



**National  
Multiple Sclerosis  
Society**  
Upstate New York  
Chapter

# **MS Ambassadors**

Guide

A handbook for MS Ambassadors

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## Purpose of MS Ambassador Guide

The purpose of this guide is to acquaint you with the National MS Society, provide a brief overview of the MS Ambassador program, and orient you to being an MS Ambassador with the Upstate New York Chapter.

## About the National MS Society

The National MS Society is a collective of passionate individuals who want to do something about MS now—to move together toward a world free of multiple sclerosis. MS stops people from moving. We exist to make sure it doesn't.

We help each person address the challenges of living with MS through our 50-state network of chapters. The Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward.

We are moving research forward by relentlessly pursuing prevention, treatment and a cure. We are moving to reach out and respond to individuals, families and communities living with multiple sclerosis. We are moving politicians and legislation to champion the needs of people with MS through activism, advocacy and influence. We are moving to mobilize the millions of people who want to do something about MS now.

## Our Mission

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

## Our Vision

A World Free of MS.

## Core Values

By living the following values every day, the National MS Society offers hope to all who live with MS. These values should guide our work as part of the National MS Society as we move toward our ultimate goal of a world without MS.

**Commitment:** We are passionate in our commitment to people affected by MS.

**Leadership:** We are leaders in the fight against MS.

**Integrity:** We are honest and straightforward in all that we do.

**Excellence:** We set high standards of performance and delivery of services, and we work towards excellence in our mission to end the devastating effects of MS.

**Teamwork:** We advance the interests of people affected by multiple sclerosis through individual and team achievements.

## The Upstate New York Chapter

The Upstate New York Chapter is the local chapter of the National Multiple Sclerosis Society which works for the prevention, treatment, alleviation and cure of multiple sclerosis while improving the quality of life of individuals with multiple sclerosis and of their families. Specifically, the chapter will...

- Provide programs and services to those with multiple sclerosis and to their families, and give assistance to clinics, hospitals and research organizations to encourage adequate treatment for individuals with multiple sclerosis.
- Help educate the general public, clients and their families, political and community leaders, and medical and social service professionals by assembling and disseminating reliable information and medical and scientific opinion concerning multiple sclerosis.
- Support research into the cause, prevention, diagnosis, treatment and cure of multiple sclerosis.
- Conduct fundraising, marketing and public relations activities in order to increase available funding and heighten public awareness of multiple sclerosis.

The above-enumerated purposes and activities are coordinated and supported through the cooperative effort of an active Board of Directors, a corps of volunteers and a dedicated professional staff.

The Upstate New York Chapter is composed of 50 counties in Upstate New York, with offices in Buffalo, Rochester, Binghamton, Syracuse, and Albany. We serve approximately 12,800 clients with MS within the chapter territory.

## About the MS Ambassador Program

MS Ambassadors are a group of dedicated volunteers who are trained to represent the National MS Society, educate the public and advocate for those living with MS. As a spokesperson for the chapter and Society, MS Ambassadors are grassroots volunteers who can 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 moving the Society closer to achieving the mission. They also play a critical role in communicating the availability of vital chapter programs and services to people with MS and their families, the general public and the healthcare community.

In general, MS Ambassadors:

- **Educate** the public about MS and the Society
- **Engage** people who want to do something about MS now
- **Encourage** involvement in the MS Movement

## Policies and Procedures for MS Ambassadors

### Community Event Booking Procedures

Community events such as health fairs or speaking engagements can be initiated by MS Ambassadors, by staff, or by community organizations. Please follow the general guidelines below for informing the chapter about upcoming engagements.

#### *Programs/Events initiated by MS Ambassadors:*

As trained volunteers, MS Ambassadors may table at health fairs or attend community events on behalf of the chapter by following the procedures outlined here:

1. Complete the "MS Ambassadors Community Event Information Form" or register your event online in the MS Ambassadors section of the chapter website. A copy of this form is provided at the end of this guide. A copy can also be obtained by contacting the Manager of Volunteer Engagement. All community events must be approved by the chapter.
2. Volunteers should make copies of the following materials to have available at the event:
  - a. "Frequently Asked Questions about Multiple Sclerosis"
  - b. "Programs and Services of the Upstate New York Chapter"
  - c. "Contact Me" cards
3. Volunteers may request additional materials depending on the event audience.
4. Once the event has taken place, MS Ambassadors are responsible for reporting information from the event to the Manager of Volunteer Engagement (i.e. number of attendees, overall outcomes of the events, anyone who requested additional information/follow-up, etc.). This can be done via email or phone within one week of the event.

