

SECOND EDITION

# Solutions for Wellness



A Guide to MSAA's  
Programs and Services

**MSAA**<sup>TM</sup>

MULTIPLE SCLEROSIS  
ASSOCIATION OF AMERICA



# Solutions for Wellness

## A Guide to MSAA's Programs and Services

SECOND EDITION

**Written by:** Susan Wells Courtney

**Edited by:** Peter Damiri, Andrea Griesé, Robert Rapp, and Cindy Richman

Copyright © Multiple Sclerosis Association of America, 2011. All rights reserved. This booklet is protected by copyright. No part of it may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without prior written permission from MSAA.

MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

Those affiliated with this booklet and MSAA cannot be held responsible for any unintentional errors in the writing of this booklet, or changes in information that may occur, possibly affecting certain details of an explanation, assumption, or treatment.

## INTRODUCTION

- Providing Information...** on MSAA and MS .....page 3  
Multiple Sclerosis Association of America (MSAA)  
Multiple sclerosis (MS)

## SECTION ONE

- Offering Lifelines...** for information and support .....pages 4-5  
Online response forum  
MSAA's toll-free bilingual Helpline  
My MS Manager™ mobile phone application

## SECTION TWO

- Finding Answers...**  
about living with MS and managing the disease .....pages 6-9  
MSAA's website  
MSAA's publications  
MSi educational online video series  
Lending Library (some books available in Spanish)  
S.E.A.R.C.H.<sup>SM</sup> program  
MRI Diagnostic Fund  
MSAA MRI Institute

## SECTION THREE

- Easing Daily Life...**  
through equipment distribution and housing ..... pages 10-11  
Equipment Distribution Program (assistive and mobility items)  
Cooling Equipment Distribution Program (for heat-sensitive MS)  
Barrier-Free Housing Program (in limited areas)

## SECTION FOUR

- Staying Connected...** with the MS community, medical experts,  
and MS organizations .....pages 12-13  
Public education and awareness events  
Networking Program  
Social media  
Multiple Sclerosis Coalition

## SECTION FIVE

- Supporting MSAA's Mission...**  
through making donations, volunteering, and fundraising .....pages 14-16  
Swim for MS  
Regional offices

# Providing Information...

## on MSAA and MS

Founded in 1970, the **Multiple Sclerosis Association of America** (MSAA) is a national, nonprofit organization whose mission is to enrich the quality of life for everyone affected by multiple sclerosis (MS). MSAA provides ongoing support and direct services to individuals with MS, their families, and their care partners. Overseeing MSAA's activities is a national Board of Directors comprised of accomplished professionals from across the country, volunteering their time for MSAA. Providing medical consultation is MSAA's Chief Medical Officer, who reviews all of MSAA's medical information and chairs our Healthcare Advisory Council. MSAA meets all criteria of the Better Business Bureau (BBB) and is in the exclusive group of national charities awarded the BBB Accredited Charity Seal.

**Multiple sclerosis (MS)** is the most common neurological disorder diagnosed in young adults. In the United States, approximately 400,000 people have MS. It is an autoimmune disease of the central nervous system, affecting the protective covering (myelin) that surrounds the nerves of the brain and spinal cord. The nerves (axons) may also be affected. MS is not contagious and usually does not shorten life expectancy. Researchers continue to seek a cause and a cure.

Individuals with MS may experience one or more of a variety of symptoms, such as visual changes, fatigue, numbness, bladder issues, and changes in mobility. However, MS affects each person differently, and with the availability of new treatments, many are experiencing fewer and less severe symptoms. Initially, most individuals with MS experience periods of symptom flare-ups (exacerbations), followed by periods of remission. A smaller population of individuals has a progressive form of MS, characterized by a slow but steady accumulation of symptoms. Additionally, heat intolerance is a classic MS trait, where a rise in temperature (internally or externally) may temporarily increase symptoms.

As of mid-2011, eight medications had been approved by the Food and Drug Administration (FDA) for the long-term treatment of relapsing forms of MS. Taken individually (not in combination with one another), five disease-modifying therapies are given through self-administered injections (Avonex<sup>®</sup>, Betaseron<sup>®</sup>, Copaxone<sup>®</sup>, Extavia<sup>®</sup>, and Rebif<sup>®</sup>); two treatments are administered via intravenous infusions at a medical facility (Novantrone<sup>®</sup> and Tysabri<sup>®</sup>); and one medication is the first oral drug to be approved for MS (Gilenya<sup>®</sup>). Many additional drug therapies are in development.

