

Winter/Spring 2023



THE Motivator

Published by the Multiple Sclerosis Association of America



Aging Well with MS

Part Two: Emerging Science & Enlightening Studies

Multiple Sclerosis Association of America

Improving Lives **Benefit** 2023

*Together—
Again*

WEDNESDAY, MAY 3

Philadelphia, PA



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Host

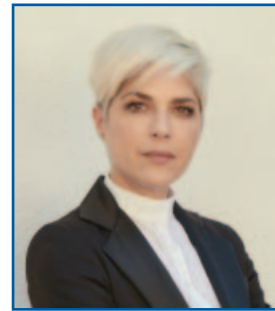


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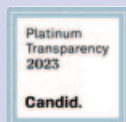
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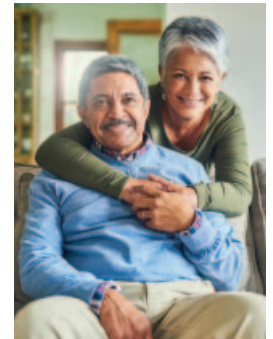


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By Tom Garry

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Multiple Sclerosis Association of America

The Multiple Sclerosis Association of America is a leading resource for the entire MS community, improving lives today through vital services and support.

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.

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Identifying and Meeting the Needs of the MS Community

By Gina Ross Murdoch

MSAA President and CEO

In the “Up Front” column of our previous issue of *The Motivator*, I shared the excitement we are all feeling with MSAA’s new and ongoing programs and events. I also talked about our current strategic plan for 2021-2023, and the many vital goals we have achieved.

We have been diligently working on the creation of our next strategic plan for 2024-2026. As part of our strategic planning process, we recently conducted a needs-assessment survey to both English and Spanish-speaking members of the MS community. Participation was voluntary and anonymous. The purpose of this survey was to gather information about the needs, interests, and concerns of individuals living with MS as well as those who provide support for them.

I am thrilled to report that so many members of the MS community responded to our survey, and I want to thank everyone who

participated! The information provided is essential in helping MSAA craft updated plans aimed at improving, expanding, and tailoring services to the needs of those impacted by MS.

In order to move forward with any strategic plan, financial support is vitally important to fund our urgently needed programs and services. The good news is that MSAA’s most successful fundraiser, our annual Improving Lives Benefit, is fast approaching! This exciting fundraiser has evolved into two events, each designed to best fit the needs and preferences of the attendees.

Our first event is Together Again, an in-person reception on Wednesday, May 3rd at the beautiful Barnes Foundation, which features an extensive art collection in Philadelphia, Pennsylvania. This is followed two weeks later by our virtual Improving Lives Benefit, taking place on Thursday, May 18th. This virtual option enables people from across the country to take part in this exciting event

Gina Ross Murdoch is a seasoned executive in non-profit management. Her career includes leadership positions with chapters of the Leukemia and Lymphoma Society as well as the American Diabetes Association. Earlier, she spent 14 years overseeing development activities at a large chapter of the National Multiple Sclerosis Society, leading explosive growth initiatives and ground-breaking strategic projects. An active member of the community, Ms. Murdoch has held several town positions and volunteers for her college alma mater, Drew University.

from the comfort of their own homes. We are thrilled to have inspirational speaker and MS community member Tyler Campbell hosting both events. Additionally, we will be recognizing two very special honorees.

Our Mission Honoree is the highly acclaimed actress and MS advocate, Selma Blair. Ms. Blair is also a New York Times Best-Selling Author, mom, and longtime supporter and friend of MSAA. Her advocacy has brought significant awareness of MS, prompting others to seek support. In 2021, a documentary of Ms. Blair's diagnosis of MS and challenging journey with the disease was released. Receiving rave reviews, *Introducing, Selma Blair*, is a candid and revealing look into her life during some of her most difficult moments with MS.

This year's Corporate Honoree is Polar Products. Under the leadership of President and CEO Jacob Graessle, Polar Products has become a leading manufacturer of cooling equipment used by the MS community. We are so proud of the partnership between MSAA and Polar Products for more than 20 years and we're inspired by their continued commitment to the MS community.

To learn more about our Improving Lives Benefit honorees, please refer to our "Thoughts About Giving" column, starting on page 38. Details are also available on our website at engage.mymsaa.org/benefit2023.

In addition, we are excited to announce that in recognition of MSAA's 53 years of dedicated service to the MS community, we will be holding our Anniversary Challenge

fundraising events in various cities across the country. As always, with our MSAA Anniversary Challenge, virtual opportunities to participate are also available. For more information, please visit engage.mymsaa.org/anniversary2023.

With great pride, I'm happy to announce another successful MS Awareness Month in March. MSAA's theme for this year's MS Awareness Month was "Life with MS: Different Stages of the Journey." Information, resources, and strategies to assist with the different stages of life with MS were highlighted throughout March. If you were not able to attend any of these educational programs, MSAA's MS Awareness Month's webinars and podcasts are archived on our website and may be accessed by going to mysaa.org/awarenessmonth. For more information, please see page 35 of our "Program Notes" column.

In conjunction with MS Awareness Month, MSAA was pleased to launch our 2023-2024 Art Showcase on MSAA's website. As always, the Art Showcase offers a vast collection of inspiring works of art by individuals living with MS. I am thrilled that we are able to continue to share this online gallery with the MS community.

And finally, in this edition of *The Motivator*, you will see that we have expanded upon the cover story from our previous edition. In this issue, we further explore the many aspects of aging with MS and the different approaches to best manage one's MS through the years. ■

**Part Two of a
Two-Part Series**

Aging Well with MS

**Emerging Science &
Enlightening Studies**

By Tom Garry

Edited by Susan Wells Courtney

Reviewed by Barry A. Hendin, MD

Aging presents challenges – and opportunities – for all people, but the challenges can be tougher to navigate and the opportunities more difficult to seize when the passage of years is accompanied by progression of multiple sclerosis (MS).

In Part One of this article, which appeared in the Summer/Fall 2022 issue



of *The Motivator*, several people with MS shared their encouraging stories about meeting the challenges of multiple sclerosis through the years. They also outlined effective strategies for making the most of opportunities to enhance health and to draw on one’s experience and hard-won wisdom

for the benefit of others. Part One of the article also addressed key medical issues and research studies related to aging and MS.

This second part of the article takes a deeper look at those clinical and scientific topics, including: changes in the focus of MS care over a person’s lifespan, how age factors into decision-making with regard to disease-modifying therapies (DMTs), important unanswered questions on aging and MS, how cognition is affected by the interplay between growing older and having MS, the study of immunosenescence (age-related decline in immune system function), and the implications of older people historically having been under-represented in MS clinical trials.

As with Part One of this article, the pages that follow include several practical steps for readers to consider in consultation with their clinicians.

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Clinicians' Evolving Approach to Managing MS as People Age



Does MS “settle down” or even become dormant as people age? It’s a controversial question with significant implications for what people with MS can expect and how the disease is treated.

MSAA Chief Medical Officer Barry Hendin, MD, says that the question is difficult to answer because so many of the manifestations of clinical worsening or disease progression that mark MS are also components of the aging process.

“Many, many people who do not have MS experience hearing loss, vision problems, slower cognitive processing, memory issues,

difficulties with balance, bladder and bowel problems, and a decrease in brain and muscle mass as they get older,” Dr. Hendin notes. He adds that this makes it challenging to sort out which problems are attributable to MS, which reflect “normal aging,” and which may arise from interplay between the two.

“Secondary progression in MS and aging run parallel to each other and seem to interact, although exactly how is unclear,” Dr. Hendin explains.

In addition, he points out that the changes typically seen in MS as people age, such as fewer relapses but increased disability, don’t

represent multiple sclerosis becoming dormant so much as they signal a shift in the prominence of the two processes that drive the disease.

He continues, “MS has both an inflammatory component and a degenerative component. Both are underway from the beginning of the disease process, but the trajectory of the two appears to differ. The inflammatory process predominates when you are younger, but diminishes decade by decade. This is why relapses usually occur less frequently as people age. The degenerative process becomes more of an issue later in life.

“In managing people across the lifespan,

clinicians’ focus needs to move in step with that transition,” adds Dr. Hendin, a neurologist who has treated people with MS for more than 50 years, caring for many of his

patients from their young adulthood to older age.

