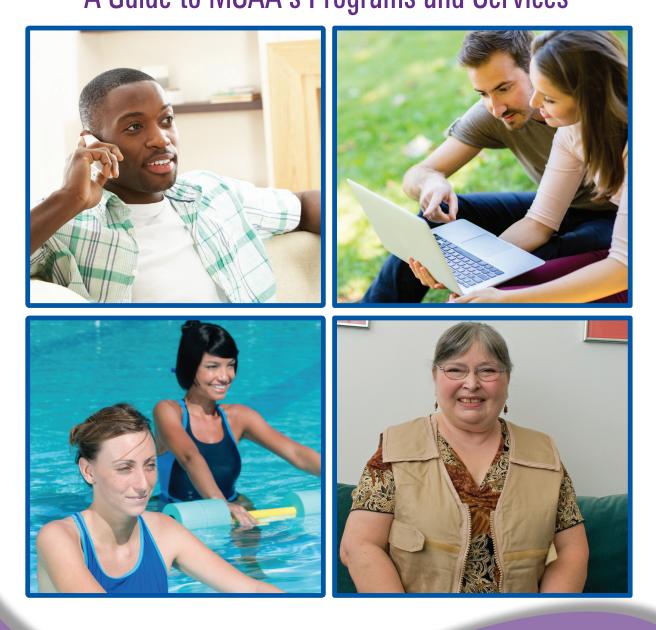
Improving Lives Today! A Guide to MSAA's Programs and Services





MULTIPLE SCLEROSIS Association of America

Improving Lives Today!™

Second Edition

Improving Lives Today! A Guide to MSAA's Programs and Services

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This booklet provides helpful information on MSAA's current programs and services, all aimed at Improving Lives Today! MSAA's numerous free programs and services have been grouped according to how they assist members of the MS community, with categories such as providing answers and encouragement, offering information and guidance, enhancing safety and daily life, and more. For more information, please visit MSAA's website at **mymsaa.org** or call **(800) 532-7667**.

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.

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Introduction

Multiple sclerosis (MS) is the most common neurological disorder diagnosed in young adults. Many experts estimate that 2.5 million people worldwide have MS. The number of people diagnosed with MS in the United States was previously estimated more than a decade ago at 400,000. However, without a comprehensive, national registry, this figure cannot be confirmed and more research is needed. MS 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 become damaged. MS is not contagious and 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 and bowel problems, depression, cognitive issues, and changes in mobility. However, 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. As of November 2016, 14 disease-modifying therapies have been approved by the Food and Drug Administration (FDA) for the long-term treatment of relapsing forms of MS. Many additional drug therapies are in development, including some aimed at treating progressive forms of MS.

The Multiple Sclerosis Association of America (MSAA) was founded in 1970 and is a leading resource for the entire MS community, improving lives today through vital services and support. MSAA provides free, 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 Consultant who reviews all of MSAA's medical information, and MSAA's Healthcare Advisory Council, comprised of top healthcare professionals who volunteer their time to MSAA. MSAA meets all criteria of the Better Business Bureau (BBB) Wise Giving Alliance and is in the exclusive group of national charities awarded the BBB Accredited Charity Seal. We also qualify as a High Performing Charity with America's Charities and achieved Gold Level status with GuideStar.

For more information on MS and MSAA, please visit our website at **mymsaa.org** or call **(800) 532-7667**. For information on how to support MSAA and its mission, please see pages 14 and 15 of this booklet.

Improving Lives Today...

By providing answers and encouragement

"I have only been diagnosed (with MS) for about a year. I wandered around in the dark for the first four months until I found the MSAA. I would like to thank the MSAA for all the help and encouragement they gave me. They helped me get through the roughest part of my life I've ever had."

– T.S. from Florida

Receiving a diagnosis of multiple sclerosis and living with the disease can be challenging, difficult at times, and understandably, life-changing. The course of the disease, the variability of its attacks and remissions, the myriad of symptoms, and its impact on work, family, and relationships often cause many uncertainties, questions, and the need for answers.