#### *Programs/Events initiated by the Chapter:*

When staff members become aware of opportunities, they will contact MS Ambassadors in their region to coordinate availability for the event.

1. MS Ambassadors will receive a copy of the completed request form and be asked to sign an agreement of their attendance in advance of the event.
2. After the event, MS Ambassadors will be asked to provide a report about the event (i.e. number of attendees, overall outcomes of the events, anyone who requested additional information/follow-up, etc.).

## MS Ambassador Description

### *Position Summary*

As a spokesperson for the chapter and Society, MS Ambassadors are grassroots volunteers who can 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 moving the Society closer to achieving the mission. They also play a critical role in communicating the availability of vital chapter programs and services to people with MS and their families, the general public and to the healthcare community.

### *Key Responsibilities*

MS Ambassadors will be assigned duties depending on their skills, interests and availability. These duties may include:

- Health Fairs: Represent the Society by staffing a booth or information table at a health fair or similar event — respond to inquiries, distribute Society materials, recruit volunteers, event participants, etc., as appropriate.
- Speaker to Community Groups: At the request of community groups (e.g., Rotary Club, Chamber of Commerce, local businesses, etc.) provide information about the National MS Society, our programs and services, fundraising and volunteer opportunities by speaking to these audiences as requested.
- Event Champion/Speaker: Connect with individual event participants as a 'buddy' or 'champion' to encourage their participation, motivate their fundraising efforts and tie them to the mission (pre-event). Engage and motivate participants at fundraising events by sharing your personal story, staffing an information table, etc.
- Community Health Volunteer: Visit targeted healthcare providers to develop and strengthen relationships between healthcare providers and the National MS Society, educate, and promote chapter programs and services, the Society's advocacy agenda and fundraising events to area clinicians and other healthcare providers, and work with healthcare providers to increase the number of people with MS and their families referred to the National MS Society for help and services. Deliver client education materials for display in the clinician's office and/or distribution to the clinician's patients.
- MS Activism: Use personal story to put a face to the policy issues impacting people affected by MS. Share personal story with public officials, write a Letter to the Editor, call local talk radio programs, and/or attend a town hall meeting.
- Media Interviews: Share their personal stories of MS with print, radio, or TV journalists requesting interviews; or share their stories of chapter and Society involvement.

### *Qualifications and Desired Skills*

- Has an understanding of MS and passion for the National MS Society mission
- Has access to reliable transportation
- Has strong interpersonal and communication skills
- Enjoys talking, presenting, and sharing knowledge with others
- Willing to speak with news reporters over the phone or in front of the camera, sharing your personal MS story, or answering reporter questions about your involvement with a certain program or event
- Willing to attend training, accept coaching, follow guidelines, and do pre-work and follow-up for assignments

### *Training and Support*

All MS Ambassadors will receive orientation and training about multiple sclerosis, the National MS Society, our programs and services available to people affected by MS and family members, and resources for healthcare providers. The Society will also provide additional training and information related to the specific duties the MS Ambassador may assume. On-going supervision, updates and support will be provided.

### *Time Commitment*

Flexible.

### *Benefits*

- Opportunity to use your enthusiasm and passion to further the Society's mission
- Opportunity to be a part of a passionate group of individuals who want to do something about MS now
- Meet others who have a close connection and interest in MS
- Develop your presentation or public speaking skills

### **Thank You**

We are exceedingly grateful for the dedication of MS Ambassadors who truly help multiply the capacity of the chapter to raise awareness while educating people about MS and advocating for people with MS. The National MS Society truly relies on volunteers as vital partners to help create a world free of MS. Thank you for your collaboration, hard work, and generosity of your most valuable resources — your time, knowledge, skills, and leadership. We could not pull this off without you!