**Please call MSAA's Helpline at (800) 532-7667 or visit [www.msassociation.org](http://www.msassociation.org) for information and support.**

# Offering Lifelines...

## for information and support

MSAA's client services department provides valuable information for individuals with MS, family members, and care partners. In an effort to expand MSAA's availability and outreach, an online response initiative has been developed to address questions via an **online response forum** at **MSquestions@msassociation.org**. Emailed questions will be answered by experienced client services consultants. Visitors to MSAA's website may also access this service by simply clicking the MS Questions link featured on **www.msassociation.org**.

In addition, individuals may call **MSAA's toll-free, bilingual Helpline at (800) 532-7667** to speak with a client services consultant (callers have the option to be connected with a Spanish-speaking consultant at extension 108). MSAA's consultants offer information and encouragement, teaming with clients and their care partners to identify obstacles and discover ways to overcome them. They may also recommend specific programs offered by MSAA and assist with the application process. MSAA's goal is to ultimately achieve overall wellness and positive health outcomes.

MSAA's client services department is an excellent resource for learning about local professionals and services through an extensive national database. Consultants may also assist with: up-to-date information on MS research, treatments, and pharmaceutical assistance programs; legal issues, such as Social Security Disability Insurance, Americans with Disabilities Act, and employment; identifying healthcare providers; information regarding patient education, counseling, rehabilitation, physical and occupational therapy; and other wellness programs. In addition, consultants can help clients and care partners prepare questions for visits with their physicians.

MSAA's Helpline may be reached by calling  
(800) 532-7667 (For bilingual service,  
please dial extension 108)

Monday through Thursday,  
8:30 am to 7:00 pm, eastern time

Friday, 8:30 am to 5:00 pm, eastern time

Individuals may also email questions to:  
[MSquestions@msassociation.org](mailto:MSquestions@msassociation.org)

When needed, MSAA staff provide follow-up services to individuals in need of additional support. These contacts are designed to help identify and manage presenting issues in relation to the client's overall health and wellbeing.



MSAA now offers a mobile phone application for individuals with MS and their care partners to use free of charge on their iPhone, iPad, or iPod touch. Titled “My MS Manager,<sup>TM</sup>” this first-of-its-kind mobile app for MS provides individuals with a convenient and effective tool to manage the ever-changing course of their disease.

My MS Manager allows users to: input and store comprehensive medical records along with vital contact information of their healthcare team; record the onset of symptoms or MS flare-ups and track their duration, frequency, and intensity; log information about medication side effects as well as effective treatment strategies; and journal other important details essential to promoting good health and wellbeing.

With My MS Manager, reports can be generated from the information logged on one's mobile device. These reports can also be shared with physicians and other members of the healthcare team via email updates and secure online access. Other features of the mobile app include an active feed of current MS-related news and links to MS resources, such as MSAA events, contact information, and a locator powered by Google Maps to find nearby emergency care, physicians, or hospitals instantly from one's mobile device.



Please visit [www.msassociation.org/mobile](http://www.msassociation.org/mobile) to learn more about this product and to download My MS Manager from the iTunes store.

# Finding Answers...

about living with MS and  
managing the disease

**MSAA's website, [www.msassociation.org](http://www.msassociation.org)**, is another excellent resource – not just for individuals with MS, but also for family, friends, and anyone interested in learning more about MS and the work MSAA performs. The "About Multiple Sclerosis" section features such topics as, "What is MS," "Types of MS," and "Treatments of MS." Visitors may also click on the "Newly Diagnosed" section, offering answers and support.

**MSAA's publications** provide a great deal of helpful and important information. These cover a range of subjects such as medical research and treatments, symptom management, complementary and alternative therapies, general information, and ways to help cope with the disease. MSAA publishes a national magazine, *The Motivator*, which includes informative and uplifting articles on vital issues, new research, treatments, and personal stories. All of MSAA's publications are available free of charge and may be viewed, downloaded, or ordered at **[www.msassociation.org](http://www.msassociation.org)**. Publications may also be requested by calling MSAA's toll-free number at **(800) 532-7667**.

**Multiple Sclerosis Information (MSi)** enables MSAA to serve more clients in more locations than ever before through enhanced web technology and updated electronic communications. The MSi library of on-demand educational videos and live webcasts brings experts on MS as well as information on its symptoms, treatments, and disease management right into the privacy and comfort of a person's home.

