

Winter/Spring 2022



THE Motivator

Published by the Multiple Sclerosis Association of America

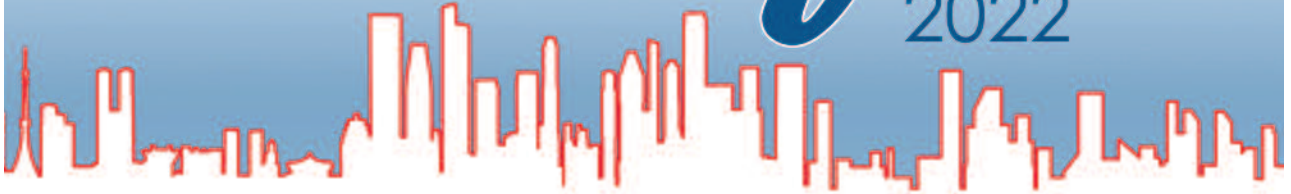
THE
Therapeutic Value
OF THE

Arts



MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA

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Benefit
2022



Tyler Campbell
Host



Alexandra von Plato
Corporate Honoree



Hannah Garrison
Mission Honoree

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By *Laura Bradford*

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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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Meeting the Challenges

By Gina Ross Murdoch
MSAA President and CEO

Historically, MSAA’s “Up Front” column has played a vital role for communicating updates on MSAA’s programs and services, its newest initiatives, and exciting successes. But particularly within the past two years, we have reflected upon the challenging events that have impacted everyone.

As the pandemic reached far and wide, we saw increases in anxiety and fear, loneliness and depression, as well as job loss and supply shortages. To promote better emotional and mental wellbeing, as well as provide individuals with vital information, MSAA created a wide variety of educational resources and extended our Helpline hours. Our Helpline specialists answered several thousands of calls, providing support to address a wide variety of needs. Despite whatever challenges are occurring around us, please know that

MSAA is committed to continue and expand upon our programs that provide the assistance so urgently needed by members of the MS community.

With regard to MSAA’s work, most of you may know that March was MS Awareness Month. Each year, throughout the month of March, MSAA works to provide the MS community with several learning opportunities. With the theme of “Shaping the MS Experience,” programs included online educational activities addressing the clinical approach to MS. Choosing an MS therapy, the science behind MS, and understanding progression, were among the vital topics presented. For more information, please refer to our “Program Notes” column beginning on page 34.

I also want to let everyone know that we have two events as part of MSAA’s annual Improving Lives Benefit coming up in May. Now in its seventh year, MSAA’s in-person event will be held in Philadelphia on May 5th,

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.

while our virtual Improving Lives Benefit, now in its second year, will take place on May 12th. By adding this virtual option, people from across the country may take part in this exciting event 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 honoring two very special individuals. Our Corporate Honoree is Alexandra von Plato, MSAA Board Member and CEO of Publicis Health. Our Mission Honoree is Hannah Garrison, a long-time visual artist and MSAA Art Showcase participant, as well as a volunteer and community leader who brings the arts to people facing life-altering health challenges. For more information, please refer to our “Thoughts About Giving” column beginning on page 38.

Another especially important event is Team MSAA’s 3rd annual Anniversary Challenge. To commemorate the founding of MSAA on June 8, 1970 (6-8-1970), we invite individuals to join us in walking six miles, running eight miles, or biking 19.70 miles... or any combination of the three! Please visit MSAA’s Anniversary Challenge at engage.mymsaa.org/anniversary2022 for more information.

Before concluding this issue’s “Up Front” column, I want to say a few words about our cover story. For many of us, we get caught up in our daily activities and we forget – or at least don’t take the time for – certain extracurricular activities. In our cover story,

we talk about how participating in the arts can benefit individuals both mentally and physically, leading to a more positive outlook and a better quality of life. Art therapists, music therapists, and other therapists, have worked with individuals with MS in achieving very positive results. Please read about this important topic, starting on page 4.

Wishing you all a happy spring! ■

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THE Therapeutic Value OF THE

Arts

BY LAURA BRADFORD

Beyond the medications and therapies, such as physical, occupational, and speech, which are a part of combatting the effects of autoimmune diseases including multiple sclerosis, there is a lesser acknowledged yet equally important component making its own impact: Art.

So often, when we think of “art,” we think of paintings and drawings... We think of our favorite bands and the musical instrument we played in elementary school... And we think of famous authors of literature toiling away over a notepad and pen or an old-fashioned typewriter.

Fortunately for all of us, that is only the tip of the proverbial iceberg. Art is our chance to express our creativity, to flex our imagination, and, in the words of Thomas Merton, an American Trappist monk, writer, theologian, and poet, “to find ourselves and lose ourselves at the same time.”

But beyond all of that, “art” in its many forms can also improve mental, and in some cases, physical health, as well.

How, you ask? Let’s take a closer look and find out...



Music

A peek at an online dictionary defines “music” as: “vocal or instrumental sounds (or both) combined in such a way as to produce beauty of form, harmony, and expression of emotion.” For a board certified music therapist like Betsy Hartman, MT-BC, NMT-Fellow at the Swedish Multiple Sclerosis Center in Seattle, it also allows for clinical intervention to help address speech, motor, and cognitive needs, as well as emotional and mental health.

“When the brain is not communicating to the body the way we want it to, music can step in as that bridge,” says Hartman. “For instance, if a patient has difficulty walking, I can use rhythm – a steady one-two-three-four tempo – to help them sync up to the beat, enabling them to walk more smoothly.”

Sometimes finding that bridge comes

down to the use of a metronome. And sometimes, verbal prompts, notes on a piano, or a favorite song are used to help a therapist find the appropriate tempo – or time keeper, if you will – for a patient. This type of gait training is known as Rhythmic Auditory Stimulation.

“A simple song like ‘You Are My Sunshine’ can be what a patient needs to improve their gait. By listening to the song as they walk, the patient entrains to the tempo and cadence which, in turn, adds structure and stability to their walking pattern. From there, they can transition to humming the song as they walk – it becomes a musical support or crutch,” says Hartman. “Sometimes a patient can pick this technique up right away, but sometimes it comes with training.”

Gait isn’t the only physical skill for which music therapy has shown improvement in MS. Balance, muscle strength, and hand function can also be positively impacted.

Researchers Josiane Lopes and Ivo Ilvan Keppers conducted a systemic review of clinical trials related to music-based therapy in the rehabilitation of people with multiple sclerosis. They selected ten trials to review. Those ten trials sampled a total of 429 individuals with a total of 253 allocated to the

*Cover story author **Laura Bradford** is a USA Today Bestselling author of more than 37 books (34 of those since her own diagnosis with MS in 2006). When she's not writing, she enjoys baking, traveling, and kayaking. She lives in South Carolina with her husband.*



experimental MBT (music-based therapy) group, and 176 to the control group (those on conventional therapies or no intervention at all). The music-based therapy areas of rhythmic auditory, playing musical instruments, dance strategy, and neurological music were all explored. Lopes and Keppers found that, overall, “the studies consistently showed that MBT was better than conventional therapy or no intervention, with regard to gait parameters, fatigue level, fatigability, emotional status, and pain.” This led to their conclusion that “MBT is a safe and effective approach for clinical rehabilitation of MS patients that leads to positive results regarding motor and non-motor functions.”