MSAA's Helpline allows individuals with MS, family members, care partners, and friends, to connect directly with one of MSAA's experienced Client Services Specialists and receive valuable information, guidance, and support. Our highly-trained specialists, who have a social services or counseling background, are available to assist individuals with MS and the people close to them adapt to the changes they may be experiencing, as they go through a life-long process of adjustments to best suit their evolving needs.

MSAA's specialists can offer encouragement to 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.



TOLL-FREE HELPLINE

EMAIL

MS CHAT

People may call our national **toll-free Helpline at (800) 532-7667, ext. 154** as well as connect to MSAA's Specialists via **email at MSquestions@mymsaa.org** and online through our **MS Chat feature**. Specialists are here to listen, provide reassurance and encouragement, answer questions, and link individuals to appropriate services. Topics commonly addressed by our specialists include:

- Updates on MS research, treatments, and prescriptionassistance programs
- MS research centers nationwide
- Health insurance and access to care
- Physical and occupational therapists
- Employment issues and vocational services
- Social Security programs
- Attorneys specializing in disability law
- Financial assistance programs
- Exercise and wellness opportunities
- Transportation services
- Overall healthcare information and resources



Improving Lives Today... By offering information and guidance

"I just wanted to really compliment you on this issue of your magazine. I have MS. I just think this is the greatest magazine talking about nutrition, diet, and how exercise has an impact on everything. Thank you very much."

– D.P. from California

Through a wide array of print, electronic, and web-based formats, MSAA provides current and easy-to-understand information as well as supportive resources on multiple sclerosis to individuals living with the disease and to their families. Additionally, the information presented explains, encourages, and promotes successful strategies to achieve overall wellness and positive health outcomes.

MSAA's website, mymsaa.org: With approximately one million visits annually, MSAA's comprehensive website provides a wealth of targeted information addressing all aspects of the disease, including currently approved treatments, symptommanagement techniques, and resources on how to adjust to the illness. The website also includes a news section to announce breaking MS news and updates, a listing of educational programs and other activities on the calendar of events, videos and archived webinars, interactive features – including a chat feature, blog, and social media plugins – and a variety of downloadable tools and guides.

Publications: All of MSAA's award-winning publications are printed in full color, with large print and interesting photos. Our explanations are clearly written, using the most up-to-date research available, and all medical information is reviewed by our Chief Medical Consultant. We provide important information along with hope for the future.

MSAA publishes a national magazine, *The Motivator*, twice per year and the widely acclaimed *MS Research Update*, annually. Additional publications include booklets and brochures covering topics such as explaining MS to young children, understanding depression in MS, managing MS relapses, discovering the benefits of aquatic exercise, obtaining health insurance, and other important issues affecting the MS community. Please visit **mymsaa.org/publications** or call (**800**) **532-7667** for more information.

Multiple Sclerosis Information (MSi) videos: MSAA offers a growing library of award-winning, on-demand video programming and archived webinars. These programs feature healthcare professionals who provide valuable insights and updated information on the latest advances in MS research, disease and symptom management, wellness strategies, and more. Please visit **mymsaa.org/videos** for more information.

Lending Library: As one of MSAA's longstanding and popular services, the Lending Library program offers a comprehensive array of books and DVDs organized into 10 categories that address disease and symptom-management updates, diet and exercise information, coping strategies offered by people living with MS, caregiving needs, and many other important topic areas. MSAA covers all outbound and return postage as participants can borrow one title at a time for up to 45 days. Please visit **mymsaa.org/library** for more information.

My Health Insurance Guide: Individuals with MS must consider an extraordinary number of factors when determining their health insurance coverage, including policy selections that impact costs as well as the ability to access treating specialists, disease and symptom-management medications, rehabilitation services, and more. My Health Insurance Guide is MSAA's online portal aimed at assisting the MS community with understanding the many details surrounding today's health insurance options, with specific focus on the Health Insurance Marketplace under the Affordable Care Act (ACA), Medicare, Medicare Advantage, and Medicaid. To learn more, please visit **mymsaa.org/healthinsurance**.