“In the past, we were so focused on relapses, and not focused enough on the degenerative process. The thrust in the last decade has been to pay

more attention to aspects of MS that don’t manifest themselves as dramatically as a relapse, but that still have a significant impact on health and quality of life, such as walking speed, bladder control, cognition, and balance.”

As one ages, the disease’s inflammatory process diminishes. However, the degenerative process becomes more of an issue later in life.



The Age-Old Dilemma: If and When to Modify Treatment



The question of how MS changes as people age, inevitably gives rise to the question of whether and how MS treatment approaches should change as people with MS grow older.

The answer is easy: “Yes” – in terms of increased use of medications, physical therapy, and other approaches to treat specific symptoms and aspects of the degenerative process, according to Dr. Hendin.

But the answer is not clear-cut when it comes to whether to continue or discontinue disease-modifying therapies as people grow older, he says.

Dr. Hendin explains, “We know when to start DMTs in a person with MS, which is as soon as possible, but whether and when to stop a DMT in a specific individual remains a matter of debate. That’s because the agents mostly provide benefit through their anti-inflammatory activity, and – as noted – the inflammatory component of MS tends to decrease with age. As this happens, the risk-

benefit calculus changes, with the benefits diminishing relative to the risk for infections or side effects. Because of this, some clinicians favor discontinuing DMTs altogether in a

person’s latter years, while others recommend a de-escalation strategy, such as shifting an older person from a high-efficacy DMT to a medication that is less potent but also has a lower risk for side effects.”

The available evidence doesn’t provide clinicians

and their patients with clear guidance on the issue. A 2017 analysis examined outcomes in more than 28,000 people with MS participating in clinical trials of immunomodulatory drugs. It found that the effect of DMTs on MS disability fell significantly with advancing age and calculated that the medications provide no efficacy beyond approximately 53 years of age. In another finding that lends support to de-escalation strategies, the analysis

How should MS treatment approaches change as one grows older?

Unfortunately, there is no clear-cut answer.

determined that high-efficacy DMTs outperform lower-potency medications in inhibiting MS disability only in people with MS younger than 40.5 years.¹

Conversely, a 2022 study conducted by physician researchers who belong to the New York State Multiple Sclerosis Consortium found that stopping a DMT in patients with stable MS led to disease worsening or progression regardless of patient age. The study looked at 161 people with MS who were classified as stable before stopping their DMTs. Fifty-three of those previously stable patients – or 32.9% of the total – subsequently saw their disability get worse or progress. Turning from the overall group to those with different types of MS, 29.2% of those with relapsing-remitting MS had worsening or progression, as did 40% of previously stable patients with secondary-progressive MS,

which tends to be more common in older age.²

With such contradictory findings, many clinicians hoped that a study called DISCOMS would serve as a tiebreaker. It didn't.

The DISCOMS (Discontinuation of Disease Modifying Therapies in Multiple Sclerosis) study was the first randomized trial of discontinuing MS drugs. The study was conducted at 20 MS centers across the United States, and enrolled more than 250 people with MS who were aged 55 years or older, and had not experienced a change in imaging results in three years or a relapse in the past five years. Study investigators randomly assigned 128 of those people to continue treatment with DMTs and 131 to discontinue therapy. The study subjects had an average age of 63 years at randomization, and the two groups were similar in terms of



other demographic characteristics. More than 80% of the participants were women.

The primary endpoint of the study was a relapse or new brain lesion over the course of two years. Importantly, the trial was structured as a non-inferiority study, meaning that it was designed to show that stopping DMTs was not worse – or inferior – to continuing them.

In reporting the trial’s much-anticipated results at the Annual Meeting of the

Consortium of Multiple Sclerosis Centers in June 2022, researchers explained that 4.69% of the participants continuing treatment and 12.21% of those discontinuing treatment had new disease activity. However, going into the trial, the investigators had specified an 8% margin for non-inferiority, so that stopping DMTs was not shown to be either statistically inferior or not inferior to continuing on therapy. Investigators did find, however, that stopping DMTs was not associated with worsening symptoms or quality of life.³

While an extension of the DISCOMS study and other discontinuation trials involving people with relapsing and secondary-progressive forms of MS may offer additional information, Dr. Hendin stresses that clinicians and patients need to work together to consider each person’s specific circumstances and come to an individualized decision.

“There’s an argument for considering de-escalation as people get older and the inflammatory aspect of MS is less prominent. At the same time, however, while relapses are less common in older people, they also are much harder to accommodate at 60 than at 30,” he says.

Dr. Hendin believes that identifying and understanding how to interpret biomarkers of disease activity, such as blood levels of the protein neurofilament light chain – which provide information on neuronal damage and increasingly are used to monitor response to DMT treatment – along with enhanced utilization of magnetic resonance imaging (MRI), will aid individualized decision-making.

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Still Far More Questions than Answers on Aging with MS

As noted in Part One of this article, which appeared in the Summer/Fall 2022 issue of *The Motivator*, a study on the impact of MS on health and functioning in aging women was conducted by Marianna Cortese, MD, PhD, a research scientist at the Harvard T.H. Chan School of Public Health.

Working with colleagues from other Harvard institutions and affiliated hospitals, Dr. Cortese drew on 25 years' worth of data from more than 200,000 participants in the Nurses' Health Study and Nurses' Health Study II to examine how 733 women with MS compared with their unaffected peers in terms of several indicators of physical and mental health as well as memory, to assess the burden of aging with MS. The study was noteworthy not only for its findings, but also

for its scope and even for the fact that such a study was conducted.⁴

As Dr. Cortese explains, until the study was published in the journal *Multiple Sclerosis* in January 2022, "There was overall little research on the topic of aging with MS, although there is a growing population aging with MS thanks to potent disease-modifying treatments. Previous studies were small, cross-sectional, and compared older and younger MS patients or MS patients to normative data unrelated to the study population. Our study is the first prospective study on this topic."

The neuroepidemiologist adds, "Although we know that individuals with MS can accumulate substantial disability during life, the disease burden has to date not been

systematically quantified. This is the first study which compared the aging and disability accumulation in individuals with MS to peers without MS drawn from the same study population, which makes them more comparable. By using health measures that are not disease-specific, such as the Physical Functioning-10 for assessing physical function, health surveys, and other health questions, we could conduct such a study and compare both groups.”

Having quantified the impact of MS on physical function and other aspects of health as women age, Dr. Cortese and her colleagues are now interested in assessing underlying factors and the role of various interventions. She explains, “Among women aging with MS, there is variability in the functional decline, even among women with the same initial disease course, with some women declining faster than others. It will be very important to investigate in future studies potential risk and protective factors that affect the speed of aging and disability accumulation.

“Modifiable factors are of special interest, as they would allow intervention. In our study, we adjusted for smoking, as smoking could both affect the risk of acquiring MS and lead to a faster functional decline directly or through smoking-related comorbidities, but smoking did not seem

to explain the large difference in aging among women with MS and women without. The Harvard cohorts with their long follow-

up of a large number of women throughout their life course and the collection of information on many exposures, including diet and other lifestyle factors, will be an ideal resource for future studies on potential modifiable factors of

aging and disability accumulation in MS.”

Dr. Cortese adds, “We only had limited data on treatment in this study. It was limited to the first-approved, lower-potency treatments. It would be interesting to compare how women with MS treated with potent disease-modifying treatments age compared to peers over the years.”

Thanks to the prevalence of effective disease-modifying treatments, there is now a growing population of individuals aging with MS.

MSAA Webinars and Videos

Check out MSAA’s latest webinars and videos covering a wide range of topics, providing helpful information and tips for the MS community. Several webinars and videos are available in Spanish. For more information, please visit mymsaa.org/videos.

A Population Missing from Phase III Clinical Trials



The issue of how high-efficacy disease-modifying therapies affect aging in people with MS is just one of many unanswered questions concerning older people and DMTs. Many of those questions remain unanswered because people in their 60's and older routinely are excluded from the Phase III clinical trials that pharmaceutical companies conduct when seeking Food and Drug Administration (FDA) approval of their investigational medications.

A review found that 16 recently conducted Phase III studies of DMTs set upper age limits for participation that ranged from 45 years to 55 years, with the latter

being the most frequently selected cut-off.⁵ Only one trial included in the review, the

open-label CONSONANCE study evaluating Ocrevus[®] (ocrelizumab) in patients with progressive MS, enabled people up to 65 years of age to enroll. (As of February 2023, the trial was still active but no longer recruiting. It has an estimated primary completion date of

January 2026.)