Still another intervention often used by music therapists focuses on psychosocial support. Therapy in this area might include listening to songs that make a person happy

and, in turn, help with the motivation needed for therapy compliance.

A German article written by H Lengdabler and WR Kiessling (*Psychother Psychosom Med Psychol*, 1989) looked at group music therapy as a psychotherapeutic treatment. Over a two-year timeframe, 225 people with MS were given an opportunity to participate in music therapy group sessions following admission to an MS clinic. The data gleaned from those sessions suggest that the group sessions were “a useful adjunct not only in actual psychological support but also in individual coping strategies.”

Another study, this one by D. Aldridge and colleagues, also looked at musical therapy in the treatment of those with multiple sclerosis. This pilot study included 14 women and six men who participated in eight-to-10 music therapy sessions over the



course of a year. A summary of the findings published in *Complementary Therapies in Medicine* in 2005, said that “individuals who participated in music therapy demonstrated improved fatigue, mood, and self-acceptance.”

Depending on the goal for an individual, music therapy can entail listening to/playing instruments, singing, songwriting, and, as we already touched on, movement. Sessions are often in-person, but the pandemic and its need for virtual visits has really widened the reach.

Megumi Azekawa, MM, MT-BC Neurologic Music Therapist, Fellow, recently began a weekly program at the Swedish MS Center called “Singing in the Brain.” The goal of this singing-based exercise group is to promote vocal health and help improve speech and voice challenges in people with MS.

“I call singing the whole brain workout. It helps people with MS to restore, maintain, and improve emotional, physical, and physiological health and wellbeing,” Azekawa explains. “When we sing, we must breathe more deeply than when we talk. Therefore, singing helps you to send more oxygen to the brain which promotes better cognitive processing, motor control, and better mood and feeling.”

Singing, Azekawa points out, also stimulates the areas of the brain involved in attention, memory, information processing, sequencing, organizing, and decision-



making. In addition, “For people with MS who are experiencing speech and swallowing difficulty, singing and vocal exercises can be a good way to strengthen the muscles that are involved in swallowing and respiratory function.”

Intrigued, but have never seen yourself as having any sort of musical ability? No worries.

“Our goal is to teach all people how to access the benefits of music to support physical and mental health. Our goal isn’t to make anyone a musician – although that can sometimes be an added bonus,” Hartman says. “Think about it this way, just like people aren’t required to be athletes to participate in physical therapy, people aren’t required to be musicians to participate in music therapy.”

Cathy Lykes has been participating in music therapy sessions for nearly five years and she is a big believer in its many benefits. Physically, she enjoys the opportunity to use muscles she might not normally use. Emotionally, she appreciates the lift it brings her on a not-so-good day. And socially, she

enjoys the opportunities it provides to connect with others who understand the MS journey.

“If I’m having a bad day, I know that if I can connect with a class, my day will go better,” Lykes says. The class she takes, led by Hartman, offers something for everyone – an aspect Lykes enjoys.

“Betsy [Hartman] uses a wide variety of instruments depending on each person’s ability. Drums, xylophones, bells, whistles, and even scarves for movement are used. And some people simply sit and listen to the music and that’s okay.”

The key, Lykes says, is to not be intimidated by the word “music.”

“Music therapy has done so much for me,” Lykes says. “You don’t have to know how to play an instrument or sing a song.

None of that is necessary. Just give it a try. I always feel better and less stressed when I attend a session.”

As for how people with MS can go about exploring the possibility of music therapy for themselves, Hartman reminds people of the importance of always advocating for oneself. She recommends talking to your healthcare provider, physical therapist, or occupational therapist, to let that professional know you’d like to see how music therapy can benefit you and your MS journey. For more information, including a list of more than 8,000 board-certified music therapists in the country, please visit the American Music Therapy Association at musictherapy.org. You can also visit msinharmony.com to find out more about how music therapy might help your mind, body, and soul.





Art

Art therapy, like its music counterpart, has its place in helping to give people a constructive way in which to work through the frustration, anxiety, and fear of living with a disease like MS.

A pilot study published in 2014 in *Journal of Neuroscience Nursing* by Fraser and Keating looked at a four-week creative art program with 14 women with MS in attendance. Each week a new art form was explored to include beading, collage-making, knitting, and watercolor. At the end of the program, there was a “statistically significant improvement on the Rosenberg Self-Esteem Scale, the Herth Hope Index, the Modified Social Support Survey, and the MS Self-Efficacy Scale.” They concluded, “The creative art program was found to be effective and had a positive influence on self-esteem, hope, social support, and self-efficacy to function and control MS.”

Outcomes like these don’t surprise Sherry Warner, MFA, MA, ATR-BC, ATCS, who works in private practice in southern New Jersey and as an adjunct professor of art therapy at St. Joseph’s University in Philadelphia. She describes art-making as a “multi-layered sensory experience that provides all humans with the ability to free up space that has been

blocked by trauma and any powerful experiences that are ‘held’ in the body and mind.” She explains that observing art can also be an act of therapy via its ability to enliven the imagination and spark creativity.

“I have a memory of finding the book, *I Never Saw Another Butterfly: Children’s Drawings and Poems from the Terezin Concentration Camp*, in my parent’s room when I was a child.” Warner explains, “The images are at once devastating and unspeakably powerful. The pictures drawn by these children tell a story that no words could express. Art was a way for a few to retain their uniqueness and dignity, and in doing so hopefully found some peace.”

Art therapists are educated in both the visual arts and psychotherapy and can assist people with the facilitation of various processes and materials that can lead to deeper levels of creative expression and relief. They can work within a wide range of unstructured to structured materials based on a person’s physical abilities, needs, and cognitive or developmental functioning levels. Some of the most widely used mediums in art therapy include: collaging, drawing, painting, and sculpting.

continued on page 12



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IMPORTANT FACTS

The information below does not take the place of talking with your healthcare professional. Only your healthcare professional knows the specifics of your condition and how ZEPOSIA® (ozanimod) may fit into your overall therapy. Talk to your healthcare professional if you have any questions about ZEPOSIA (pronounced zeh-poe'-see-ah).

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

ZEPOSIA may cause serious side effects, including:

1. Infections. ZEPOSIA can increase your risk of serious infections that can be life-threatening and cause death. ZEPOSIA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 months of stopping treatment. Your healthcare provider may do a blood test of your white blood cells before you start taking ZEPOSIA.