My MS Journey: Whether newly diagnosed or living with multiple sclerosis for many years, MSAA recognizes that each person's journey with MS is unique, complex, and ever-changing. To help individuals with MS find a clear, direct path to information they need now, MSAA developed My MS Journey, found at **mymsaa.org/journey.** This robust web portal guides visitors along the site through current and evergreen articles, useful links, and a wealth of on-demand videos and archived webinars. My MS Journey organizes MS-specific content and information into three distinct channels:

- Just Starting Out appropriate information guiding newly or recently diagnosed individuals
- **Staying On Course** targeted resources to help strengthen the day-to-day management of MS
- The Seasoned Traveler support services to address mobility, independence, and caregiving needs

Improving Lives Today...

By developing supportive tools and resources

When patients and their healthcare team are sharing information and working together rather than apart, the results of this teamwork can lead to great success. Known as "Shared Management," this philosophy 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.

Supported by MSAA, Shared Management is a learned skill involving education, training, use of technology, and "tools" to promote healthy outcomes. To support this effort, MSAA is continuing to develop a series of tools and resources to help members of the MS community take steps toward better health and an improved quality of life.

My MS Manager™: MSAA's mobile phone application, My MS Manager, is provided free of charge to individuals with multiple sclerosis or their care partners to use on their iPhone, iPad, iPod touch, or Android mobile device. This first-of-its-kind app for MS allows individuals to track disease activity, store medical information, and generate charts and reports across various metrics such as treatments, moods, symptoms, and more. Other HIPAA-compliant features include optional private reminder settings, links to further educational materials from MSAA, and – exclusive to My MS Manager – the ability to connect to physicians and other clinicians on your care team via the app to share your progress and reports securely and as needed. Please visit mymsaa.org/mobile for more information.



From a My MS Manager app user:

"Thanks for this, MSAA. This is a nice tool for tracking MS-related symptoms, medications, treatments, and so forth...I can see how this would be a good thing to bring with [me] to doctor visits because it can track lots of detailed info and might provide doctors with a level of detail you don't normally bring. Plus, it's free!"

- Review received via the Apple store

"This information (on SEARCH) is concise and takes one through the information in an organized and intelligent way. Having MS is complicated and finding one's way through all of this can seem insurmountable. I suspect this will be a very useful tool to the people who are willing to use it."

– MSAA's website visitor and SEARCH user

MSAA's S.E.A.R.C.H.™ Program: While having more than a dozen diseasemodifying therapies (DMTs) available to treat MS is encouraging, the safety, effectiveness, and tolerability of any given medication varies considerably from one individual to another. Among the many questions people should ask their physician when considering a treatment option include:

- What are the therapies and am I a candidate?
- What should I know about each one?
- How will my body react to taking one of these medications?
- How are the different medications administered?
- What about the costs or insurance?
- Once I have begun taking a DMT, how do I know if the one I am prescribed is working?

Additionally, people with MS must recognize the need to prioritize their issues, questions, and concerns in order to maximize the time with their healthcare team. With so much information to remember, organize, and prioritize, MSAA recognizes the need to help frame these important discussions. By doing so, MSAA is able to support people with MS and their physicians in their SEARCH for the most appropriate therapy.

Designed as a memory aid, the SEARCH acronym represents the key areas that should be considered when "searching" for the most appropriate MS treatment. Each letter represents an important topic that must be considered by patients, physicians, and other healthcare and social service professionals. SEARCH stands for:

- Safety
- Effectiveness
- Access
- Risks
- Convenience
- Health Outcomes (overall wellness and quality of life)



Reference Card

How to SEARCH for the Right MS Therapy for You!

