

Accelerated Cure Project for MS

May 2018



Accelerating research towards a cure for multiple sclerosis

Partner Spotlight – Multiple Sclerosis Association of America

The Multiple Sclerosis Association of America (MSAA) is a national, nonprofit organization dedicated to improving the quality of day-to-day living for everyone affected by MS. They do this by providing a wide range of valuable services to the MS community free of charge. MSAA's programs are centered on the MS patient and their care partner's needs and perspective. They strive to keep in touch with the MS community to optimize the benefit of their programs. According to Gina Murdoch, President and CEO of MSAA, "we welcome feedback from the MS community and try to adjust information and services to meet their needs and interests."



One mainstay of MSAA's programs is a [shared management](#) philosophy in which patients and healthcare providers work together toward the best quality of life for the patient. MSAA has developed a number of tools to help those living with MS communicate with their physicians and proactively manage their healthcare. [My MS Manager™](#) is a free mobile phone application that can track disease activity and store medical information. My MS Manager also has a journaling function that enables patients to keep a log of their symptoms. All of this information can be securely shared with one's healthcare team, enabling MS patients and their

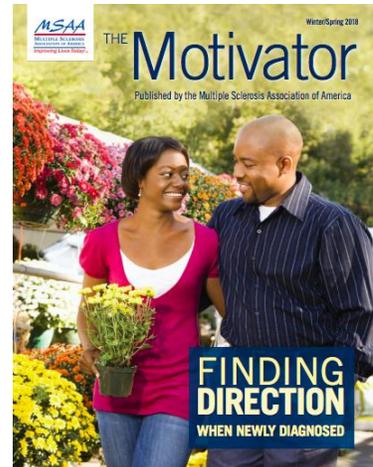
physicians to closely track and manage disease activity. In Gina’s words, “The journaling function provides the opportunity to have that dialogue going with your provider...it helps patients make the most of their time with providers.” With more than 31,000 downloads and 15,000 users to date, My MS Manager was named one of [Healthline’s](#) best MS apps in 2018. MSAA’s [S.E.A.R.C.H.™ Program](#) helps individuals with MS and their healthcare teams make choices in the evolving landscape of MS treatments in order to achieve the best treatment outcome. Each letter of the program’s acronym represents an important topic that should be considered when choosing an MS treatment for the first time, or when making treatment adjustments – safety, effectiveness, access, risks, convenience and health outcomes. [My MS Resource Locator®](#) is an online database of helpful information and support services for those living with MS.

Recognizing that chronic illness can feel very lonely at times, MSAA offers ways for people affected by MS to connect with and support one another. [My MSAA Community](#) is a secure online community in which members can interact through online conversations. MSAA has featured “[Ask Me Anything](#)” sessions with neurologists, in which an expert is available for one hour for questions on the My MSAA Community forum. Gina states, “We’re able to offer a safe environment for our members to share experiences, get feedback and ask questions...It’s up to you how involved you want to be.” [MS Conversations](#) is the official blog of MSAA. MS Conversations includes posts from guest bloggers living with MS, as well as interactive discussions on topics of importance to the MS community. According to Gina, “It’s a whole host of conversations of people living with MS...MS Conversations isn’t singularly focused on treatment and medical topics. A lot of it is life in general and dealing with chronic disease.” MSAA also hosts a toll-free [Helpline](#) that offers free support and encouragement to those encountering challenges, experiencing changes in their symptoms, or simply looking for information. Helpline specialists, all with a social services or counseling background, can be reached by phone, email, through the [chat feature](#) on the MSAA website, or through MS Conversations.



MSAA believes that knowledge is empowering. Their [educational programs](#) provide an opportunity to connect and learn from the country’s leading healthcare professionals. Each program contains a question and answer session during which attendees and the presenting

professional interact. Their booklets provide up-to-date information on relevant topics (for example, [About MS](#) or [Understanding Progression in MS](#)) in easily understood language. MSAA also publishes a national magazine, *The Motivator*, twice per year. This publication includes cover and feature stories of relevance to the MS community, as well as regular columns such as “Ask the Doctor,” “Research News,” and “Stories to Inspire,” to name a few. The [MSAA Lending Library](#) program offers a comprehensive selection of books and a variety of DVDs that cover disease and symptom management, wellness, personal stories from people living with MS, care partner issues, and many other important topics. Their lending policy makes these resources readily available. Participants can borrow one title at a time for up to 45 days. MSAA covers all outgoing and return mailing costs. In addition, MSAA offers an extensive library of on-demand videos, webinars and webcasts that offer a wealth of information that can be conveniently accessed online.