Call your healthcare provider right away if you have any of the following symptoms of an infection during treatment with ZEPOSIA and for 3 months after your last dose of ZEPOSIA:

- fever
- feeling very tired
- flu-like symptoms
- cough
- painful and frequent urination (signs of a urinary tract infection)
- rash
- headache with fever, neck stiffness, sensitivity to light, nausea or confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

Your healthcare provider may delay starting or may stop your ZEPOSIA treatment if you have an infection.

2. Progressive multifocal leukoencephalopathy (PML). ZEPOSIA (ozanimod) can increase your risk for PML, which is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems but has happened in people who do not have weakened immune systems. Symptoms of PML get worse over days to weeks. Call your doctor right away if you have any new or worsening symptoms of PML that have lasted several days, including:

- weakness on 1 side of your body
- loss of coordination in your arms or legs
- decreased strength
- problems with balance
- changes in your vision
- changes in your thinking or memory
- confusion
- changes in your personality

3. Slow heart rate (also known as bradyarrhythmia) when you start taking ZEPOSIA. ZEPOSIA may cause your heart rate to temporarily slow down, especially during the first 8 days that you take ZEPOSIA. You will have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of ZEPOSIA. Call your healthcare provider if you experience the following symptoms of slow heart rate:

- dizziness
- lightheadedness
- feeling like your heart is beating slowly or skipping beats
- shortness of breath
- confusion
- chest pain
- tiredness

Follow directions from your healthcare provider when starting ZEPOSIA and when you miss a dose. See **"How should I take ZEPOSIA?"**.

IMPORTANT FACTS (CONT'D)

See **“What are the possible side effects of ZEPOSIA (ozanimod)?”** for more information about side effects.

What is ZEPOSIA?

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

It is not known if ZEPOSIA is safe and effective in children.

Do not take ZEPOSIA if you:

- have had a heart attack, chest pain (unstable angina), stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months.
- have or have had a history of certain types of an irregular or abnormal heartbeat (arrhythmia) that is not corrected by a pacemaker.
- have untreated, severe breathing problems during your sleep (sleep apnea).
- take certain medicines called monoamine oxidase (MAO) inhibitors (e.g., selegiline, phenelzine, linezolid).

Talk to your healthcare provider before taking ZEPOSIA if you have any of these conditions or do not know if you have any of these conditions.

Before taking ZEPOSIA, tell your healthcare provider about all of your medical conditions, including if you:

- have a fever or infection, or you are unable to fight infections due to a disease or take or have taken medicines that lower your immune system.
- received a vaccine in the past 30 days or are scheduled to receive a vaccine. ZEPOSIA may cause vaccines to be less effective.
- Before you start treatment with ZEPOSIA, your healthcare provider may give you a chicken pox (Varicella Zoster Virus) vaccine if you have not had one before.
- have had chickenpox or have received the vaccine for chickenpox. Your healthcare provider may do a blood test for the chickenpox virus. You may need to get the full course of the vaccine for chickenpox and then wait 1 month before you start taking ZEPOSIA.
- have a slow heart rate.
- have an irregular or abnormal heartbeat (arrhythmia).
- have a history of a stroke.
- have heart problems, including a heart attack or chest pain.
- have high blood pressure.
- have liver problems.
- have breathing problems, including during your sleep.
- have eye problems, especially an inflammation of the eye called uveitis.
- have diabetes.
- are pregnant or plan to become pregnant. ZEPOSIA may harm your unborn baby. Talk with your healthcare provider if you are pregnant or plan to become pregnant. If you are a female who can become pregnant, you should use effective birth control during your treatment with ZEPOSIA and for 3 months after you stop taking ZEPOSIA. Talk with your healthcare provider about what birth control method is right for you during this time. Tell your healthcare provider right away if you become pregnant while taking ZEPOSIA or if you become pregnant within 3 months after you stop taking ZEPOSIA.
- are breastfeeding or plan to breastfeed. It is not known if ZEPOSIA passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take ZEPOSIA.

Tell your healthcare provider about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Using ZEPOSIA with other medicines can cause serious side effects. Especially tell your healthcare provider if you take or have taken:

- medicines that affect your immune system, such as alemtuzumab
- medicines to control your heart rhythm (antiarrhythmics), or heart beat
- CYP2C8 inducers such as rifampin
- CYP2C8 inhibitors such as gemfibrozil (medicine to treat high fat in your blood)
- opioids (pain medicine)
- medicines to treat depression
- medicines to treat Parkinson's disease
- medicines to control your heart rate and blood pressure (beta blocker medicines and calcium channel blocker medicines)

You should not receive **live** vaccines during treatment with ZEPOSIA, for at least 1 month before taking ZEPOSIA and for 3 months after you stop taking ZEPOSIA. Vaccines may not work as well when given during treatment with ZEPOSIA.

Talk with your healthcare provider if you are not sure if you take any of these medicines. 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 take ZEPOSIA?

You will receive a 7-day starter pack. You must start ZEPOSIA by slowly increasing doses over the first week. Follow the dose schedule of: Days 1-4: 0.23 mg 1 time a day; Days 5-7: 0.46 mg 1 time a day; Days 8 and thereafter: 0.92 mg 1 time a day.

This may reduce the risk of slowing of the heart rate.

- Take ZEPOSIA (ozanimod) exactly as your healthcare provider tells you to take it.
- Take ZEPOSIA 1 time each day.
- Swallow ZEPOSIA capsules whole.
- Take ZEPOSIA with or without food.
- Avoid certain foods that are high (over 150 mg) in tyramine such as aged, fermented, cured, smoked and pickled foods. Eating these foods while taking ZEPOSIA may increase your blood pressure.
- Do not stop taking ZEPOSIA without talking with your healthcare provider first.
- Do not skip a dose.
- Start taking ZEPOSIA with a 7-day starter pack.
- If you miss 1 or more days of your ZEPOSIA dose during the first 14 days of treatment, talk to your healthcare provider. You will need to begin with another ZEPOSIA 7-day starter pack.
- If you miss a dose of ZEPOSIA after the first 14 days of treatment, take the next scheduled dose the following day.

What are the possible side effects of ZEPOSIA?