- A quick and easy way to remember key questions to ask your healthcare team MSAA has created a SEARCH "toolkit" with helpful written materials to assist with the program. The tools include:

- The SEARCH Program Overview booklet
- New, archived webinar, *How to SEARCH for the Right MS Therapy for You!*, and accompanying PowerPoint presentation
- The SEARCH Patient Workbook
- An MS Disease-Modifying Therapy Chart showing currently approved treatments
- An MS Resource Guide
- A laminated, wallet-sized reference card

These written materials may be downloaded at **mymsaa.org/search**. Individuals without internet access may request this same information by calling MSAA at **(800) 532-7667**.

My MS Resource Locator[®]: Given the complex and ever-changing nature of multiple sclerosis, people living with MS and their care partners often need access to a wide array of accurate, targeted information and reliable resources. Unfortunately, navigating the vastness of the internet to locate MS-specific information can be challenging and lead to frustration and poor health decisions. As a result, MSAA has created an MS-specific, online database known as My MS Resource Locator.

Offering information and support services, My MS Resource Locator is designed to make the search for MS-related information and resources as easy as possible. The site organizes content into 10, client-requested MS categories ranging from insurance to housing needs. It allows people to conduct zip code searches to identify local, regional, and national resources. Additionally, the site provides supportive companion guides to help visitors better understand and utilize the information. To access this specialized database, please visit **resources.mymsaa.org**.

MS Relapse Resource Center: Relapses, also referred to as exacerbations or attacks, are initially experienced by most people diagnosed with multiple sclerosis. When someone experiences a relapse, he or she may be having new symptoms or an increase in existing symptoms. To help the MS community better understand and effectively manage their relapses, MSAA created the MS Relapse Resource Center. This special section of MSAA's website provides written and video content to help explain the onset and duration of a relapse, treatment options including various medications and rehabilitation approaches, and additional supportive tools to assist with the recognition and management of these attacks. To learn more about the MS Relapse Resource Center, please visit **relapses.mymsaa.org**.

Improving Lives Today... By enhancing safety and daily life

"I just wanted to write that I am so thankful for the cooling vest, walker, and leg lift. They are wonderful and so are you. I could not afford these items on my own. You are a Godsend to me and are making my life easier."

– D.T. from Nevada

Equipment Distribution Program: Some people with MS experience difficulty with balance and coordination, fine motor skills, and mobility. The MSAA Equipment Distribution Program offers products designed to improve their safety, dignity, mobility, and independence. MSAA provides these products at no charge and ships directly to the client. Items distributed through the program include a variety of bathroom and home-safety products such as shower chairs, grab bars, and hand rails, as well as mobility devices including canes, walkers, and wheelchairs. For more information, please visit **mymsaa.org/equipment**.

Cooling Distribution Program: Many people with MS are heat sensitive. MS research has proven that heat and humidity often aggravate common MS symptoms, and has also proven that cooling the body can help lessen these negative effects. The most common cooling product is a full-size vest with insulated pockets that hold small ice packs. The vests are worn over clothing and provide a temporary cooling relief that can last up to a few hours. In addition to the vests, companies have created a variety of cooling wraps to fit the neck, wrists, and ankles, giving people more options and the ability to stay active while cooling. The MSAA Cooling Distribution Program offers cooling vests and accessories at no charge for adults with multiple sclerosis as well as children diagnosed with pediatric MS. For more information, please visit **mymsaa.org/cooling**.

MRI Access Fund: Magnetic resonance imaging (MRI) is a valuable tool for diagnosing multiple sclerosis and tracking its progression. Both aspects are critically important in helping people find answers, monitor disease activity, and make informed treatment and healthcare decisions. The MSAA MRI Access Fund assists individuals who are uninsured, under-insured, or financially unable to pay for the exam, acquire a cranial MRI to confirm a diagnosis of MS or evaluate current MS disease progression. MSAA works with eligible individuals, physicians, imaging centers, and insurers to help fund the necessary MRI exam. For more information, please visit **mymsaa.org/mri.**

Online Aquatic Center: MSAA recognizes the importance of regular exercise as part of an overall wellness approach to effectively manage multiple sclerosis. For individuals who may have difficulty with traditional land-based activities, the unique properties of water combined with its cool temperature can create an inviting and sometimes ideal exercise environment for people with MS.