Researchers note that the practice of excluding people age 65 and older from Phase III studies reflects safety concerns rather than a lack of interest in the older population. The historical rationale, they explain, is that older people tend to have

The practice of excluding people 65 and older from Phase III studies reflects safety concerns, rather than a lack of interest in the older population.

more comorbid conditions and be on more medications than younger people, thus increasing their risk for adverse events and interactions between medications. Similarly, people who have age-related declines in kidney function or other processes that are essential for metabolizing drugs can face an elevated likelihood of problems. Further, they note that post-approval studies of DMTs often include people age 65 years and older or even focus specifically on that population.

Advocates for including older people in Phase III trials counter that the typical 65-year-old person today is in better overall health than their counterpart from earlier

years, when the age limits often were established. They add that safety concerns can be addressed by establishing exclusion criteria that address specific risks – such as other diagnoses, medicines the person may be taking, or impaired renal function – rather than using an arbitrary age cut-off as a generalized substitute for those factors.

While the debate about age limits for Phase III trials continues, what seems beyond debate is that further research of all kinds is needed to better understand the nature, impact, and treatment of MS in the growing population of older individuals living with the disease.

MSAA is very
proud to
present our
2023-2024

ART SHOWCASE

Each year, MSAA features the work of artists living with MS in the annual **MSAA ART SHOWCASE**, highlighting one artist each month as our Artist of the Month.

We received many wonderful submissions from more than 50 artists across the country and are delighted to share their work and inspiring stories!

View the complete gallery by visiting mymsaa.org/artshowcase2023



If You Are an Older Person with MS and Want to Participate in Research...

Although Phase III trials of new therapies typically will not enroll people in their 60s, there are still many opportunities for older people to be part of the research that is driving advances in MS care.

Asking your MS clinician about studies that may be appropriate for you is an excellent first step. Comprehensive MS centers and large neurology practices typically will have a nurse or other staff member acting as their clinical trials coordinator, and that person can also be a wealth of information.

The Multiple Sclerosis Association of America (MSAA) has an easy-to-use clinical trials search engine on our website: mymsaa.org/clinicaltrials. Powered by Antidote Technologies, the search engine can provide information on nearby suitable studies.

The government's clinicaltrials.gov website also has extensive information on clinical trials that are recruiting participants. If you're using the site, however, just be sure to look at the Eligibility Criteria box on the left and check the appropriate "Age Group" box so that you'll generate results applicable for you.



Finally, remember that not all research involves a trial evaluating a new therapy or other intervention. Some of the findings that have had the greatest impact on shaping MS care have emerged from patient registries and other observational studies that collect data on the lives and experiences of thousands and thousands of patients and then allow researchers to draw on that information (without patients' identities being revealed) to answer all sorts of questions.

The North American Research Committee on Multiple Sclerosis (NARCOMS) Registry collects information on roughly 42,000 people with MS, providing investigators with a treasure trove of insights into all aspects of living with MS. It is easy to enroll in NARCOMS, which is a project of the Consortium of Multiple Sclerosis Centers (CMSC), online at narcoms.org or via a paper form available at the same website address.

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The Science of Aging with MS: A Focus on Immunosenescence

A long word for a process that is a long time in the making, “immunosenescence” refers to an age-related decline in immune system function. This reduced immune capacity makes older people more susceptible to infection, autoimmune disease, cancer, and the effects of inflammatory processes.^{5,6}

While immunosenescence is a hallmark of aging in all people, it can take a particularly heavy toll on those with MS by:^{5,6,7,8}

- affecting production of the T cells and B cells that help regulate the immune system and fight off disease
- diminishing the brain’s capacity to repair tissue damaged by inflammation
- reducing response to disease-modifying therapies (DMTs)

The negative effects of aging on T cells begin not at age 65, or even at age 40, but at puberty, when the thymus – a small gland in the upper chest – stops growing and begins a process of involution, meaning a reduction in its size and function.⁶ This is significant because the thymus is where T cells, a type of white blood cell, mature before circulating throughout the body to find and attack

specific harmful foreign substances, known as antigens.

Meanwhile, B cells, which also are white blood cells, fight antigens by creating antibodies, proteins that neutralize foreign substances by binding to their surface to prevent them from entering a normal cell. B cells and T cells cooperate with one another in the fight against antigens through molecular processes that help identify and target those foreign substances.

One result of thymic involution is that the thymus produces a smaller proportion of naïve T cells that can be “programmed” to respond to newly recognized antigens. In addition, the number of regulatory T cells is increased, and these inhibit the action of their antigen-hunting counterparts. At the same time, there is reduced production of other specialized T cells – such as those known as CD4+ T cells – that interact with B cells to generate an immune response. Meanwhile, the bone marrow produces fewer immature B cells as people age. While the processes are complex, and not yet fully elucidated, the net effect is that older people have a reduced ability to make antibodies and respond to newly introduced antigens.⁶



Ongoing, low-grade inflammation is another frequent aspect of the aging process, and immune cells affected by immunosenescence may facilitate this process by secreting cytokines and other substances that further fuel inflammation. Rather than playing a role in repairing tissue damage, as immune cells do in younger people, the senescent cells “switch sides” and instead facilitate tissue damage, including neurodegeneration in the brain. MS can compound the problem because the disease damages oligodendrocytes, the central nervous system (CNS) cells that produce myelin. When these cells are damaged, they release iron, which can accumulate in the CNS, contributing to oxidative stress that causes even more neurodegeneration.^{6,9,10}

Researchers’ understanding of how immunosenescence and aging overall affect the efficacy and safety of DMTs in older individuals remains unclear, in part because people over the age of 55 are routinely excluded from Phase III clinical trials of those therapies (see “Still Far More Questions than Answers on Aging with MS” on pages 12-13). What scientists have documented, however, is

that many DMTs that are effective in treating relapsing-remitting MS, have less efficacy, or no demonstrated efficacy, when people move to non-active secondary-progressive multiple sclerosis (SPMS).

As one team of researchers noted, “Whether it is aging and age-related factors or the underlying immune senescence that qualitatively alter immune

response as the disease transitions to SPMS that diminish DMT effectiveness, or both, is currently not known.” However, the researchers noted that immunosenescence has numerous effects on the immune system that could detract from the efficacy of DMTs.⁸

As scientists seek to better understand and then address the factors that affect the health of the growing population of older people with MS, unraveling the dynamics of immunosenescence promises to be a major focus of their investigations.

◆

Immune cells affected by immunosenescence may facilitate ongoing, low-grade inflammation, which is also a frequent aspect of the aging process.

Aging, MS, and Cognitive Changes: Thinking Through the Complexities

Sorting out the degree to which declining function is attributable to aging, multiple sclerosis, or a combination of the two, is not easy for any aspect of health, but it is particularly challenging when it comes to cognition.

Several factors contribute to the challenge. First, of course, MS is a condition of the central nervous system, one marked by the presence of lesions in the brain and changes in brain volume, so the organ directly responsible for cognition is directly affected. Second, there are many components of cognition, from short-term and long-term memory to processing speed, verbal fluency, and more. Emerging evidence indicates that MS affects these different domains in different ways. And third, people's perception of their cognitive function is subjective and may itself be impaired by cognitive problems, so that a rigorous neuropsychological examination is often needed to obtain a reliable picture of a person's cognitive status.

Despite those challenges, researchers are making steady progress in better characterizing the nature of cognitive decline in older people with MS. Here are some key findings thus far:



- Aging and MS appear to have independent effects on memory, but there are indications that MS accentuates age-related declines in higher executive functions, such as planning and problem solving, as well as processing speed.¹¹
- Older people with MS tend to have lower scores than people of the same age without MS on tests of processing speed and verbal fluency.¹²
- The main cause of cognitive decline appears to be from atrophy of the cerebral cortex. This outermost layer of the brain is composed mostly of grey matter and contains 14 billion to 16 billion nerve cells. A high number of MS lesions in this area of the brain is associated with a high degree of cognitive disability.^{5,13}

While those results are discouraging, research has also yielded a number of encouraging results, particularly regarding the role of disease-modifying therapies (DMTs) in slowing or reducing cognitive decline in people with MS:

- A review of several relatively large (more than 100 patients) studies of DMTs showed those medications to have positive effects on various aspects of cognition.¹⁴
- An ongoing, long-term study involving almost 695 people with MS indicates that early initiation of high-efficacy DMTs significantly lowers risk for cognitive worsening.¹⁵
- A study involving 279 military veterans with MS receiving care at the Oklahoma City Veterans Affairs Medical Center showed that study participants who adhered to their DMT regimens had significantly less cognitive decline than those who did not adhere or who poorly adhered to treatment.¹⁶

Studies of investigational MS treatments and recently approved medications are examining how those therapies affect various aspects of cognition. However, even more research is needed, and some investigators argue that obtaining definitive information on how DMTs affect cognition will require conducting randomized controlled trials that specify cognitive measures

as their primary endpoints, not as secondary measures.¹⁷

While researchers gather more evidence, people with MS can help protect their cognitive health by adopting the brain-friendly practices that the National Institute on Aging recommends for all people, including keeping blood pressure at a healthy level, being physically active, not smoking, eating a healthy diet, and staying engaged with other people.¹⁷ ■

Please see page 26 for references.