## Appendix – Useful Forms and Resources

Included in this section you will find useful forms for your role as an MS Ambassador. Below are the instructions for these forms and resources.

1. Community Event Information Form: Please complete this form prior to committing to a community event to which you have been invited. You can also use the submission form on the website. This form is primarily for tracking purposes, and we like to see all the places where MS Ambassadors are spreading the movement.
2. Frequently Asked Questions: This two-page document, which presents the basics about multiple sclerosis, can be copied and made available as an educational resource at your events.
3. Programs and Services of the National MS Society: This document is also an information resource to show the programs available to people who have MS. Please have copies available at your events.
4. Contact Cards: These cards should be made available at your events in case you make a connection with someone who would like to be contacted by the local chapter. Be sure to copy and cut these cards and bring some pens so people can submit their information. Please remember, this information is confidential and should be returned to your local chapter contact immediately after your event.
5. “Try on MS” Toolkit: Use this toolkit to give people a taste of what it can be like to live with MS.



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## Community Event Information Form

The National Multiple Sclerosis Society Upstate New York Chapter is extremely grateful that you are interested in joining the movement and working toward a world free of MS. Please complete the form below to provide more details about the community event you plan to attend or host.

Please return this form to: National MS Society Upstate New York Chapter  
ATTN: Ashley Greenman  
1650 South Ave. Ste. 100  
Rochester, NY 14620  
[Ashley.Greenman@nmss.org](mailto:Ashley.Greenman@nmss.org)

### Contact Information

Your Name: \_\_\_\_\_  
Organization/Company Name (if applicable): \_\_\_\_\_  
Email: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone # (include area code): \_\_\_\_\_

### Event Information

Please provide the name of the event/activity/fair in which you will be hosting/tabling/participating:

\_\_\_\_\_  
Date of event: \_\_\_\_\_ Location: \_\_\_\_\_  
Target audience of the event \_\_\_\_\_  
Do you plan to solicit any donations? \_\_\_\_\_

### If so, this event will be considered a Do-It-Yourself Fundraising Event.

*Please Note: The Society defines a Do-It-Yourself Fundraising event as any fundraising activity by a non-affiliated group or individual volunteer (third party), where the Society has no fiduciary or agency responsibilities and little or no staff involvement. Please see the DIY Toolkit for more information.*

Thank you again for your commitment to work toward a world free of MS.

1650 South Ave, Suite 100, Rochester, NY 14620-3901 Tel. 585 271 0801 Fax 585 442 2817 [www.msupstateny.org](http://www.msupstateny.org)





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Upstate New York  
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## Frequently Asked Questions about Multiple Sclerosis

### What is multiple sclerosis?

Multiple sclerosis is a chronic, unpredictable disease of the central nervous system (the brain, optic nerves, and spinal cord). It is thought to be an autoimmune disorder. This means the immune system incorrectly attacks the person's healthy tissue. 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 come and go. Most people are diagnosed between the ages of 20 and 50, although individuals as young as two and as old as 75 have developed it. MS is not considered a fatal disease, as the vast majority of people with it live a normal lifespan, but they may struggle to live as productively as they desire, often facing increasing limitations.

### Who gets MS?

Anyone can develop MS, but there are some patterns. More than twice as many women as men have 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?

MS affects about 2.5 million people worldwide.

### What are the typical symptoms of MS?

Symptoms of MS are unpredictable, 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. Yet another person 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 symptoms on a permanent basis including 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 (the brain and spinal cord). Myelin is destroyed and replaced by scars of hardened "sclerotic" tissue. Some underlying nerve fibers are permanently severed. The damage appears in multiple places within 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.**

### **Is MS fatal?**

**In rare cases, MS is so malignantly progressive it is terminal, but most people with MS have a normal or near-normal life expectancy. Severe MS can shorten life.**

### **Does MS always cause paralysis?**

**No. Moreover, the majority of people with MS do not become severely disabled. Two-thirds of people 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 assist with conserving energy.**