ZEPOSIA can cause serious side effects, including:

- See **“What is the most important information I should know about ZEPOSIA?”**
- **liver problems.** ZEPOSIA may cause liver problems. Your healthcare provider will do blood tests to check your liver before you start taking ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
 - unexplained nausea
 - vomiting
 - stomach area (abdominal) pain
 - tiredness
 - loss of appetite
 - yellowing of the whites of your eyes or skin
 - dark colored urine
- **increased blood pressure.** Your healthcare provider should check your blood pressure during treatment with ZEPOSIA. A sudden, severe increase in blood pressure (hypertensive crisis) can happen when you eat certain foods that contain high levels of tyramine. See **“How should I take ZEPOSIA?”** section for more information.
- **breathing problems.** Some people who take ZEPOSIA have shortness of breath. Call your healthcare provider right away if you have new or worsening breathing problems.
- **a problem with your vision called macular edema.** Your risk for macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis. Your healthcare provider should test your vision before you start taking ZEPOSIA if you are at higher risk for macular edema or at any time you notice vision changes during treatment with ZEPOSIA. Call your healthcare provider right away if you have any of the following symptoms:
 - blurriness or shadows in the center of your vision
 - sensitivity to light
 - a blind spot in the center of your vision
 - unusually colored vision
- **swelling and narrowing of blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) is a rare condition that has happened with ZEPOSIA and with drugs in the same class. Symptoms of PRES usually get better when you stop taking ZEPOSIA. If left untreated, it may lead to a stroke. Your healthcare provider will do a test if you have any symptoms of PRES. Call your healthcare provider right away if you have any of the following symptoms:
 - sudden severe headache
 - sudden confusion
 - sudden loss of vision or other changes in your vision
 - seizure
- **severe worsening of multiple sclerosis (MS) after stopping ZEPOSIA.** When ZEPOSIA is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your healthcare provider before you stop taking ZEPOSIA for any reason. Tell your healthcare provider if you have worsening symptoms of MS after stopping ZEPOSIA.

The most common side effects of ZEPOSIA can include:

- upper respiratory tract infections
- elevated liver enzymes
- low blood pressure when you stand up (orthostatic hypotension)
- painful and frequent urination (signs of urinary tract infection)
- back pain
- high blood pressure
- headache

These are not all of the possible side effects of ZEPOSIA. For more information, ask your healthcare provider or pharmacist. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

General information about the safe and effective use of ZEPOSIA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not take ZEPOSIA for conditions for which it was not prescribed. Do not give ZEPOSIA to other people, even if they have the same symptoms you have. It may harm them. You can ask your healthcare provider or pharmacist for information about ZEPOSIA that is written for health professionals. For more information, call 1-833-ZEPOSIA (1-833-937-6742) or go to ZEPOSIA.com.

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“If someone is trying to develop a sense of structure in their life, an art activity that a therapist may use is the creation of a calendar or a visual journal,” says Warner. “If someone is looking to be less restrictive and more open to self-forgiveness, watercolors may help build patience by way of their unpredictability.”

A more unstructured soft clay material may be used with a person lacking hand strength or needing to release frustration. A more structured material like colored or regular pencils might be used with a person needing to improve fine motor control or to help reflect on something that involves a higher level of cognitive processing.

Some of the common items Warner uses in her therapy space include self-hardening clay, “Model Magic” clay, watercolors, acrylic

paints, collage materials and glue, chalk and oil pastels, colored pencils, thin markers, and so much more.

“The level of benefit may certainly align with which material brings forth the most cathartic experience and allows for the most creative and energetic expression for that person’s individual needs,” Warner says.

In Warner’s career in art therapy she has, on occasion, worked specifically with people who have MS. One such person was a single mother who was newly diagnosed. “So much changes for a person with a new diagnosis and there is a lot to sort through, including physical and mental changes,” says Warner.

This person, she goes on to share, suffered from mobility issues in her legs due to pain and numbness, making it hard to get up and moving some days.



“We worked on using loose art materials such as watercolor and oil pastels to allow for more freedom of expression. Because she was working so hard to hold it all together for her children, meant that some emotions were not being expressed. And as we know, emotions tend to go somewhere, and in her case, they were manifesting themselves in the body.

“We found that just the act of moving a body part that is not affected by pain with an art material can radiate some relief to other parts as well. Using art materials may help to take attention away from chronic pain and perseverating [repeating] thoughts and help create room for new experiences of the mind and body.”

As is the case with musical know-how and music therapy, you don't need an artistic base to benefit from art therapy. You just have to be open to the experience.

“As children, we seem to be less judgmental of our creativity, allowing ourselves to release ideas and expression more easily. As we age, outside influences can sometimes have a negative effect on how freely we express ourselves, so it can be a more challenging process to get started,”

Women with MS were studied in an art program with beading, collage-making, knitting, and watercolor. Improvements were seen in self-esteem, hope, social support, and self-efficacy.

Warner says. “But I feel it is crucial to say that making art in any form (be it writing, performance, music, etc.) can be a therapeutic and life-enhancing act at all stages of life.”

Hannah Garrison, a participant in MSAA's Art Showcase, who has also led MSAA's Improving Lives Through Art virtual paint-along events, couldn't agree more. For Garrison, who graduated from college with a degree in Fine Arts, art was a natural place to turn when MS muscled its way into her life.

“There's a state-of-mind that some artists refer to as a 'flow state.' If you can manage to focus long enough, then all that's left is your art and your thoughts,” Garrison says. “I talk about this because, a lot of times, in order to deal with the reality of having MS, I need to be able to jog my brain a bit to cope with the reality of having MS.”

She finds that “the act of making art just for the sake of creating” allows her thoughts to roll and drift into one another. “While my hand is doing the heavy lifting of making marks on the paper, my brain gets to drift and wander to wherever my body can't go.”

In the immediate aftermath of her diagnosis, Garrison says she found the Beatles tune, “Let It Be,” playing over and over in her head. Those lyrics eventually led her to a place of acceptance by way of art. “If I can accept my brush strokes for what they are, instead of fighting for them to be anything other than what they want to be, then I can accept my MS. If I can just let my hand and brushstrokes be, then I can let my MS be.”

Hope Angel, another MSAA Art Showcase participant, is one who came to art after her diagnosis – sixteen years later, in fact. The enjoyment she felt at a paint-and-sip class with her daughter, followed by more paint-along classes with her other adult children, led her to watching Bob Ross tutorials and other YouTube videos on painting techniques. Soon, she was painting on her own and sending pictures of her work to her children. Their encouragement of her efforts led her to showing (and selling!) her work at a Christmas craft fair.

Today, Angel has a website and social media sites. She sells her paintings in various

venues, and has even taught paint-along virtual events through MSAA.

Art, for Angel, has become an important part of her MS journey. “For me, painting is the calm amidst the MS storm. With MS, you never know from day to day what life looks like. But I find now that I can be looking out the window and see a cloud formation and think, ‘wow, that would make an incredible painting,’” Angel says. “It’s helped me feel less like MS is in control of my life, and more like I am in control of how I view my life.”

Garrison and Angel are both quick to point out that you don’t have to be proficient in art to see if it’s a creative expression that might work for you.

“It’s the mark-making journey that matters,” Garrison says. “Just like exercise or yoga, art provides a different kind of mind-body connection. Nobody expects a beginner exerciser to automatically strive to become a triathlete. The same goes



Wonder what this is?
by Hannah Garrison

Included as part of
MSAA’s 2022 Art
Showcase

Waterfall

by Hope Angel

Included as part of
MSAA's 2022 Art
Showcase

for art. Nobody expects a beginner to one day become the next Picasso or DaVinci.”