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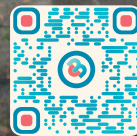
MS=multiple sclerosis.

For adults only. Walt D. takes KESIMPTA and has been compensated for his time.

*In 2 studies vs AUBAGIO[®] (teriflunomide).

[†]Once monthly after 3 weekly starter doses. Typical injection time; ensure indicator is full and stops moving.

Visit [kesimpta.com](https://www.kesimpta.com) or scan here to see more stories like Walt's.



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Indication

What is KESIMPTA (ofatumumab) injection?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including clinically isolated syndrome (CIS), relapsing-remitting disease, and active secondary progressive disease.

It is not known if KESIMPTA is safe or effective in children.

Important Safety Information

Who should not take KESIMPTA?

Do NOT take KESIMPTA if you have active hepatitis B virus (HBV) infection.

 NOVARTIS

Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936-1080

Important Safety Information (cont)

What is the most important information I should know about KESIMPTA?

KESIMPTA can cause serious side effects such as:

- **Infections.** Serious infections can happen during treatment with KESIMPTA. If you have an active infection, your healthcare provider (HCP) should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections. Tell your HCP right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.
- **HBV reactivation.** If you have ever had HBV infection, it may become active again during or after treatment with KESIMPTA (reactivation). If this happens, it may cause serious liver problems including liver failure or death. Before starting KESIMPTA, your HCP will do a blood test to check for HBV. They will also continue to monitor you during and after treatment with KESIMPTA for HBV. Tell your HCP right away if you get worsening tiredness or yellowing of your skin or the white part of your eyes.
- **Progressive Multifocal Leukoencephalopathy (PML).** PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your HCP right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory, which may lead to confusion and personality changes.
- **Weakened immune system.** KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

Before you take KESIMPTA, tell your HCP about all your medical conditions, including if you:

- Have or think you have an infection including HBV or PML.
- Have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- Have had a recent vaccination or are scheduled to receive any vaccinations.
 - You should receive any required 'live' or 'live-attenuated' vaccines at least 4 weeks before you start treatment with KESIMPTA. You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with KESIMPTA and until your HCP tells you that your immune system is no longer weakened.
 - Whenever possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with KESIMPTA.
 - Talk to your HCP about vaccinations for

your baby if you used KESIMPTA during your pregnancy.

- Are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your HCP about what birth control method is right for you during this time.
- Are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your HCP about the best way to feed your baby if you take KESIMPTA.

Tell your HCP about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How should I use KESIMPTA?

See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready pens or prefilled syringes.

- Use KESIMPTA exactly as your HCP tells you to use it.
- Your HCP will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars, or stretch marks.

KESIMPTA may cause serious side effects including:

- **Injection-related reactions.** Injection-related reactions are a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. Talk with your HCP if you have any of these signs and symptoms:
 - **at or near the injection site:** redness of the skin, swelling, itching, and pain or
 - **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, and tiredness.
- **Low immunoglobulins.** KESIMPTA may cause a decrease in some types of antibodies. Your HCP will do blood tests to check your blood immunoglobulin levels.

The most common side effects of KESIMPTA include:

- Upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache.
- Headache.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see accompanying Consumer Brief Summary on the following page.

Consumer Brief Summary

The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment.

To learn more about KESIMPTA (ofatumumab) injections, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-888-669-6682 or visit www.kesimpta.com.

What is the most important information I should know about KESIMPTA?

KESIMPTA can cause serious side effects, including:

Infections. Serious infections can happen during treatment with KESIMPTA. If you have an active infection, your healthcare provider should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections.

Tell your healthcare provider right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.

- **Hepatitis B virus (HBV) reactivation.** Before starting treatment with KESIMPTA, your healthcare provider will do blood tests to check for HBV. If you have ever had HBV infection, the HBV may become active again during or after treatment with KESIMPTA. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. You should not receive KESIMPTA if you have active hepatitis B liver disease. Your healthcare provider will monitor you for HBV infection during and after you stop using KESIMPTA. Tell your healthcare provider right away if you get worsening tiredness or yellowing of your skin or white part of your eyes during treatment with KESIMPTA.
- **Progressive Multifocal Leukoencephalopathy (PML).** PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your healthcare provider right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory which may lead to confusion and personality changes.

Weakened immune system. KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

What is KESIMPTA?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including:

- clinically isolated syndrome
- relapsing-remitting disease
- active secondary progressive disease

It is not known if KESIMPTA is safe or effective in children.

Do not use KESIMPTA if you:

- have active hepatitis B virus infection.

Before using KESIMPTA, tell your healthcare provider about all of your medical conditions, including if you:

- have or think you have an infection, including HBV or PML. See **“What is the most important information I should know about KESIMPTA?”**
- have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- have had a recent vaccination or are scheduled to receive any vaccinations.
 - **You should receive any required ‘live’ or ‘live-attenuated’ vaccines at least 4 weeks before you start treatment with KESIMPTA.** You **should not receive** ‘live’ or ‘live-attenuated’ vaccines while you are being treated with KESIMPTA and until your healthcare provider tells you that your immune system is no longer weakened.
 - **Whenever possible, you should receive any ‘non-live’ vaccines at least 2 weeks before you start treatment with KESIMPTA.**
 - Talk to your healthcare provider about vaccinations for your baby if you used KESIMPTA during your pregnancy.
- are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your healthcare provider about what birth control method is right for you during this time.
- are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take KESIMPTA.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use KESIMPTA?

See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready[®] pens or prefilled syringes.

- Use KESIMPTA exactly as your healthcare provider tells you to use it.
- KESIMPTA is given as an injection under your skin (subcutaneous injection), in your thigh or stomach-area (abdomen) by you or a caregiver. A caregiver may also give you an injection of KESIMPTA in your upper outer arm.
- Your healthcare provider will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars or stretch marks.
- The initial dosing is 20 mg of KESIMPTA given by subcutaneous injection at Weeks 0, 1, and 2. There is no injection at Week 3. Starting at Week 4 and then every month, the recommended dose is 20 mg of KESIMPTA administered by subcutaneous injection.

If you miss an injection of KESIMPTA at Week 0, 1, or 2, talk to your healthcare provider. If you miss a monthly injection, give it as soon as possible without waiting until the next scheduled dose. After that, give your KESIMPTA injections a month apart.

What are the possible side effects of KESIMPTA?

KESIMPTA may cause serious side effects, including:

See **"What is the most important information I should know about KESIMPTA?"**

- **Injection-related reactions.** Injection-related reactions is a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. Talk with your healthcare provider if you have any of these signs and symptoms:
 - **at or near the injection site:** redness of the skin, swelling, itching and pain or
 - **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, and tiredness.
- **Low immunoglobulins.** KESIMPTA may cause a decrease in some types of antibodies. Your healthcare provider will do blood tests to check your blood immunoglobulin levels.

The most common side effects of KESIMPTA include:

- upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache. (See **"What is the most important information I should know about KESIMPTA?"**)
- headache

These are not all the possible side effects of KESIMPTA. Call your doctor for medical advice about side effects.

You may report side effects to FDA at 1-800-FDA-1088.

How should I store KESIMPTA?

- Store KESIMPTA in a refrigerator between 36°F to 46°F (2°C to 8°C).
- Keep KESIMPTA in the original carton until ready for use to protect from light.
- If needed, KESIMPTA may be stored for up to 7 days at room temperature, up to 86°F (30°C).
- Write the date taken out of the refrigerator in the space provided on the carton.
- If stored below 86°F (30°C), unused KESIMPTA may be returned to the refrigerator and must be used within the next 7 days. If this KESIMPTA is not used within those 7 days, then discard the medicine.
- Do not freeze KESIMPTA.
- Do not shake KESIMPTA.