### **Is MS contagious or inherited?**

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

### **Is there a cure for MS?**

**Not yet. There are now FDA-approved medications that have been shown to "modify" or slow down the underlying course of MS. In addition, many therapeutic and technological advances are helping people manage symptoms. Advances in treating and understanding MS are made every year, and progress in research to find a cure is very encouraging.**

### **What medications and treatments are available?**

**The National Multiple Sclerosis Society recommends that a person consider treatment with one of the FDA-approved "disease-modifying" drugs as soon as possible following a definite diagnosis of MS with active or relapsing disease. These drugs help lessen the frequency and severity of MS attacks, reduce the accumulation of lesions (areas of damage) in the brain and slow the progression of disability. In addition to drugs that address the basic disease, there are many therapies for MS symptoms such as spasticity, pain, bladder problems, fatigue, sexual dysfunction, weakness and cognitive problems. People should consult a knowledgeable physician to develop a comprehensive approach to managing their MS.**

### **Why is MS so difficult to diagnose?**

**In early MS, symptoms come and go and apply to any number of possible disorders. Some people have symptoms that are very difficult for physicians to interpret, and these people must wait and see what else develops. 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.**



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## Programs and Services of the National MS Society

The National MS Society 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. These resources can be accessed in person at chapters, online, by phone and by mail. To receive copies of these materials or learn more about these programs, call 1-800-344-4867 or e-mail [contactusnmss@nmss.org](mailto:contactusnmss@nmss.org).

### Programs in Your Community

In addition to the programs and services mentioned on this page, Society chapters offer 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. To learn more about all of the programs offered in your community, please contact the Upstate New York Chapter at 1-800-344-4867 or [www.MSupstateny.org](http://www.MSupstateny.org).

### For the Newly Diagnosed

**MS Next Step®** Hearing the diagnosis of MS is never easy. MS Next Step® is designed to answer questions that are commonly asked immediately following a diagnosis and provides an introduction to MS and the programs and services of the National MS Society. (Also available in Spanish)

**Knowledge is Power** Knowledge Is Power is a free, in-home educational series for people newly diagnosed with MS and their families. This comprehensive program provides up-to-date facts about many aspects of MS. (Also available in Spanish)

### Health & Wellness

**Living Well with MS** This series of workbooks includes exercises and reflection pieces that challenge individuals to problem solve and think creatively about living with MS.

**Fatigue: Take Control** This program focuses on the fatigue and mobility issues associated with MS. Participants learn how to reduce the effects of fatigue on everyday life.

### Employment Resources

**Career Crossroads** This program focuses on the legal rights of employees with MS and examines ways to mitigate the effects of MS on work performance.

**MS & the Workplace: Employer Education DVD** Provides basic information to employers about managing the impact of MS in the work setting.

### General Information

**MS Navigator®** Finding answers and making decisions relies on having the right information at the right time. MS Navigator® provides answers to your questions and access to information about all of the options available to you. Learn more by downloading our MS Navigator brochure (.pdf) or call an MS Navigator at 1-800-344-4867.

**MS Learn Online** MS Learn Online is the Society's educational webcast series. New webcasts appear bimonthly and past webcasts can be viewed at any time from the Society's Web site.

**Client 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. You can also request publications at 1-800-344-4867 or [contactusnmss@nmss.org](mailto:contactusnmss@nmss.org).

**Connection Programs** The 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.

**Financial Assistance Program** This nationwide program is comprised of a range of initiatives that support independence, safety, health and quality of life for people living with MS, as well as their families. This program offers guidance and resources to help contain the financial impact of MS.

**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.

**My Life, My MS, My Decisions** This program helps people with MS make decisions about all aspects of their health. My Life, My MS, My Decisions includes a DVD and four online classes.

**Relationship Matters: A Program for Couples Living with MS** This program can help couples strengthen their partnership and minimize the impact of MS on their life. By choosing from in-person, teleconference and online options, couples can learn techniques and information to keep their most important relationships moving forward.