As part of the Swim for MS initiative, MSAA has created a comprehensive online Aquatic Center dedicated to increasing awareness, understanding, and availability of water-based exercise programs as a positive wellness opportunity for the MS community. The online Aquatic Center contains an informative guide, helpful articles, inspirational videos, webinars, tip sheets, links to available community pools and aquatic exercise programs, and additional supportive resources. To visit the site, please access **aquatics.mymsaa.org.**

Improving Lives Today... By engaging the MS community

"I want to thank you for putting together the wonderful seminar on April 2nd. It was nice hearing about all different MS treatments and learning how they differ. Also sharing our MS experiences with other patients at the table was very rewarding."

– B.B. from New York

Educational Programs: The landscape of multiple sclerosis is ever-changing. For this reason, individuals and family members urgently need to be proactive in managing their MS and to remain engaged in the conversation about their disease. Ranging from the latest advances in disease and symptom-management treatments, to new strategies on managing employment, relationships, and other life issues, MSAA's educational programs provide an excellent opportunity to connect our clients with many of the country's leading MS healthcare professionals. For more information, please visit **mymsaa.org** and select "Educational Programs," or call **(800) 532-7667**.

MSAA Art Showcase: These annual collections of beautiful artwork celebrate the talents of individuals with MS. Each year people with MS submit their work – often with a story about their love of art – and each month, an artist is featured. Website visitors may view these annual art galleries while reading the inspirational stories. Please visit **mymsaa.org/artshowcase** for details.



My MSAA Community: This free, peer-to-peer online forum enables people with MS, their families, and their care partners to share information and their experiences with multiple sclerosis. As a member of this friendly, supportive, and safe online community, individuals may:

- connect with other people affected by MS
- contribute to ongoing conversations
- start their own conversation with a question or a post about their journey

To join MSAA's online community, please visit **healthunlocked.com/mymsaa**. Please note that when you visit My MSAA Community, you will not be on MSAA's website. The online community is accessed through a separate site hosted by HealthUnlocked.com.

Social Media: Stay connected to MSAA! Receive the latest information about our programs and services, fundraising opportunities, important MS news, and more. Please follow MSAA on:



facebook.com/MSassociation



twitter.com/MSassociation



google.com/+MymsaaOrg



pinterest.com/MSassociation



Instagram.com/MSassociation



youtube.com/msaa



linkedin.com/company/multiplesclerosis-association-of-america



blog.mymsaa.org

MSAA's blog, **MS Conversations,** features timely, interactive discussions of topics important to the entire <u>MS community.</u>

Supporting MSAA's Mission of Improving Lives Today...

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 to continue to improve lives today for people affected by MS. Individuals may give to MSAA in many ways.

- Individual Contributions via MSAA's website at support.mymsaa.org/donate, or through a check or credit card payment directly to MSAA. Make an even bigger impact by joining our monthly giving program only \$10 per month provides a shower chair, bathtub-safety rail, and grab bar for one individual with MS.
- **Planned Giving** planned gifts benefit donors by allowing them to support MSAA beyond their lifetime and by offering tax advantages, income, and personal satisfaction. Planned-gift options include bequests, life insurance, and charitable-gift annuities.
- **Corporate Giving** workplace giving is an easy and efficient way for employees to make tax-deductible donations to charities through their employer payroll. To double the impact, employers can provide matching gifts for employee contributions that directly meet their corporate social-responsibility goals.
- Other Donations examples include honor and memorial donations, used vehicles, and even donations to MSAA in place of conventional wedding favors.
 - Volunteer Fundraising individuals and groups are encouraged to create their own fundraisers such as bake sales, golf outings, bowling tournaments, or your own unique idea. Swim for MS, MSAA's signature fundraising initiative, 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 mymsaa.org to inquire about supporting MSAA.