Keep KESIMPTA and all medicines out of the reach of children.

General information about the safe and effective use of KESIMPTA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use KESIMPTA for a condition for which it was not prescribed. Do not give KESIMPTA to other people, even if they have the same symptoms that you have. It may harm them.

You can ask your pharmacist or healthcare provider for information about KESIMPTA that is written for health professionals.

What are the ingredients in KESIMPTA?

Active ingredient: ofatumumab

Inactive ingredients: Sensoready pen and prefilled syringe: arginine, disodium edetate, polysorbate 80, sodium acetate trihydrate, sodium chloride, and Water for Injection. Hydrochloric acid may be added.

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Questions from Our Readers

By Dr. Barry Hendin

MSAA's Chief Medical Officer

Q: I'm in my twenties and was recently diagnosed with MS, although I've been having symptoms for years. At least by getting this diagnosis, I was relieved to know there was a reason for my many problems, including dizziness, weakness, and being constantly tired. In addition to treating my symptoms, my doctor mentioned long-term treatments, but I have no idea what the best options are, or if I should even go on this type of medication.

I know I have a lot of questions, but if you can at least give me an idea of where to start and what treatments I might consider, this would be very helpful.

A: I think that anyone who has been recently diagnosed with multiple sclerosis has, and should have, a lot of questions regarding therapies. The answers should evolve collaboratively from discussions with your clinician or team of clinicians. These physicians should be your best guide and should take the time to think with you, answer your concerns, and consider your

options. An excellent tool for understanding the available therapies for multiple sclerosis is MSAA's new Ultimate MS Treatment Guide, which lists, describes, and compares all of the medications approved by the Food and Drug Administration (FDA) for the treatment of MS. To access this online, interactive guide, please visit **[MStreatmentguide.org](https://www.mstreatmentguide.org)**.

The best long-term approach to treating multiple sclerosis is with a disease-modifying therapy (DMT) – in order to reduce relapses and disability progression – plus an emphasis on “wellness,” which includes a healthy diet, exercise, avoidance of tobacco, and maintaining good mental health and social connections.

The specific choice of a disease-modifying therapy will depend upon your discussions with your clinician. It should be comforting to know that more than 20 agents are available at the present time, with more therapies anticipated during the coming year. With such a variety of treatments available, this should allow you to find the therapy that is most compatible with your individual MS presentation as well as your individual concerns.

Q: I recently experienced a very uncomfortable and unexpected symptom of extreme pressure and tightening around my chest and ribs, making it hard to breathe and lasting for a few minutes. I thought I was having a heart attack, but the symptom subsided before I was able to call for help. I immediately consulted my doctor, who wanted me to get checked to make sure I was okay, but as my doctor suspected, this was diagnosed as an “MS hug.”

I had never heard of this symptom and am hoping I won't have to experience it again. Do many people get this, and can you tell me what causes an MS hug? Is there anything I can do to keep it from happening again?

A: Although this was your first episode of an “MS hug,” you seem to have done everything right. You saw your clinician in order to rule out other causes. Fortunately, the episode was brief and did not require any interventions. When the episodes are brief and infrequent, a conservative approach is correct.

People can experience MS hugs quite differently. Although it is commonly experienced in the chest or abdomen, it can affect any part of the body. The quality is often one of tightness or spasm, but for some people, it can be quite painful. The episodes are generally brief and infrequent, but may occasionally be more persistent.

Various factors may be involved with the MS hug. The MS hug falls under the category of “dysesthesia,” meaning an “unpleasant abnormal sensation” in Greek. Dysesthesia

in MS is caused by inflammation or injury to the nerves of the central nervous system, interrupting the smooth flow of nerve impulses and sending mixed signals to the body and its muscles. Muscle spasms around the ribs can also cause uncomfortable sensations of tightening and squeezing.

Additionally, the same triggers that cause one's MS symptoms to temporarily worsen may also trigger an MS hug. These include conditions such as overheating, being under too much stress, being overly fatigued, or when fighting an illness or infection.

When the episodes are persistent or frequent, a variety of medications may be tried. These include baclofen, amitriptyline, and gabapentin. For most people, however, medication won't be required.

Certain “home remedies” may also be tried to help reduce the intensity of the pain or help the body to “translate” the sensation into a pain-free feeling of pressure, but many are specific to each individual. These might include wearing loose clothing (others may find that wearing tight clothing is helpful), applying heat or taking a warm bath, or using relaxation techniques, including meditation, yoga, and deep breathing. Lifestyle changes such as avoiding stress, treating an infection or illness, eating a balanced diet and drinking enough water, staying cool, and getting plenty of rest – may help prevent or minimize an MS hug.

For more information, please visit this section of MSAA's website at mymsaa.org/ms-hug.

Q: My husband has secondary-progressive MS and recently started having trouble while eating. He often coughs or even chokes a bit not only with food but also with any liquid he drinks – including water. Are there any treatments that can help this problem, and is there anything I can do to make eating more comfortable for him? I’ve also heard he can get some kind of pneumonia from coughing or choking while eating or drinking, but I’m not sure what this is.

A: Your husband’s problem is not uncommon in multiple sclerosis. People with MS may have occasional or persistent problems swallowing solids, or more frequently liquids. This is known technically as “dysphagia.” This certainly can be disconcerting when it does occur.

You are correct that it can increase the possibility of a type of pneumonia called “aspiration pneumonia.” This isn’t a common occurrence, but dysphasia does increase the risk for pneumonia when food particles or liquids get into the lungs.

Sometimes the solution is as simple as cutting food into smaller bite sizes or adding thickening to liquids. Sometimes it is behavioral, and strategies such as slowing down at meals, making sure that one’s posture is upright when eating, or clearing

one’s throat to eliminate retained food or liquid, can be helpful.

When the problem doesn’t resolve simply, professionals such as an ear, nose, and throat specialist (ENT) or a speech therapist can test swallowing directly and help to provide appropriate, individual therapies.

It is important to remember that although swallowing problems can be disconcerting, they are treatable. ■

Barry A. Hendin, MD, is a highly accomplished neurologist who specializes in MS. He is the chief medical officer for the Multiple Sclerosis Association of America (MSAA) and has spoken at several of MSAA’s educational programs. After 45 years as a neurologist with Phoenix Neurological Associates, Ltd., Dr. Hendin is now director of the Arizona Integrated Neurology MS Center. He is also director of the Multiple Sclerosis Clinic at Banner University Medical Center and clinical professor of neurology at the University of Arizona Medical School.

*Please submit questions
for Ask the Doctor via
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Recent News and Study Updates in MS Research

By Susan Wells Courtney

Reviewed by Dr. Barry A. Hendin

MCAA's Chief Medical Officer

Recently Approved Briumvi™ Now Available for Relapsing Forms of MS

In December, TG Therapeutics announced that the United States Food and Drug Administration (FDA) approved Briumvi™ (ublituximab-xiiy) for the treatment of relapsing forms of multiple sclerosis (MS) in adults – including clinically isolated syndrome, relapsing-remitting MS, and active secondary-progressive MS. This medication is a monoclonal antibody that targets CD20, a protein on the surface of B cells, and induces B-cell depletion within 24 hours. B cells are white blood cells shown to play a role in MS. Briumvi is given by infusion, with two initial doses administered 14 days apart, followed by a one-hour infusion every 24 weeks.

The Phase III ULTIMATE I and ULTIMATE II trials were identical, double-blind, and double-dummy (placebo) studies taking place at 104 sites throughout 10 countries. Enrolled participants were between the ages of 18 and 55, were diagnosed with relapsing MS, were limited to the use and timing of certain disease-modifying treatments, and had an Expanded Disability Status Scale

(EDSS) score of 0 to 5.5 (with greater scores indicating more significant disability).

Between September 2017 and October 2018, the ULTIMATE I trial enrolled 549 individuals and the ULTIMATE II trial enrolled 545. Participants were randomized and the numbers were split in half to receive either Briumvi with an oral placebo or Aubagio with an intravenous placebo. The median follow-up of these studies was 95 weeks (a little less than two years) and some of the results were determined through a pooled analysis of both trials.

In studies, Briumvi met its primary end point of reducing annualized relapse rates when compared to individuals taking the oral medication, Aubagio® (teriflunomide). It also met certain secondary endpoints, including the reduction of gadolinium-enhancing lesions as seen on magnetic resonance imaging (MRI), compared to individuals taking Aubagio. Among those taking Briumvi, the most common adverse event was infusion-related reactions (47.7%). Fever, headache, chills, and flu-like symptoms were the most commonly reported symptoms when experiencing an infusion-related reaction.