**You CAN!** The National MS Society teamed with Can Do Multiple Sclerosis (formerly The Heuga Center for Multiple Sclerosis) to develop this comprehensive series of articles to remind you that, despite the challenges MS brings, you have a whole life to live. You CAN! covers a wide variety of topics and tips.

**Timmy's Journey to Understanding MS** In this cartoon, a young boy named Timmy gains a better understanding of MS and becomes more accepting of the unpredictability MS can bring.

**Keep S'myelin': A Newsletter About MS for Children** This newsletter is for children ages 5–12. Each issue addresses a different topic related to MS. Interactive versions are also available on the Web.

**Children & Teens with MS: A Network for Families** A support and education network for children and teens with MS and their families.

**Spanish Resources/Información en Español** A variety of resources are available for people who speak Spanish.

# Contact Cards



National Multiple Sclerosis Society  
Upstate New York Chapter

Name: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Email: \_\_\_\_\_

Please contact me about:

- Programs and services provided locally
- Volunteer opportunities
- Getting involved with fundraising events



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## “Try on MS” Toolkit

### **An Awareness and Educational Activity**

Since many of the symptoms of multiple sclerosis are “invisible,” people may not understand the disease. Through “Try on MS,” volunteers use everyday props to help community members learn more about MS.

#### **Where to use the “Try on MS” toolkit:**

- Walk MS or Bike MS: promote events and recruit members for your team
- Community fundraising events
- Team wrap-around events
- MS Awareness Week
- Health fairs
- At a local mall or community center (be sure to contact the organization ahead of time to receive permission)

#### **For most venues, a team of 2 - 3 volunteers is all that is needed:**

- Moderator (preferably a person living with MS)
- Greeter(s) — (1 or 2 people)
- Optional: Booth (1 or 2 people) — basic materials and publications are available from the chapter

#### **Props:** (most are easy to find at local thrift shops or home improvement stores)

- High heels (foot drop)
- Flippers (balance)
- Wide belt or leg brace (spasticity)
- Thick rubber gloves and button shirt (numbness)
- Sun or safety glasses with scratched lenses (vision problems)
- Thick foam cushion (dizziness/vertigo)
- Leg and/or arm weights (fatigue)

**Be sure to introduce yourself to your “audience” and use a leading question or statement to provoke interest in the information you are sharing. For example, you may start a mini-presentation or conversation with the following:**

- “Are you familiar with MS?”
- “Have you heard of multiple sclerosis?”
- “We’re volunteers with the National MS Society, and we’re here today to spread awareness about multiple sclerosis.”
- “We’d like to invite you to learn a bit about MS and even experience some of the symptoms first hand.”

**Use props to demonstrate symptoms and be sure to explain what the props represent:**

"Today we want to give you the opportunity to 'Try on MS.'"

- Foot drop: (high heels) "Sometimes people with MS have difficulty lifting or flexing their foot, and this can greatly affect the way they walk."
- Balance: (flippers) "People with MS can experience difficulties with balance, resulting in a swaying or 'drunken' type of walk."
- Spasticity: (belt or leg brace) "People with MS can experience muscle tightness and stiffness called 'spasticity'. With spasticity, a person can experience muscle spasms or sudden muscle movements."
- Numbness: (kitchen gloves while buttoning shirt) "Numbness of face, body, arms and legs is one of the most common symptoms of MS."
- Vision Problems: (blotchy, blurry glasses) "Vision problems are common in people with MS and can cause blurring, blindness in one eye or dark spots in vision."
- Dizziness/Vertigo: (cushions) "People with MS may feel off balance or lightheaded, affecting their equilibrium and ability to feel 'grounded'."
- Fatigue: (leg/arm weights) "Fatigue is one of the most common symptoms of MS, occurring in about 80% of people."

**Questions to ask:**

- What does it feel like?
- Can you imagine living with this symptom?
- What advice would you give to a person experiencing this symptom?

421 New Karner Road - **Albany, NY** 12205 • 457 State Street - **Binghamton, NY** 13901  
4245 Union Road - **Buffalo, NY** 14425 • 1650 South Avenue - **Rochester, NY** 14620  
[www.MSupstateny.org](http://www.MSupstateny.org) – 1-800-344-4867 (press 2)