MSAA staff members recognize the importance of personalizing and building interactivity with the MS community. To help us achieve this goal, viewers are encouraged to submit individual questions electronically to our highly trained Helpline staff and to complete online evaluation surveys.

All of MSAA's programs and services are featured on [www.msassociation.org](http://www.msassociation.org). Visitors may also find public education and awareness events through MSAA's **Calendar of Events**. Visitors may refer to a particular MSAA program or service and download an application. As always, any personal information supplied to our website is secure.

MSAA's **Lending Library** offers a collection of nearly 300 MS resources on diagnosis, symptoms, treatments, general health, and support, along with books that inspire through personal experiences and life stories. The Lending Library also includes a number of books in Spanish and is expanding its offerings of DVDs of MSi programs and MS-related topics. MSAA loans and mails the books and DVDs free of charge, along with instructions for returning them at no cost.

MSAA introduced the **S.E.A.R.C.H.<sup>SM</sup> program** to assist the MS community with the complicated process of learning about different treatment choices. The first treatment for relapsing-remitting multiple sclerosis (RRMS) was approved by the United States Food and Drug Administration (FDA) in 1993. Since then, numerous effective disease-modifying therapies (DMTs) for MS have become available, giving neurologists and patients a variety of treatment options for slowing disease activity.

Designed as a memory aid, the S.E.A.R.C.H. acronym represents the key areas that need to be discussed with one's healthcare team when "searching" for the most appropriate MS treatment. S.E.A.R.C.H. stands for **S**afety, **E**ffectiveness, **A**ffordability, **R**isks, **C**onvenience, and **H**ealth outcomes (overall wellness and quality of life).

MSAA has created a S.E.A.R.C.H. "toolkit" with helpful written materials to assist with the program. The tools include: a detailed article about the specifics of the S.E.A.R.C.H. program; a S.E.A.R.C.H. Patient Workbook; an MS Disease-Modifying Therapy Chart showing the currently approved treatments; an MS Resource Guide; and a laminated, wallet-sized S.E.A.R.C.H. reference card. These written materials may be downloaded at [www.msassociation.org/search](http://www.msassociation.org/search) and the reference card may be ordered online. Individuals without internet access may request this same information by calling MSAA at **(800) 532-7667**.

The MRI Diagnostic Fund helps individuals obtain an initial diagnostic MRI, and the MSAA MRI Institute provides advocacy and assistance for follow-up MRI exams.



# Finding Answers...

## about living with MS and managing the disease

MSAA helps people find answers. One way is through assistance in acquiring magnetic resonance imaging (MRI) scans, which are used to help diagnose MS and to evaluate both disease progression and treatment efficacy. Given the nature of MS, with its characteristic flare-ups and remissions, MS can be very difficult to diagnose.



Additionally, MS activity is often sub-clinical, which means that the illness may continue to progress without any outward signs or increased symptoms. An MRI exam can often give physicians the answers they need to help diagnose MS and to get an “inside view” of disease activity.

The **MRI Diagnostic Fund** helps individuals obtain an initial diagnostic MRI by working with imaging centers and physicians’ offices. For individuals with no insurance or who have been denied insurance coverage, MSAA can also assist with payment for a diagnostic MRI. To qualify for financial assistance, certain income limits apply.



The **MSAA MRI Institute** provides insurance advocacy and financial assistance to those in need of a follow-up

MRI scan to examine disease activity and/or treatment effectiveness. Similar to the MRI Diagnostic Fund, certain income limits apply for financial assistance. Individuals with any income are eligible for advocacy to assist in gaining approval for an MRI through their own insurance companies.

# Easing Daily Life...

## through equipment distribution and housing

MSAA eases daily life through products and services that assist clients with their day-to-day needs and comfort. Requested equipment is shipped to clients at no charge. (Please note that certain income requirements apply, as well as limits to the number of items obtained.) These products increase comfort, safety, and/or mobility.

MSAA provides cooling vests (such as the one pictured here) to individuals with MS who qualify for the program.



MSAA's **Equipment Distribution Program** provides a varied inventory of equipment to clients at no charge, designed to increase patient safety and provide greater accessibility. Examples of equipment available include bathroom safety items such as tub/shower chairs and grab bars; daily living aids consisting of wide-grip utensils and leg lifts; and mobility products such as canes, walkers, and wheelchairs. MSAA continues to explore new equipment options to address various physical symptoms and exercise needs.