Angel agrees. “You absolutely have the ability to create something – anything, really,” Angel says. “I said multiple times during the paint-along session I taught that I hoped the participants weren’t trying to paint by numbers. In other words, I wanted them to explore their vision of what I was teaching and make it their own.”

Giving art a whirl doesn’t have to be difficult. Garrison recommends purchasing affordable materials as they are less intimidating. Or, if purchasing materials isn’t an option, grab some paper and pencils.

“Just do your own thing and know that all art-makers, professional or beginner, have bad art. Every. Single. One of them,” Garrison says.

After her own diagnosis, Garrison gravitated toward water-based materials – watercolor, watercolor pencils, acrylic flow art,

and alcohol inks, as they all required minimal effort and they look great regardless of what you do with them.

“It’s easy to learn how to use a medium if you keep an open mind while exploring how it works,” Garrison says. “Whatever sparks your interest and keeps it, do that. And, if you get bored with it after a while, try something else.”

To learn more about the field of art therapy and/or to find a board certified art therapist in the United States, please visit the American Art Therapy Association at arttherapy.org

MSAA will be offering an Improving Lives Through Art Fall Series. Please check MSAA’s website at mymsaa.org for details.



Writing

Like music and art, writing is an artistic expression that can shift a person's focus away from pain or repetitive thoughts and make a real-life difference in overall wellbeing. And like music and art, writing is something that can be done either solo or in collaboration with others.

In March of 2020, the Swedish MS Center launched a creative writing program for people living with MS. "Finding your Own Voice in Writing," as the course is called, was initially planned as a monthly in-person group but moved to a virtual format out of necessity because of the pandemic. As the group formed and grew comfortable with one another, they started meeting twice a month under the direction of Richard and Evelyn Arvey.

On paper, the class was about writing technique: learning to write clearly, cohesively, and in an engaging way. And each of the six participants learned to do just that with the help of writing prompts, teaching materials, and the instruction of Richard and Evelyn. Slowly but surely, the participants moved from assignments involving writing a "good paragraph" to eight-page stories and memoir

pieces. The subject of those pieces varied, with some participants wanting to write about their MS almost exclusively and others barely mentioning it at all. But the Arveys felt it was important to coax MS stories from everyone along the way, as well. And so every few months, the pair would give an assignment that dealt specifically with MS.

"Some people found it difficult to write about such a potent subject, so we always primed the class ahead of time, telling them that an upcoming assignment would be about how MS affects their lives, or a similar concept," explains Richard.

In an effort to help them, Evelyn would supply them with a list of questions to help them see a way into a potential story, or to show ways that other people have written about difficult subjects.

The end result is the self-published book, *Stories from our Center: Lives Challenged by MS*. Available on Amazon, all proceeds from sales of the book go to the Swedish Foundation Fund for the MS Center Supportive Care Services.

Seeing their stories in a book – particularly one that circles back around to benefit a



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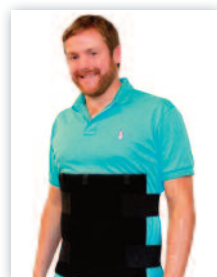


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center they all care about – was exciting and validating, sure, but it’s proven to be just one piece of an even bigger story.

“An important and unexpected aspect for all of us has been that our class evolved into something akin to a support group,” says Evelyn. “As writers shared their personal experiences in the form of stories and memoir pieces, they received thoughtful feedback from their classmates and from us. Often, the pieces would spark heartfelt discussions that went beyond the scope of the class.”

John Mistur, one of the participants in the class, treasures the closeness that has been forged.

“We followed the one and only honorary rule that was in the movie *Fight Club*: we

don’t talk about Writers’ Club,” Mistur says. “Once you build that kind of trusting relationship with people, you get more comfortable.” And with that increased comfort comes the courage to really open oneself up in their writing – something, Mistur believes, has helped him learn to accept his MS diagnosis.

“I’m forming bonds and friendships with other people who also have MS. We are able to share relatable stories about diagnosis or how everyone is dealing with

symptoms,” says Mistur. “Since MS is different for everyone, we learn from each other.”

For Katie Yusuf, another participant in the class, writing has enabled her to shed some of the pressure that comes with

“Writing lets me take my time and find the right words and phrases so that everything makes sense.”

– Katie Yusuf

communication issues related to her MS.

“MS has confused and twisted my thinking, making it difficult to string words together at times. The correct ones are blocked or just out of reach, making it hard for me to express myself,” Yusuf says. “When I do finally dig the words out of the jumble, it’s either too late or I can’t always articulate them correctly for others to understand me. But writing lets me take my time and find the right words and phrases so that everything makes sense.”

Yusuf and Mistur would encourage anyone facing a challenge like MS to give writing a chance.

“Start off by writing anything you want in a journal for at least five minutes a day. You can write about something happy, or about frustrations, or even about flaring symptoms. I find it very therapeutic,” Mistur says. “There are so many times I’ve been able to create a sweet story from a past journal entry.”

From journal writing, you can move into the 100-word challenge he did in Richard and Evelyn’s class. “Just take any old object, like your favorite flower, and write about it for exactly one hundred words. What does it look like? Does it bring back memories? What does the area look like where you found it?” Mistur

says. “We had fun doing this because everyone had their own perspective on the object. “Just think of it as a 100-word therapy challenge and have fun with it.”

Another fun writing exercise anyone can do is to think of a place – a classroom, the beach, a doctor’s office, etc. – and write a three-or-four sentence paragraph using your senses to describe it. What does it smell like? Sound like? Feel like? See if a loved one can know what your chosen setting is without telling them.

Writing can, indeed, be a way to escape. It can also be a way to work through feelings and emotions. And all you need is a pen (or pencil) and a piece of paper.





Photography

A visual art in and of itself, photography, too, can allow the person behind the camera an opportunity for creative self-expression. American photographer and film maker Paul Strand is quoted as saying, “your photography is a record of your living, for anyone who really sees.”

The subjects one captures with their camera can show so many things. They can be an escape, a place to dream, a way to record one’s thoughts, fears, and hopes, and/or a commentary on a particular moment in time or life in general.

For Giovanni Arroyo, a past MSAА Art Showcase participant, photography has been an enormous part of his life ever since his father placed a camera in his hands at the tender age of 3 or 4. His passion for capturing moments and places led to him being a professional photographer who taught classes, exhibited at art gallery shows, and loved roaming city streets for stories he could tell with his camera.

In fact, it was while roaming the streets of San Juan, Puerto Rico, doing what he loved, that Arroyo noticed the first sign of what would, eventually, lead to his MS diagnosis. Today, he may not be able to go off on hours’ long photography jaunts the way he once did,

but with some adapting, his love of photography continues to serve him well.

