassadors have access to Chapter and Society publications in order to adequately relay information about the Society. Additionally, Ambassadors will receive training in:

- Greater Northwest Chapter Volunteer Orientation, including education on MS, the Society, and the Greater Northwest Chapter
- MS Ambassador Training and Orientation

- Training on how to effectively share your story in various formats
- Quarterly update meetings to provide MS Ambassadors with information on the latest MS Research, the NMSS, and the Greater Northwest Chapter news
- Other training and orientation, as needed.

QUALIFICATIONS:

- Proactive and passionate about the mission of the National MS Society
- Comfortable speaking to groups and individuals about multiple sclerosis, the Society and the Chapter
- Demonstrated reliability and professionalism
- Basic computer skills and ability to respond to emails from Chapter staff
- Reliable transportation to and from presentation locations
- Strong interpersonal communication skills
- Maintain knowledge of current programs and services offered by the Greater Northwest Chapter
- Establish and cultivate relationships with community-based agencies in an effort to expand programs and services for people with MS
- Ability to speak in alignment with the National MS Society's mission and brand

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COMMITMENT:

- Minimum one-year commitment to the MS Ambassador program
- Specific time commitments for each Ambassador will vary depending on how many community events they attend. At the least, Ambassadors can expect the following:
    - Attend quarterly update conference calls
    - Attend or participate in at least four community engagements per year

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PROCESS:

- Fill out an MS Ambassador Interest Form
- Attend a Chapter Orientation session or complete the Virtual Volunteer Orientation
- Participate in MS Ambassador trainings
- Have a conversation with Chapter staff member to learn how your skills and interests can be best utilized through the MS Ambassador program

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CONFIDENTIALITY:

The Greater Northwest Chapter of the National Multiple Sclerosis Society has an obligation to safeguard the confidential nature of personal information and shall not disclose, in an individually identifiable way, information about a particular person without the person's expressed authorization. All volunteers are expected to safeguard confidential information to the degree that their volunteer position is given access to the identity and details of persons living with multiple sclerosis and their families.

I have read and understand this position description and agree to work to accomplish the responsibilities outlines above. I also agree to work with a team spirit to support the National Multiple Sclerosis Society in accomplishing its mission to end the devastating effects of multiple sclerosis.

Ambassador Name (please print): _____ Date: _____

Ambassador Signature: _____ Date: _____

Supervisor Name: _____ Date: _____

Supervisor Signature: _____ Date: _____

Contact Lauren Spero at lauren.spero@nmss.org for more information.

National
Multiple Sclerosis
Society
Greater
Northwest
Chapter

MILEAGE REIMBURSEMENT REQUEST

Date	Purpose	Starting Address	Ending Address	Miles Traveled

_____ **x** $.23 per mile _____ + _____ = **$**_____
Total miles traveled Reimbursement rate Additional Expenses Total amount requested
Attach Receipts
(I.e. ferry, tolls, etc)

Make check payable to:

Name: _____

Address: _____

City: _____ **State** _____ **Zip** _____

Telephone: _____ **Email** _____

_____ _____
SIGNATURE **DATE**