MSAA’s robust website is another source of valuable information for those living with MS. Recognizing that every individual’s experience is different and constantly evolving, [My MS Journey](#) is designed to help individuals find relevant information that matches where they are in their journey with MS. This area of the website is divided into three sections: [Just Starting Out](#) (for those newly or recently diagnosed), [Staying On Course](#) (for day-to-day management of MS), and [The Seasoned Traveler](#) (for those with mobility, independence or caregiving needs). The [MS Relapse Resource Center](#) contains detailed information on relapses and treatment options. This section also provides the opportunity for individuals to learn about the experiences of others by reading completed survey summaries. In addition, on-demand videos are available featuring MS experts discussing relapses. [My Health Insurance Guide](#) is aimed at helping the MS community better understand the details surrounding their health insurance options. This guide covers a range of important topics, including The [Affordable Care Act](#), [non-Medicare insurance](#), and [Medicare insurance](#) programs.

General good health and wellbeing are especially important to people with MS. MSAA provides considerable information relating to [overall wellness](#). Their website includes helpful tips and resources to help individuals both emotionally and physically. Regular exercise is an important part of staying healthy. For people with MS, exercising in water is often easier

because of the buoyancy and cooling effect it provides. With this in mind, MSAA's [online Aquatic Center](#) is aimed at spreading awareness of the availability and benefit of water-based exercise programs. The overall wellness section of the MSAA website also includes information on many other relevant topics, such as health and disability insurance, employment and financial planning.

In addition to providing essential information to those living with MS, MSAA's programs are aimed at providing valuable equipment to improve their quality of life. Many people with MS find that heat and humidity often aggravate their MS symptoms. The MSAA [Cooling Distribution Program](#) offers cooling vests, smaller



products to wear under clothing and other accessories to help cool the neck, wrists and ankles. The [Equipment Distribution Program](#) offers products designed to help those with balance, coordination, and mobility issues. Items distributed through this program include shower chairs and grab bars, as well as canes, walkers and wheelchairs. MSAA ships products for both of these programs to qualified individuals free of charge.

Recognizing that the cost of Magnetic Resonance Imaging (MRI) scans can be prohibitive, MSAA's [MRI Access Fund](#) helps qualified individuals who are uninsured or under-insured obtain the tests they need as recommended by their healthcare providers. This fund assists with the payment of brain and c-spine MRI's to help determine a diagnosis of MS or to evaluate MS disease progression. In Gina's words, "This program is the hallmark of our organization. We can work with those with commercial insurance, Medicare or Medicaid. We contract with imaging centers across the country. We figure out what the doctor wants, find the most convenient imaging center for the patient and pay the center directly." The MRI Access Fund was recently expanded to include retroactive reimbursement for scans done as of July 1, 2017.

Every year, MSAA celebrates the work of artists affected by MS through their [art showcases](#). Their MS Ability Art Showcase features artwork that portrays people, places or things and their Four Seasons Art Showcase features artwork that depicts a specific season or holiday. According to Gina, "Art has been an anchor for many people living with MS. Many have also found it to be a respite. There's a sense of normalcy to it. It's something people are still able to do despite MS." Artists include background or a story from their journey with MS, which adds a personal touch to each piece of artwork. In Gina's words, "It's therapeutic on both sides. It's

therapeutic for the person doing the artwork, and it's also therapeutic for people to see the artwork and read the story behind it." In addition to the online showcases, some artwork is also used for calendars or notecards. Submissions for both showcases are accepted between October and December each year.

In addition to her role at MSAA, Gina also serves on the Engagement Committee for [iConquerMS](#). In her words, "We appreciate the collaboration and partnership with the Accelerated Cure Project. I think there's a collaborative effort between the organizations to bring forward the patient voice." The importance of patient experience and perspective is evident in MSAA's mission and programs. They offer a wealth of information, resources and encouragement to help those living with MS manage the challenges they may encounter, and live the fullest life possible. As Sara, one of MSAA's clients, shares in this [video](#), these programs are a meaningful gift to the MS community.