“I have had to pivot my photography. Instead of thinking about walking around to capture interesting images, I make sure to do research and head to one particular location,” Arroyo says.

It’s also kept him from being bored now that he is unable to work. “I am always able to fire up the computer and work on images

“I don’t think I would be able to maintain a positive life outlook if I didn’t have art.”

— Giovanni Arroyo, photographer

and even, occasionally, discover gems that I did not pay attention to years ago.”

And then there’s sharing the art of photography with his own daughters in much the same way his father did with him...

“I have to think that without art, and particularly photography, dealing with MS would be much more difficult,” Arroyo says.

To that end, Arroyo believes that focusing on his photography helps when he’s having a

difficult time and needs to quiet down the world. And when he is feeling well, he likes to reach for his camera and use that time to capture new images, try out new techniques, and simply be creative.

“I cannot imagine my life without creating. Art has helped make dealing with MS easier. While it has taken some things away, that constraint has improved my creativity and allowed me to explore other forms of

expression,” Arroyo shares. “I feel that even if you are not an artist, or do not wish to become a photographer, you need to have art in your life. I don’t think I would be able to maintain a positive life outlook if I didn’t have art.”

His advice to someone with MS who might feel even the slightest pull toward photography? You don’t have to be a professional photographer like he is to enjoy photography. You just have to pick up a camera (your phone will work) and start taking photos. Then, learn how to take better photos. As is the case with most things, your technique will get better with practice.

In the end though, at least in terms of seeking a creative outlet in which to lose yourself for a while, Arroyo leaves us with a simple piece of advice regardless of art form. “Just create,” he says. ■



San Juan Streets by Giovanni Arroyo

Included as part of
MSAA’s 2021 Art Showcase

***ALSO: Please see accompanying sidebar
“A Closer Look at The Therapeutic
Value of the Arts” on page 26.***



RMS=relapsing multiple sclerosis.

*After three weekly starter doses.

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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.

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

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'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.

KESIMPTA, the KESIMPTA logo, and SENSOREADY are registered trademarks of Novartis AG.

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 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 healthcare provider if you have any of these signs and symptoms:
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- **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.

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.

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.
- Do not freeze KESIMPTA.
- Do not shake KESIMPTA.

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

A Closer Look at the Therapeutic Effects of the Arts

BY LAURA BRADFORD

As someone who has made a career as a writer and also happens to have MS, I found myself more than a little intrigued by the therapeutic effects of the arts as shared by the therapists and patients in this issue's cover story. So, in an effort to explore this topic even more, I spent a little time talking with Francois Bethoux, MD, Chair of the Department of Physical Medicine and Rehabilitation at the Cleveland Clinic Neurological Institute.

Q: Dr. Bethoux, I've been fascinated to hear of the emotional lift that comes from the arts. In our cover story, a patient in Music Therapy spoke of knowing she'd have a better day after attending a Music Therapy session. Those who engage in the visual arts speak about that same lift, as well, but also the outlet and hope it provides them. One of the writers I spoke to, talked about the way writing has enabled her to collect her thoughts in a way she often has difficulty doing verbally because of her MS. Can you tell us a little bit about why you think these kinds of outlets help MS patients in an emotional sense?

Dr. Bethoux: “Although it's well known that the arts connect with us at an emotional level, we haven't yet fully grasped the therapeutic potential of generating positive emotions. Now that the connection between our emotional health and our physical health has been demonstrated, we can hope that more research will look into the therapeutic effects of the arts. There can be two aspects to interacting with the arts: enjoying music or a piece of visual art (which is seen as more passive, even though there is an active investment from the person if they connect with the artwork), and participating in creative arts (which is seen as more active). I think that both can generate positive emotions in anyone, including people with MS. Because we know that MS is often associated with emotional difficulties, it is all the more important to create opportunities for positive emotions through the arts. The arts can also create opportunities for positive social interactions (e.g. group art or music therapy), which may also generate positive emotions.”

Q: How about physical benefits to art and/or music therapy?

Dr. Bethoux: “This is an area that hasn't been extensively researched yet. People can report improved perceived physical health after participation in art or music therapy. There may also be physical benefits from the actual physical activity related to art/music

therapy. There are specific music and art therapy techniques designed to enhance a person's physical abilities. For example, a neuro-music therapy technique called rhythmic auditory stimulation has been used for gait training in people with Parkinson's disease, and is being studied in MS."

Q: MS affects different people in different ways. Can art or music be tailored to meet various challenges? And if so, how?

Dr. Bethoux: "The opportunities to interact with the arts should be tailored to a person's physical, cognitive, and emotional status and needs. Art and music therapists are trained to adapt to everyone's unique situation and needs. Also, the art should be tailored to a person's interests, culture, and taste. It is therefore essential to start by getting to know each person with MS better before engaging them in an art-related activity. Technology is a great help in making art more accessible to people with various abilities."

Q: Who would you recommend these forms of therapy for, patient-wise?

Dr. Bethoux: "I would say that anyone who experiences physical, cognitive, and/or emotional challenges related to MS could benefit from art and music therapy."

Q: Do you feel that these types of therapy (art, music) have a real place in the treatment of diseases like MS?

Dr. Bethoux: "In my opinion, art and music therapy should be part of the comprehensive management of MS, along with other therapeutic approaches. Art and music therapy can be made accessible to anyone with MS, in person or online. They are low-cost and safe interventions, which can be delivered individually or in a group setting, and sometimes combined with other interventions. For example, some rehabilitation hospitals employ music therapists to work alongside physical therapists. As we said before, the arts can generate positive emotions, which can in turn enhance a person's ability to participate in other activities, including other treatments." ■



Francois Bethoux, MD, psychiatrist, currently serves as Chair of the Department of Physical Medicine and Rehabilitation in the Cleveland Clinic Neurological Institute. He is also director of rehabilitation services at the Mellen Center for MS Treatment and Research, and medical director of the Arts and Medicine Institute at the Cleveland Clinic. He has served as the editor-in-chief of the *International Journal of MS Care* since 2014. Dr. Bethoux's research interests include neurorehabilitation, spasticity management, and interventions (including therapeutic arts) to improve walking in persons with MS and other central nervous system disorders.



Questions from Our Readers

By Dr. Barry Hendin

MSAA's Chief Medical Officer

Q: I was diagnosed with MS at 68 and am now 73. I have been having symptoms since my early 20s, but no one diagnosed it previously. I am told I have “inactive MS,” aka, benign MS. Doctors have taken a wait-and-see stance so far. I have developed optic neuropathy and have lost part of my sight in my right eye in the form of a grey spot. I am told the nerve cells have died and my peripheral eyesight will not return.

My question is, at which point should I be taking medication? I am being treated by my primary doctor and I am not on any medication at this time.

A: Your letter raises a number of interesting points. I will try to discuss each one.