This new therapy is now available to individuals with MS through their healthcare providers. For more information, please refer to MCAA's online news item, "FDA approves Briumvi™ for the treatment of relapsing forms

of MS” at mymsaa.org; readers may also visit TG Therapeutics’ dedicated patient support website at briumvipatientsupport.com or call **1-833-BRIUMVI (1-833-274-8684)**.

First Orally Disintegrating Version of Fingolimod Now Available

A new Gilenya® (fingolimod) biosimilar has been approved by the United States Food and Drug Administration (FDA) for relapsing forms of MS and is now available. Marketed under the brand name, Tascenso ODT® (fingolimod), this new formulation is the first and only Gilenya biosimilar to be available in convenient, orally disintegrating tablets.

A biosimilar medication is one that is very similar, but not identical to, the original

medication. In order to bring a biosimilar to market, manufacturers need to follow specific guidelines set by the FDA before submitting an application. It must include clinical data showing that the product is of the same efficacy (effectiveness), along with the same safety and purity, as the original biologic, making it “highly similar” to the original, with “no clinically meaningful difference.” This is why the term “biosimilar” is used.

Tascenso ODT® (fingolimod) is an orally disintegrating tablet taken once daily, with or without water or food. It is available in two strengths: 0.25mg and 0.5mg. This formulation dissolves on the tongue within seconds, providing an easy and convenient administration of a DMT. Parent company

Shop and Support the MS Community

Online shopping is a great way to support MSAA’s mission of Improving Lives Today, with several brands making donations to MSAA with every purchase!



To see all of your shopping options to support MSAA, please visit mymsaa.org/ShopAndSupport



Cycle Pharmaceuticals Ltd (Cycle) offers an in-house patient-support program called Cycle Vita™. For those who want to initiate or continue treatment with fingolimod, the Cycle Vita program will help to take the place of Gilenya's patient-support Go Program, which is no longer available to individuals with MS.

Tascenso ODT is specifically indicated for the treatment of relapsing forms of multiple sclerosis (MS), including clinically isolated syndrome, relapsing-remitting disease, and active secondary-progressive disease, in adults as well as pediatric patients 10 years of age and older. The dose for adults and children weighing more than 88 pounds is 0.5mg daily; children weighing 88 pounds or less receive 0.25mg daily.

As a biosimilar to Gilenya, which was originally FDA-approved in 2010, Tascenso ODT has the same benefits and risks as Gilenya. In studies over the course of two years, individuals taking Gilenya, experienced significant reductions in: relapses; new or enlarging/enhancing lesions; three-month confirmed disability progression; and [reductions in] brain volume loss. Common side effects with Gilenya include headache, flu, diarrhea, back pain, respiratory infections, abnormal liver tests, and cough.

For more information, the Cycle Vita patient-support team may be contacted by calling **1-888-360-VITA (1-888-360-8482)** or visiting **www.cyclevita.life**. ■

Become an MSAA Monthly Improver!

MSAA Monthly Improvers are a generous group of donors making automatic, monthly gifts to improve the lives of people with MS.

Recurring donations make it easy for you to support MSAA's free programs and services – while also providing MSAA with a reliable stream of revenue each month.

Questions?

Contact Donor Relations at
(800) 532-7667, ext. 174, or
DonorRelations@mymsaa.org



SIGN UP TODAY!

engage.mymsaa.org/improver



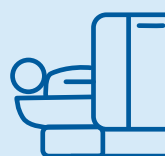
\$10/month (\$120/yr)
provides shower chairs for two individuals with MS



\$15/month (\$180/yr)
provides a wheelchair for an individual with MS



\$25/month (\$300/yr)
provides a cooling vest for two individuals with MS



\$60/month (\$720/yr)
provides an MRI exam for an individual with MS

MSAA's Vital Programs and Services Improve Lives Today

By Susan Wells Courtney

MSAA's Helpline Supports the MS Community

We can all use resources, information, and support in our lives... and MSAA's Helpline, with its trained and experienced Client Services Specialists, is ready and able to provide these invaluable services when you need them. Whether you are seeking vital resources, have questions about MS – including symptoms and treatments – or are in need of comfort and reassurance, our Helpline Specialists are here to help.

Several thousand members of the MS community reach out to our Helpline each year for assistance and support. If you are in need of information or have questions, please

contact **MSAA's Helpline** via phone, email, or online chat. Helpline hours are Monday through Friday, 8:30 AM to 8:00 PM (Eastern). We invite you to call our toll-free number at **(800) 532-7667, ext. 154** or connect with our Helpline Specialists through email at **MSQuestions@mymsaa.org**.

To reach a Spanish-speaking Client Services Specialist, please call **(800) 532-7667, extension 131**. Para comunicarse con un Especialista de Servicios al Cliente que habla español, llame al **(800) 532-7667, extensión 131** o envíe un correo electrónico a **MSQuestions@mymsaa.org**. El horario de la línea de ayuda es de lunes a viernes, de 8:30 AM a 8:00 PM, hora del este.

MSAA's Webinars

MSAA hosts a number of educational and supportive webinars throughout the year. All of MSAA's live programs are hosted by top MS specialists, providing up-to-date, expert information on topics vital to the MS community. To view upcoming webinars and register, please visit our calendar of events at **mymsaa.org/calendar**.



MSAA's MSi Video Library

Have you recently visited our full library of MSi (MS information) videos, plus recorded webinars? If not, you may be interested in the vast collection of informative videos and recorded webinars available! Topics range from disease and symptom management to lifestyle strategies to programs addressing health equities and diversity. Several of our webinars and videos are also available in Spanish. To access this full library of webinars and videos, please visit **mymsaa.org/videos**.

MS Awareness Month Recap

Every year in March, MSAA offers a series of educational programs and other vital activities for the MS community, all in recognition of MS Awareness Month. During March, our programs centered on “Life with MS: Different Stages of the Journey,” and included podcast episodes and webinars that addressed MS management within different age groups. These stages and areas of focus included pediatric MS, young adults and MS, family planning, and aging well with MS. The programs, which were recorded and are now available on MSAA’s website, are as follows:

- **“Navigating the Pediatric MS Journey”** podcast episode with Dr. Yolanda Wheeler and Elena McDaniel, a parent of a child with MS

- **“Young Adults Living with MS”** podcast episode with Dr. Nuriel Moghavem
- **“Family Planning and Living with MS”** webinar with Dr. Rohini Samudralwar
- **“Healthy Aging with MS”** webinar with Dr. Lana Zhovtis Ryerson

Other activities during MS Awareness Month included: our Improving Lives Through Art® Spring Series, the launch of MSAA’s digital Art Showcase, posts on MSAA’s MS Conversations blog, plus TikTok videos and other updates through MSAA’s social media channels. For more information or to access these podcast episodes and webinars, please visit mymsaa.org/awarenessmonth for more information.

Fulfilling MSAA’s Mission through Our Programs and Services

Those of you who are familiar with MSAA, know that we are dedicated to fulfilling our mission of Improving Lives Today through vital services and support. For more than 50 years, we have worked closely with the MS community to identify the most urgent needs and learn how to best address such challenges.

Of significant concern is safety, along with mobility, accessibility, and comfort. **MSAA’s Equipment Distribution Program** is one of MSAA’s longest running programs, providing a range of much-needed items, from grab bars, shower chairs, and walkers, to wide-grip utensil sets and yoga mats. In addition to

safety and mobility, these types of equipment products greatly improve quality of life and enhance activities of daily living.

These items are provided at no charge to those with MS who qualify for assistance and products are shipped directly to the client. MSAA is able to offer equipment items every three years to eligible individuals with MS.

Another urgent need that is very common among members of the MS community stems from an issue known as “heat sensitivity.” When heat and humidity increase, the symptoms of MS often worsen, causing problems such as changes in vision, overwhelming fatigue, extreme weakness,

and more. However, research has shown that cooling the body with cooling vests and accessories can reduce the negative effects of heat and humidity on a person with MS.

MSAA's Cooling Distribution Program offers free cooling vests and accessories to eligible individuals with MS to provide relief from heat sensitivity and the symptoms it causes. Those who qualify may receive cooling products from MSAA once every five years.