MSAA's **Cooling Equipment Distribution Program** helps individuals whose symptoms worsen from heat. In association with the National Aeronautics and Space Administration (NASA), MSAA has conducted extensive research into the effects of moderate, controlled cooling on individuals with heat-sensitive MS. These and other studies have repeatedly shown that cooling the body can help lessen the negative effects of heat and humidity for individuals with heat-sensitive MS. This technology enables some patients to continue such activities as exercise and physical therapy programs by controlling the effects of heat and reducing fatigue.

The Cooling Equipment Distribution Program provides special cooling vests at no charge to individuals with MS who are sensitive to heat. These cooling vests contain insulated pockets that hold small ice packs. MS clients who wear these vests often experience temporary cooling relief, allowing them to spend a few hours outdoors when the weather is warm.



MSAA Commons in  
Cherry Hill, New Jersey

For individuals with MS who have limited mobility or who have other physical needs, MSAA may be able to help through MSAA's **Barrier-Free Housing Program**. The program offers 125 specially constructed apartments that are completely wheelchair accessible, offering income-eligible residents a safe and comfortable environment in which to live. Located in New Jersey and North Carolina, on-site social services are available at each housing complex to provide additional support to residents.

# Staying Connected...

with the MS community, medical experts,  
and MS organizations

Information is one of the most powerful tools used by individuals to understand and manage multiple sclerosis. In addition to our comprehensive publications, online educational videos, and Lending Library program, MSAA also organizes and sponsors a wide array of **public education and awareness events**. These events often feature expert neurologists and healthcare professionals who bring clients the latest information on the advances in MS research, available treatment options, and new techniques to meet the physical, emotional, and social challenges which arise from living with a chronic illness.

MSAA coordinates these events in a variety of formats to help best present the information and resources to our clients and healthcare providers. These events include conferences, workshops, health fairs, and seminars. Topics are carefully selected to help cover a broad range of issues with important and useful information that enables participants to change their lives. Examples of topics include research updates, symptom management, physical and rehabilitative medicine, pain management, and a myriad of other real-life issues that are important to those with MS and their care partners. MSAA also conducts **live webinars** covering many topics that are vital to the MS community.

MSAA's "Staying Connected" area of service facilitates peer support through its **Networking Program**. This is an online community of individuals with multiple sclerosis and their care partners who are interested in corresponding via email with others who are affected by MS and face similar challenges. Email correspondence is especially helpful for those who are unable to attend traditional support group meetings but still want to stay connected to the MS community. The Networking Program's online directory is password protected and available through MSAA's website.





**MSAA's social media** presence allows for communication with a much wider audience about programs and services, urgent MS updates, fundraising initiatives, and other important news.

**Please follow MSAA on:**

- Facebook – [facebook.com/msassociation](https://facebook.com/msassociation)
- Twitter – [twitter.com/msassociation](https://twitter.com/msassociation)
- YouTube – [youtube.com/msaa](https://youtube.com/msaa)



**Multiple Sclerosis Coalition**

MSAA is a founding member of the Multiple Sclerosis Coalition (MSC), an affiliation of independent MS organizations dedicated to the enhancement of the quality of life for all individuals affected by multiple sclerosis. The MSC's mission is to increase opportunities for cooperation, and provide greater opportunity to leverage the effective use of resources for the benefit of the MS community.

**For more information, please visit [www.ms-coalition.org](http://www.ms-coalition.org).**

# Supporting MSAA's Mission...

## through making donations, volunteering, and fundraising

MSAA's programs and services are vital, helping to fulfill the many needs of individuals affected by MS. As a nonprofit organization, MSAA depends on the generosity of others for funding. Anyone wishing to help may do so in many ways.

**(1) Making donations:** MSAA exists and continues to expand to serve people with MS thanks to generous support through donations. Donations may be made through:

- Individual contributions (a check or credit card payment directly to MSAA; contributions may also be made through MSAA's website at [support.msassociation.org/donate](http://support.msassociation.org/donate))
- Planned giving (such as bequests and charitable gift annuities)
- Corporate giving (individual contributions along with matching gifts from one's employer; or grants given by a company – sometimes for a particular project)
- Other donations (such as used cars or used cell phones)

**(2) Volunteering:** The needs of the MS community are constantly evolving. Anyone interested in supporting MSAA's programs and services through volunteering may contact MSAA (via phone or website) to learn more about local volunteer opportunities.