I first want to distinguish the term inactive progressive MS from benign MS. We usually use the term benign MS to refer to people who have had MS for a long period of time such as 10 or 15 years with little or no disability. It's a very small number of people. (I hesitate to use the phrase “benign MS,” because for so many people, even mild signs

and symptoms, do not feel benign. I prefer the term “mild MS.”) Inactive, secondary-progressive MS refers to a large number of people who previously had relapsing forms of MS, and later notice progressive worsening in the absence of relapses or new lesions on MRI, for a period of time such as a year or two.

In your case, the additional question is whether at age 73 the use of our current disease-modifying therapies is approved for your type of MS and if potentially worthwhile. The commonly used disease-modifying therapies are approved for active forms of MS rather than inactive forms of MS. As people with MS age, the likelihood of a new attack or relapse diminishes, and the usefulness of our disease-modifying therapies changes relative to the risk.

It remains worthwhile to be evaluated periodically by a neurologist, and possibly an MS specialist, to see if there are any therapies or interventions for specific symptoms such as bladder dysfunction, or mood change, or gait change. Symptomatic treatment can be very important in maintaining a best quality of life, in addition to our general recommendations for a healthy diet and regular exercise.

Q: I am a 66-year-old female who has been treated for MS for 15 years. In 2001, I had an episode of double vision that put me in the hospital for three days and then resolved. My cerebrospinal fluid showed nothing. I had no other symptoms until 2005, when I had optic neuritis in my left eye and was once again hospitalized and put on IV steroids. My spinal fluid at this subsequent flare-up showed "weak" oligoclonal bands. The optic neuritis resolved and I was left with no visual deficits. Please note that I cannot have an MRI due to an old cerebral aneurysm clip (not titanium) placed in 1993.

I have been on a disease-modifying therapy for 15 years and have had no symptoms or relapses. I am a registered nurse and I plan on working until at least 70. I might have to stop my medication once I retire due to the cost. What are your thoughts on stopping my medication at that time?

A: Your question centers on when it is appropriate to stop taking disease-modifying therapies. There is good evidence for initiating disease-modifying therapy as soon as possible after a diagnosis of MS or clinically isolated syndrome (CIS). It is less clear when people should stop their medications.

As people with multiple sclerosis age, the degree of immune inflammation generally decreases, so that there are fewer relapses and fewer new brain lesions. There is an important trial currently underway at the University of Colorado, under the auspices of Dr. John Corboy, to determine the age at which stopping or de-escalating disease-modifying therapy is warranted. The results of this trial will tell us about risk and benefits in specific MS populations, however, the advice for an individual, though better informed, still requires the consideration of other factors specific to that individual patient.

A second interesting point is your diagnosis of MS without an MRI scan. It reminds me that neurologists, myself included, were diagnosing MS before the advent of MRI scanners. Although MRI scans have been very useful in validating a clinical assumption of multiple sclerosis, you do meet the requirement of "dissemination in time and space," even in the absence of an MRI. Dissemination in time and space may be simply defined as attacks or relapses occurring in different parts of the brain, spinal cord or optic nerves at different points in time.

Ultimately, advice for any individual will need to be based on your unique discussion with your neurologist.

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 newly created Multiple Sclerosis Center of Arizona. 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.

Q: I have MS. I have had two immunizations – one for the flu and one for tetanus – and in both cases, my optic nerve was affected and I lost my sight. After receiving large doses of steroids, I regained some sight. I have not had any immunizations since then. What should I do about COVID-19 immunization?

A: Generally, we have recommended that people with MS be vaccinated against influenza and against COVID-19. Your situation, however, is complicated and I would hesitate to give a generic answer. I recommend a consultation with your MS neurologist/immunologist. The COVID-19 mRNA vaccinations are formulated differently

from your prior vaccinations and should allow for a unique discussion and decision.

Q: Are swelling and pain in the bones symptoms of MS? If so, what is the treatment for this?

A: Although many people with MS experience pain, when there is localized swelling, the explanation is generally not MS. In these situations, a medical evaluation or a visit with a rheumatologist or orthopedist is warranted. Joint swelling and pain is caused by local inflammation at the joint, which occurs in conditions such as arthritis. ■

Please submit questions for Ask the Doctor via email to askdr@mymxaa.org

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Researchers Continue to Suspect Epstein-Barr Virus as a Possible Factor in Developing MS

By Susan Wells Courtney and Tom Garry

Reviewed by Dr. Barry A. Hendin,
MSAA Chief Medical Officer

In an article published in *Science* (Bjornevik K, et al. 13 Jan 2022. Vol 375, Issue 6578. pp. 296-301.), “Longitudinal analysis reveals high prevalence of Epstein-Barr virus (EBV) associated with multiple sclerosis,” researchers present the results of a study that looks at a possible connection between these two conditions. These researchers analyzed EBV antibodies in blood serum from 801 individuals who developed MS among a cohort of more than 10 million people active in the United States military during a 20-year period (1993–2013).

According to the article, infection with the Epstein-Barr virus (EBV) has long been postulated to trigger multiple sclerosis. Prior analyses demonstrated increased serum antibodies to EBV in approximately 99.5% of individuals with MS, versus approximately 94% of healthy individuals. In the current study, all but 35 of the 801 MS cases were EBV seropositive. Eventually 34 of the 35 became infected with EBV prior to the onset of their MS. Only one individual was EBV seronegative at the time of MS onset.

According to the study authors, these findings provide compelling data that implicate

EBV as a trigger for the development of MS. While nearly everyone is infected with EBV, only a small fraction develops MS, so other factors such as genetic susceptibility appear to be involved in MS pathogenesis. Multiple studies have identified EBV-infected B cells in the brains of people with MS. Researchers now look to understand how infection of B cells with EBV initiates the pathology seen in MS.

New ACTH Gel Available for Acute Exacerbations

People with MS have a new option for treating acute exacerbations with an adrenocorticotropic hormone (ACTH) preparation. ANI Pharmaceuticals, Inc. announced in late January 2022 that its Purified Cortrophin™ Gel (Repository Corticotropin Injection USP) 80 U/mL is commercially available in the United States.

ACTH is a hormone that stimulates the adrenal gland to secrete cortisol, corticosterone, and aldosterone, which can help ease exacerbations. Cortrophin Gel also is approved by the FDA for several other autoimmune conditions, including exacerbations of rheumatoid arthritis and psoriatic arthritis.

Positive Study Findings with Several Experimental Disease-Modifying Therapies for MS

ANK-700: Anokion SA, a Swiss biotechnology company with United States' offices in Cambridge, Massachusetts, announced this month that it has initiated patient enrollment in the multiple-ascending dose portion of its MoveS-it trial. Multiple-ascending dose trials have separate groups of participants taking different initial doses of a medication, then doses are increased to assess if and when people experience side effects or have difficulty tolerating the therapy.