When talking about the needs of the MS community, virtually everyone is familiar with the necessity and the expense of magnetic resonance imaging (MRI). Individuals who meet eligibility requirements and are in need of an MRI to help determine a diagnosis of multiple sclerosis or evaluate current MS disease progression, can receive help through **MSAA's MRI Access Program**.

For eligible individuals who do not have insurance or cannot afford their deductible, MSAA will cover the cost of new cranial and/or c-spine MRIs at an imaging center that is under contract with MSAA. For eligible individuals with insurance, MSAA will cover the cost of one's medical insurance co-pay or

co-insurance balance up to a maximum of \$750 per new MRI (cranial and/or c-spine).

For eligible individuals who previously had a cranial and/or c-spine MRI, MSAA will cover up to \$750 per MRI with a date of service within the past six months of the date of one's application. MSAA pays the imaging center directly and does not reimburse the client.

To Learn More About These MSAA Programs and Services:

MSAA's Equipment Distribution Program:
mymsaa.org/equipment

MSAA's Cooling Distribution Program:
mymsaa.org/cooling

MSAA's MRI Access Program:
mymsaa.org/MRI

In addition to these programs noted above, MSAA offers a wide range of educational materials and other vital services. Please visit mymsaa.org or call **(800) 532-7667** for more information.

STAY CONNECTED

Follow MSAA on social media:
[@MSassociation](https://twitter.com/MSassociation)



To sign up for MSAA email updates, please visit mymsaa.org/email-signups

MSAA's 2023-2024 Art Showcase

As previously mentioned, in conjunction with MS Awareness Month in March, MSAA launched our 2023-2024 Art Showcase!

This unique program features a wide variety of beautiful artwork created solely by individuals with MS, along with their personal stories of how art has been a positive influence in their lives. A call for submissions is announced each year in the fall for the following year's collection.

This year's 2023-2024 Art Showcase received works of art submitted by more than 50 artists in locations across the country. Accepted mediums include works in oil, watercolor, and acrylic, as well as pastels, pencil, and ink. MSAA also accepts digital artwork, including graphic design and photography.

Each month throughout the year, we highlight one artist and their work. This year's collection of artwork and personal/inspirational stories may be viewed by going to mymsaa.org/artshowcase2023. We hope you will browse through and enjoy these beautiful works of art from this year's Art Showcase, as well as those from previous years. ■



Georgia On My Mind
Jennifer Reida in CA



Unbroken
Maria Sammartino in NJ



1947 Chris Craft DCFB Sally Haas in MI



The Barn Stanley Gilbert in VT

MSAA Honors Inspirational Advocates

By **Rebecca Mooney**

MSAA Vice President of Development



MSAA's Improving Lives Benefit, "Together Again" will be held at the beautiful Barnes Foundation in Philadelphia on May 3rd, and for MSAA's friends and family across the country, we will gather again at our "Together at Home" virtual reception on May 18th. These exciting events will recognize Selma Blair as our Mission Honoree and Polar Products as our Corporate Honoree. Both events will be hosted by our friend and MS community inspiration, Tyler Campbell.

MSAA's Improving Lives Benefit Mission Honoree: Selma Blair

The world was first introduced to Selma Blair on the big screen – perhaps it was from the movie *Cruel Intentions*, *Legally Blonde*, or the *Hellboy* franchise. For MSAA, we were first introduced to Selma as a client in 2019, after her diagnosis in August 2018. Similar to many people living with multiple sclerosis, Selma had a daunting road to diagnosis.

For much of her life, Selma dealt with trigeminal neuralgia, thought by doctors to be caused by dental issues. In addition, over the years she lived with vision loss, balance issues, temporary paralysis, muscle spasms, and extreme fatigue. For Selma, she describes the diagnosis as, "...almost a relief. I finally knew that everything I had been experiencing was real, and I could start to trust myself again."



Selma Blair
Actress, MS advocate, New York Times Best-Selling Author, mom, and longtime supporter and friend of MSAA

When Selma met Gina Ross Murdoch, President and CEO of the Multiple Sclerosis Association of America, she was surprised to learn that there were things she could do to relieve some of the symptoms she dealt with each day. One in particular was heat sensitivity. An avid horseback rider, and mom of a young boy, Selma struggled to manage in the heat – causing vertigo, dizziness, and even passing out – all of which had a serious impact on her life. When she learned about MSAA’s cooling program, she reached out to Polar Products and their cooling vest was a game changer. Also during that initial meeting with MSAA, the guidance she received included learning about the need for a strong support network. Selma says, “I didn’t really understand support until I met MSAA.”

“In the beginning, at the start of engaging with MS in a public way, I met the incredible Gina Ross Murdoch with MSAA and I was heartened. While I was compelled to find speedy answers, this was an organization for MS that was truly active in improving lives of people adjusting to MS, in profoundly simple, moving, generous ways. That meeting, and what MSAA offers like the MRI program, stayed with me. I am genuine in my appreciation of MSAA and so proud to have joined forces here.”

Since that meeting in 2019, Selma has worked to share her personal journey in a variety of ways. Her Instagram provides a view of her life and has opened the doors for her to connect with others, both as an inspiration and to draw support. Additionally, in her 2021 documentary, *Introducing, Selma Blair*, she shares an intimate and raw portrait of her personal journey with MS. Selma has become a staunch advocate for those living with MS, as well as the disability community as a whole, using her status as a well-known actress to draw attention to work that still needs to be done.

Dancing with the Stars

Selma appeared as a contestant in the 2022 season of Dancing with the Stars, and ultimately left because of the impact the experience was having on her body. Selma said, “I was getting stress fractures throughout my body, and because of the MS, I couldn’t tell so they kept getting worse.”

Her work on Dancing with the Stars and in so many other ways introduced the subject and struggles of MS to the general public. Selma worked closely with her dance partner, Sasha Farber, to overcome some of her challenges related to MS — for example, they never led with her left foot. Although Selma did not see herself as a very good dancer, leaning on her partner Sasha, along with the adrenaline from the experience, pushed her through... and she loved every moment.

Thoughts About Giving

Through her partnerships with Guide Beauty, Google, and QVC, who recently named her their first-ever Brand Ambassador for Accessibility, Selma has advocated for disability inclusion and accessibility for all. She has also been steadfast in spreading the word about MSAA. Selma works diligently to ensure that everyone living with MS knows where they can find assistance. She ensured MSAA was listed as the key resource and source of support at the end of her documentary. In addition, she has hosted two Instagram takeover events, where she took over MSAA's Instagram account for a day and shared information about her experiences with MS as well as MSAA's resources with her large following – driving traffic to MSAA's website and resources.

Each year, MSAA looks for a Mission Honoree who has been generous in sharing their own MS story in support of others living with the challenges of MS. MSAA seeks someone who has inspired and humbled us with their strength and their openness. Selma fit the bill for all that and more.

“With Selma's substantial efforts around advocacy as part of the MS and disability communities, the timing seemed perfect,” Gina Ross Murdoch said. “She is not afraid to lean into her triumphs and her struggles with equal intensity. She is the epitome of an ‘advocate’ and an ideal choice for MSAA's Mission Honoree.”



President and CEO Jacob Graessle and his wife, Erin, representing their company, Polar Products, which has proudly partnered with MSAA for 20 years

MSAA's Improving Lives Benefit Corporate Honoree: Polar Products

In the 1990s, MSAA pioneered the scientific research of cooling technology for MS symptom management. Partnering with NASA engineers and researchers at several top MS centers, results from MSAA-funded studies proved the beneficial effects of temporarily cooling the body for people with MS. As a result of these vital findings, MSAA's Cooling Distribution Program was born in 2003. Since its inception, this program has been providing cooling vests and accessories to people with MS, helping to reduce symptoms and alleviate the effects of heat sensitivity.

To learn more about MSAA's Improving Lives Benefit and to register, please visit engage.mysaa.org/benefit2023. The first 500 virtual registrants by May 8th will receive a special gift from MSAA!

To meet the needs of the MS community, MSAA reached out to a variety of companies marketing wearable cooling technology, and thus began a 20-year partnership with Polar Products. Last year alone, MSAA provided nearly 1,500 cooling products to clients in need.

Each year MSAA works to recognize a single corporation for their work in making a difference in the lives of those impacted by MS, and in 2023, Polar Products was the obvious choice.

Beyond serving as a key partner for two decades since the inception of MSAA's Cooling Program, the team at Polar has always gone above and beyond to serve the MS community. A small, family-run business, the relationship with MSAA began through Bill Graessle, affectionately known as "Polar Bill," and has continued with his son, CEO Jacob Graessle.