Dive into Action for the MS Community!

Swim for MS is a national fundraiser making waves all across the country! People of all ages and skill levels are raising awareness about MS while recruiting online donations to help the MS community. Funds are generated by establishing goals and asking others to support their efforts with a pledge or direct donation.

Volunteers create their own Swim for MS fundraising event such as swimming laps or setting a specific distance as a goal... individually or as part of a team... at home or at a swim facility... in honor of a family member or friend with MS... it's entirely up to you! Past Swim for MS challenges range from cannonball-jumping contests to college swim-team competitions, to synchronized swims, and to birthday parties. This is why we say, "Any Pool, Any Time!"



MSAA will guide you through the process to set up a personal web page to collect donations and to tell others about your Swim for MS fundraiser. You can even promote your challenge on Facebook and Twitter using #SwimForMS to gain awareness and additional support.

Please visit www.SwimForMS.org or email SwimForMS@mymsaa.org for more information, to register, and to check out some current Swim for MS challenges.

MSAA's Regional Offices

For information about regional events and activities, please visit **mymsaa.org** and select **"Calendar of Events."** While MSAA's national office serves the MS community throughout the United States, MSAA's regional offices can provide additional assistance on a more local basis.

Our regional offices support MSAA's mission by:

- Conducting awareness and educational programs
- Bringing people together through networking and events
- Fundraising activities, such as Swim for MS, an annual Wyoming-Yellowstone Snowmobile Ride, and the annual Lone Star Roundup Cattle Drive

MSAA Northeast Regional Office

For New Jersey, Delaware, New York, Pennsylvania, Connecticut, Vermont, Rhode Island, Massachusetts, Maine, Maryland, Washington DC, and New Hampshire

Toll-free: (800) 532-7667, ext. 144 Fax: (856) 488-8257 Email: northeast@mymsaa.org

MSAA Southeast Regional Office

For Florida, Georgia, North Carolina, South Carolina, Virginia, Alabama, Tennessee, and Mississippi

Toll-free: (800) 532-7667, ext. 160 Fax: (404) 842-0551 Email: southeast@mymsaa.org

MSAA South-Central Regional Office

For Texas, Arkansas, Oklahoma, Missouri, Louisiana, Colorado, Kansas, and New Mexico

Toll free: (800) 532-7667, ext. 137 Fax: (860) 646-4849 Email: southcentral@mymsaa.org

MSAA Midwest Regional Office

For Ohio, Illinois, Indiana, Kentucky, Michigan, Minnesota, West Virginia, Wisconsin, Iowa, North Dakota, South Dakota, and Nebraska

Toll-free: (800) 532-7667, ext. 150 Fax: (708) 223-0299 Email: midwest@mymsaa.org

MSAA Western Regional Office

For California, Oregon, Nevada, Utah, Arizona, Hawaii, Washington, and Alaska

Toll free: (800) 532-7667, ext. 155 Fax: (415) 520-1113 Email: western@mymsaa.org

MSAA Northwest Regional Office

For Idaho, Montana, and Wyoming

Toll free: (800) 532-7667, ext. 137 Fax: (860) 646-4849 Email: northwest@mymsaa.org



Multiple Sclerosis Coalition

MSAA is proud to be one of the three founding members of the Multiple Sclerosis Coalition (MSC). The MSC is an affiliation of independent MS organizations whose 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.**



MSAA's Mission: The Multiple Sclerosis Association of America (MSAA) is a leading resource for the entire MS community, improving lives today through vital services and support.

To help support MSAA's vital programs and services, please visit **support.mymsaa.org/donate** or call (800) 532-7667.

To learn more about MSAA's Swim for MS fundraising initiative, please visit **SwimForMS.org** or call (800) 532-7667, extension 157.



MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA

Improving Lives Today!™

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Stay Connected with MSAA:



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