

History of the Multiple Sclerosis Association of America

Founded on June 8, 1970, the Multiple Sclerosis Association of America (MSAA) developed as a grass-roots nonprofit organization in Southern New Jersey dedicated to providing free, direct care services and support for people living with MS and their families. The organization was created by a loving couple where the wife was living with MS and the husband was legally blind. MSAA began serving the local MS community with peer-to-peer support, information and referral services, advocacy for those living with a disability, and development of a much-needed durable medical equipment loan closet.

Throughout the course of the next two decades, our organization began to grow in membership, service activities, and geographic reach. With the addition of aquatic exercise classes, educational dinner programs, and family-focused events, MSAA grew in admiration as the “patient services” organization which led the Board of Directors and leadership team to expand outreach not just regionally, but nationally.

In 1988, the organization expanded its unique, personalized, and dedicated patient-care approach to the MS community throughout all 50 states. Increasing its current menu of services, MSAA pioneered the scientific research of using cooling technology to improve MS symptom management. Working with NASA engineers and researchers at several prestigious MS Centers in the early 1990s, results from the MSAA-funded studies proved the beneficial effects of temporarily cooling the body for people with MS, as they often experience extreme heat intolerance as part of their symptoms. As a result of these studies, private industry began manufacturing “cooling vests” which use frozen ice packs to provide effective symptom relief for the MS



population. Recognizing the tremendously beneficial support and quality of life impact from these cooling vests, MSAA immediately began a free [Cooling Distribution Program](#), providing free vests and supportive accessories to MS families across the US. As one of MSAA’s most successful programs, the Cooling Distribution Program serves more than 3,000 people annually, lessening symptoms and improving quality of life.

As MSAA entered the new millennium, opportunities to develop significant, impactful programs grew through the decade as the organization expanded in-person educational programs, launched a comprehensive website with ongoing video and webinar content, and established its highly successful [MRI Access Fund](#). With advancements in medical technology, the role of magnetic resonance imaging (MRI) became the preferred physician tool to diagnosis and treat multiple sclerosis. However, many people with MS (then and now) often lack health insurance or the ability to pay their insurance copays which leaves them unable to obtain the testing required to learn of a diagnosis or effectively manage the disease.



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Recognizing this tremendous gap in care for the MS community, MSAA created the MRI Access Fund to pay for much-needed cranial and c-spine MRI scans for people who lack health insurance or the financial ability to pay for the exam. Each year the MRI Access Fund provides MRI assistance to more than 1,000 people with MS across the country.

From the mid-2000s into the next decade, the MS community greatly benefited from the continued advancement of Food and Drug Administration (FDA) approved disease modifying therapies (DMTs) aimed at slowing the progression of the disease and lessening the frequency and severity of relapses. With nearly a dozen medications available at the time and many associated with serious side effects and other health concerns, MSAA helped develop the concept of [Shared Management](#) between patients and their doctors in order to make smart, effective, and beneficial treatment decisions. This philosophy of shared management encourages members of the MS community to proactively manage their healthcare needs and overall wellness by researching information, tracking and reporting results, and developing direct and open communication with their neurologist and other treating specialists.

To aid the MS community with these efforts, MSAA launched several innovative tools and programmatic outreach efforts including our:

- [S.E.A.R.C.H. Program](#) which provides guidance on making treatment decisions based on a medication's Safety, Effectiveness, Access, Risk, Convenience, and Health Outcomes
- [My MS Manager free mobile phone application](#) which is a first-of-its-kind app for MS which allows patients to track disease activity, generate reports, share data with healthcare professionals, and more
- [Navigating MS global initiative](#) comprised of more than 40 leading MS neurologists, nurses, physical therapists, and MS patient advocacy organizations from the United States, Europe, and Australia with a shared goal of helping to improve the way that healthcare professionals, patients, and care partners effectively communicate about benefits, risks, and the overall management of MS

Continuing to advance our goal of Improving Lives Today, MSAA recently created an online, peer-to-peer support system known as [My MSAA Community](#). With more than 5,000 members and growing, this free online forum provides a safe and effective place where people can connect with their peers, contribute to ongoing conversations, and learn effective strategies for managing the day-to-day challenges of living with a chronic illness.

As MSAA recognizes its 50th Anniversary this year and reflects on these and many additional accomplishments, we fully understand the ongoing and complex challenges which still face people living with MS and their loved ones. Current MSAA activities and innovative approaches to MS patient care moving us forward into the next decade include continuing to provide education and [resources on the coronavirus pandemic](#) and its impact on MS including an evaluation tool to capture real-time data measuring the effects COVID-19 is having on MS patients' quality of life, expanding wellness and mental health services through telemedicine and technology partnerships, and continuing our efforts to reach and support the underserved MS populations including people of color and those living in rural geographic areas through online educational learning and community partnerships and engagement.