MSAA has also worked closely with Fundación de Esclerosis Múltiple de Puerto Rico (the Puerto Rico Multiple Sclerosis Foundation) for several years, ensuring that clients in need can access our key services. Puerto Rico has suffered the compounded effects of multiple disasters in recent years, including the devastating impacts of two

hurricanes in 2017, a major earthquake in 2020, and the COVID-19 pandemic, as well as economic challenges. In 2022, when

clients in Puerto Rico were dealing with an increased need for cooling equipment, MSAA put out a call to our cooling vendors to help ensure that need was met. Polar Products stepped up with a sizable donation, and the MS Foundation in Puerto Rico (MSAA's 2020 Mission Honoree) worked to hand deliver vests across the island for clients with limited ability to travel.

"The MS community

is an integral part of the Polar Products family, and we are proud of our 20-year partnership with MSAA supporting the needs of those members of the MS community whose quality of life could be significantly improved with the help of our unique line of cooling products," explains Polar Products CEO Jacob Graessle. "We are thankful to be featured in the 2023 Improving Lives Benefit, and are steadfast in our commitment to working together to improve lives of those living with MS."

MSAA is grateful for our strong partnership and look forward to continuing our work with Polar Products and the Graessle family. We are proud to recognize them as the 2023 Corporate Honoree. ■

"Today I used my cooling vest and neck wrap for the first time. I received it this past Thursday. I cannot thank you enough for sending this to me! I was able to walk around in the heat, at the Farmers' Market with my kids with no MS symptoms! Thank you!"

– Peggy from Arizona

"Just received my cooling equipment and want to thank you so much! This is life changing in this Texas heat. I so appreciate it. I'm still learning my limitations and the heat was a tough lesson to learn, but now I feel safer having this. ❤️"

– Lauren from Texas

Taking Small Steps and Changing My Life for the Better

By Virginia Oman

My name is Virginia Oman and I have secondary-progressive multiple sclerosis (SPMS). I was diagnosed back in 1988, and my first symptoms were visual changes, numbness, and loss of balance. Many have described me as a “phoenix in human form,” because I have transformed my life from “ashes” to “flight.”

Currently, I am a personal fitness trainer, wellness coach, instructor for the YMCA, licensed mental health therapist, and life coach. Several years ago, I served as an ambassador for MSAA, extolling the many life-changing benefits of aquatic exercise. My passion is to share my knowledge with others to help them transform their lives into a brighter and healthier state of mind, body, emotions, and spirit.

However, things were not always this positive – and I want to tell you my story of how I changed my life for the better. Having been to the depths of despair and seriously planning to exit out of this world due to all the losses I sustained from MS, I suddenly heard a voice inside me that gave me the message that would turn everything around and give me my life back. I now have more energy, more joy,



Personal fitness trainer Virginia Oman uses her own life experiences to help others transform their lives into a healthier state of mind, body, emotions, and spirit.

more vitality, and more fulfillment than even before MS came into my life.

My body had declined to the point of being in a wheelchair, with no energy despite doing everything my doctors recommended. This resulted in many losses... including my career, my home, and treasured activities I once loved. It was one loss after another.

I am sending out a message to anyone reading this who has MS – and especially those who may be struggling. I have been to the bottom and I found a way out. I not only have my life back, but a much better life.

While most individuals with MS may be able to make positive changes mentally, emotionally, and spiritually, I also recognize that everyone is affected by MS differently and not all are able to make the types of positive physical changes that I have experienced. By setting very small goals for yourself, you may be able to find that you can make a difference in your life. My advice is to listen to your body and ask it to tell you what it needs most in order to heal.

I listened to my intuition and followed the call of what it was my body was telling me it needed. I felt the need to increase my physical capabilities and to take a more

natural direction. Then I designed a course of action and went to work. I started in the pool, setting small goals. My legs were too weak to even kick. But I started anyway, utilizing a stroke I made up myself.

I did not see any improvement at first, but I kept at it every day. After a few weeks, I saw a bit of improvement in my energy level, which was very exciting. Then after another month, I started to get a little movement in my legs. Three months later, my legs were actually able to start doing small kicks again. This progression kept going because I refused to give up. By the end of eight months, I was actually swimming 30 minutes of continuous laps!

I also want to mention that by using a similar, very gradual process of setting small goals and increasing my activity level, I was

able to regain my ability to ride a bicycle. I started with a small, children's bike without pedals. This allowed me to walk while seated on the bike, and from there, I worked to balance and glide, starting with just two-second intervals at a time.

The process continued, as I got up every day at 4:00 AM to fit in two hours of specific bike exercises before leaving for work – and then did the same when I got home. It

required 64 specific steps that I developed and a total of 11 months to complete. This was a long journey, but certainly worth every effort, as I am now riding a full-

sized, two-wheeled bike, and yes, with pedals!

I have continued to listen to my body and work out, not only in the water or on a bicycle, but now I'm walking with lightweight hiking poles. Even if it's 15 degrees outside... I'm out in my parka walking because I know all this movement has given me my life back. Nothing is more vital to me. In the evenings I'll do some cardio on my stationary bike as well as stretching. I learned my lesson loud and clear: find your path and pursue it daily. Don't give up. Be stubborn! Be determined!

I am now living the life of my dreams and have totally dedicated my life to helping others be able to do the same. That's my passion, my gift, and I am happy to share it with others in need.

Virginia shares her story on her website at virginiaoman.com. ■

“By setting very small goals for yourself, you may be able to find that you can make a difference in your life.”

Connect with others and find support on My MSAA Community



Join more than 8,000 members who have similar experiences with multiple sclerosis in this online peer-to-peer forum.

- Get advice and support while connecting directly with people affected by MS
- Feel more confident managing one's own health or family's health
- Solve day-to-day challenges

Join My MSAA Community today:

healthunlocked.com/msaa



MSAA's Ultimate MS Treatment Guide

New Treatment Updates for 2023

This unique online tool helps individuals with MS and their care partners make an informed choice on treatment in conjunction with their physician:

- Compare FDA-approved MS treatments and filter results
- View videos of experts and advocates discussing treatment information and their experiences
- Learn about treatment philosophy



Find out more at MStreatmentguide.org

TEAM
MSAA

ANNIVERSARY
CHALLENGE



Run | Walk | Bike | Come Together

Are you ready for MSAA's **Anniversary Challenge?**

To recognize our 53 years of service in 2023, we are building a bigger, wider, and more inclusive Team MSAA.

- **No registration fees**
- **New way to create and track your progress**
- **Support for virtual and in-person options**



Scan to learn more

NEW THIS YEAR: FIVE REGIONAL LOCATIONS

That's right - while the Anniversary Challenge is and always will be a nationwide event, we're excited to announce that this year, **MSAA will also be coming to five cities:**

PENNSAUKEN, NJ

June 10

FORT COLLINS, CO

June 17

AUSTIN, TX

June 17

ST. LOUIS, MO

September 9

HOUSTON, TX

October 14

LEARN MORE AT engage.mymsaa.org/anniversary2023

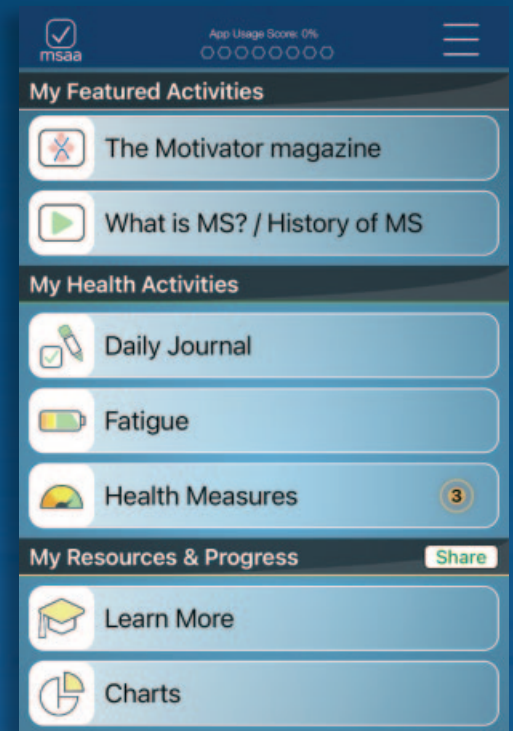
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to join the tens of thousands of people already using the app to help stay on top of their MS symptoms.



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