**(3) Fundraising:** MSAA and its regions conduct various fundraising activities. Volunteers are vital to the success of these events. Individuals and local groups are also encouraged to hold fundraisers of their own. Examples include bake sales, golf outings, and restaurant events, just to name a few. Swim for MS is an exciting way to raise money. Please see the next page for more information!

**Help in any way is vitally needed and deeply appreciated. Please contact MSAA at (800) 532-7667 or through [www.msassociation.org](http://www.msassociation.org) to inquire about making donations, volunteering, and fundraising.**



## Dive into action with MSAA's exciting fundraising initiative: Swim for MS!

**Swim for MS** is a great way to incorporate an interest in swimming with the desire to help the MS community. Whether someone belongs to a swim team or club, swims for recreation or exercise, or simply enjoys the backyard pool, just about anyone can take part in Swim for MS – **Any Pool, Any Time!**

Individuals may create their own Swim for MS fundraising event and MSAA will help guide them through the process. Funds are generated by establishing goals (such as laps, dives, or even cannonballs!) and asking others to support their swimming or diving efforts with a pledge or direct donation. Some of these fundraisers are held in honor of a family member or friend with MS.

Swimming also serves as a beneficial therapy for people with MS, helping to improve strength, balance, and flexibility. As a result, several MSAA clients have taken on their own Swim for MS challenge while raising funds to support MSAA.

**Please contact MSAA at (800) 532-7667, extension 157 or visit [www.msassociation.org/swimforms](http://www.msassociation.org/swimforms) for more information, to register, and to check-out current Swim for MS events, photos, and personal success stories.**

# MSAA's Regional Offices

While MSAA's national office serves clients throughout the United States, MSAA's regional offices can provide additional assistance on a more local basis, facilitating outreach and awareness. Our regional offices support MSAA's mission by:

- Conducting awareness and educational events (conferences and workshops)
- Bringing people together through networking and events
- Employing volunteers to assist with regional activities
- Fundraising activities, such as Swim for MS, the annual TransWyoming and TransMontana Snowmobile Rides, and the annual Lone Star Roundup Cattle Drive

## **Midwest Regional Office:**

5441 N. East River Road #380  
Chicago, Illinois 60656-1199  
(800) 532-7667, extension 150

**Event line:** extension 184

**Email:** [midwest@msassociation.org](mailto:midwest@msassociation.org)

## **Northeast Regional Office:**

706 Haddonfield Road  
Cherry Hill, New Jersey 08002  
(800) 532-7667, extension 133

**Event line:** extension 180

**Email:** [northeast@msassociation.org](mailto:northeast@msassociation.org)

## **Northwest Regional Office:**

600 Central Plaza, Suite #10  
Great Falls, Montana 59401  
(800) 532-7667, extension 131

**Event line:** extension 185

**Email:** [northwest@msassociation.org](mailto:northwest@msassociation.org)

## **South-Central Regional Office:**

14902 Preston Road, Suite 404-345  
Dallas, Texas 75254  
(800) 532-7667, extension 137

**Event line:** extension 182

**Email:** [southcentral@msassociation.org](mailto:southcentral@msassociation.org)

## **Southeast Regional Office:**

c/o MSAA National Headquarters  
706 Haddonfield Road  
Cherry Hill, New Jersey 08002  
(800) 532-7667, extension 154

**Event line:** extension 187

**Email:** [southeast@msassociation.org](mailto:southeast@msassociation.org)

## **Western Regional Office:**

1819 Polk Street  
Mailbox #326  
San Francisco, California 94109  
(800) 532-7667, extension 155

**Event line:** extension 189

**Email:** [western@msassociation.org](mailto:western@msassociation.org)

For information about regional events and activities, please visit [www.msassociation.org](http://www.msassociation.org) and select “**Calendar of Events.**”



*Enriching Lives Today!*

**MSAA**<sup>TM</sup>

**MULTIPLE SCLEROSIS  
ASSOCIATION OF AMERICA**

**National Headquarters**

**706 Haddonfield Road  
Cherry Hill, New Jersey 08002**

**Toll-free: (800) 532-7667**

**Fax: (856) 661-9797**

**[www.msassociation.org](http://www.msassociation.org)**



This booklet has been printed on partially recycled paper using soy-based inks.