The MoveS-it trial is a randomized, double-blind, placebo-controlled Phase I trial of ANK-700 for the treatment of relapsing-remitting MS. In a press release, the company explained that ANK-700 is designed to “re-educate the immune system by introducing antigen-specific tolerance to myelin-based autoantigens in order to reduce neuroinflammation in the brain and spinal cord.” Initial results from the trial are expected in the second half of 2022.

Masitinib: An article first published online February 21, 2022 in *Neurology: Neuroimmunology & Neuroinflammation*, “Efficacy and Safety of Masitinib in Progressive Forms of Multiple Sclerosis” (Vermersch P, et al.), provided the results of a randomized, double-blind trial assessing two dose levels of masitinib versus placebo. The trial had 611 individuals with either primary-progressive MS or nonactive secondary-progressive MS and was conducted at 116 hospital clinics and

specialized MS centers in 20 countries.

The article explains that Masitinib is a selective tyrosine kinase inhibitor, targeting innate immune cells (mast cells and microglia) that are involved in the pathophysiology of progressive multiple sclerosis (MS). Study AB07002 assessed oral masitinib in people with progressive MS who were progressing but not clinically active.

The primary end point was overall Expanded Disability Status Scale (EDSS) change from baseline using repeated measures. Looking at the primary end point, Masitinib showed significant benefit over placebo, with no elevated risk of infection.

NVG-291: NervGen Pharma announced in late December 2021 that it had received ethics board approval to proceed with the multiple ascending dose portion of the Phase I trial of its investigational therapy NVG-291. NervGen describes NVG-291 as a therapeutic peptide that mimics the activity of a cell surface receptor involved in regulating central nervous system repair.

The company, which is based in Vancouver, British Columbia, said, “In preclinical studies, NVG-291 has been demonstrated to promote repair mechanisms in the nervous system, including axonal regeneration, remyelination, and enhanced plasticity.”

PIPE-307: In March 2022, Pipeline Therapeutics announced that the U.S. Food and Drug Administration (FDA) cleared the

company to initiate its Phase Ib/IIa clinical trial of PIPE-307 in patients with relapsing-remitting multiple sclerosis (RRMS). PIPE-307 is the company's lead program for myelin restoration. It is an oral, highly selective antagonist of the muscarinic M1 receptor that is being developed for the treatment of MS.

According to Pipeline Therapeutics, multiple Phase I studies of PIPE-307 were recently completed in healthy volunteers. Results from the study, which used positron emission tomography (PET), demonstrate that doses tested in the Phase I study achieve a level of uptake in the human brain that have been associated with remyelination observed in preclinical studies.

The Phase Ib/IIa clinical trial of PIPE-307 will be conducted at multiple sites across the United States. Participants will receive daily oral dosing for three months.

Tolebrutinib: Tolebrutinib is an investigational medication that inhibits an enzyme called Bruton's tyrosine kinase, or BTK. The enzyme affects the B cells and microglial cells believed to play a role in the development of MS, and researchers hope to modulate the neuroinflammation of MS through inhibiting BTK and, thus, targeting those immune system cells.

After a 12-week Phase II study of tolebrutinib showed encouraging results, researchers extended the trial of this oral medication. Although different doses were used initially, all 122 participants received 60 mg per day in the latter part of the study, which is also the dose being studied in the ongoing Phase III GEMINI 1 and GEMINI 2 trials (expected to

be completed in 2023).

At Week 48, the mean number of new gadolinium-enhancing lesions seen on magnetic resonance imaging (MRI) remained low in people who had been on 60 mg since the initial study, and those who had switched to the 60 mg dose had a reduction in the number of gadolinium-enhancing lesions. The annualized relapse rate in people receiving 60 mg of tolebrutinib was 0.17, with 89.5% of patients having no relapses during the study period. No new safety signals emerged during the 48-week study.

Ublituximab: Reduction in lesion volume and number were seen on MRI following treatment with ublituximab in the ULTIMATE I and ULTIMATE II studies. T1-hypointense lesions seen on magnetic resonance imaging (MRI) of the brain and spinal cord are indicative of white matter destruction and axonal loss in people with MS. Recently presented data from two Phase III studies of ublituximab found that the investigational agent reduced those lesions to a greater extent than did the FDA-approved disease-modifying therapy Aubagio® (teriflunomide).

As noted, the data are from the ULTIMATE I and ULTIMATE II studies, which involved almost 1,100 people with relapsing MS. Those studies evaluated outcomes with intravenous infusions of ublituximab, a monoclonal antibody, relative to daily use of Aubagio, an oral medication, over the course of 96 weeks. In December 2021, the FDA accepted an application to consider approving ublituximab for the treatment of relapsing MS. ■

Upcoming Webinars, MS Awareness Month Review, and Ongoing Programs Serving the MS Community

By Susan Wells Courtney

MSAA's Informative Webinars

At MSAA, we know that providing urgent information on a wide range of topics – from diagnosis and treatments to healthy lifestyles and family relationships – is critical to the health and wellbeing of the entire MS community. One great way to provide this information is through live webinars with top MS professionals, where attendees can listen in from the comfort and convenience of their home. And if unable to attend the live presentation, MSAA's webinars are always recorded and available on our website for on-demand viewing.

Currently, we have two very informative webinars scheduled for May and June:

- **May 2022:** Working to Destigmatize Mental Health and MS: A Mental Wellness Discussion
- **June 2022:** Understanding Your MRI

These digital educational programs are free to attend. To register, please visit our calendar of events at mymsaa.org/calendar. Also, previous webinars on topics such as “The African American Experience and MS,” “Approaches to Managing MS in 2022: A Research Update,” “What’s for Dinner? Let’s Talk About Nutrition and MS,” as well as the “Living Rural with MS” series, and more, are now available for on-demand viewing on the MSi video webpage at mymsaa.org/videos.

MS Awareness Month Recap

MSAA proudly supported Multiple Sclerosis Awareness Month during the month of March and offered several online educational activities, including an Instagram Live, two podcast episodes, and two webinars featuring experts in the field of MS. MSAA supported this year’s national campaign by focusing on “Shaping the MS Experience,” with specific programs addressing the many facets of the clinical approach to MS.

The weekly online educational activities held in March were as follows:

- Instagram Live with Dr. Mitzi Williams and Damian Washington, Patient Advocate and Actor
- “How to Choose the Right MS Therapy for You” podcast with Dr. Barry Singer
- “The Science Behind MS” webinar with Dr. Esther Melamed
- “3 M’s of MS: Mangia, Microbiome, and Molecules” podcast with Dr. Andrew Woo
- “Understanding Progression in MS” webinar with Dr. Carrie Hersh

Those interested in these topics may go online to access any of these programs. Please visit mymsaa.org/awarenessmonth for more information!

Cooling, Equipment, and MRI Access Programs

Cooling Distribution Program

If you are a member of the MS community, chances are you are very familiar with a common 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.

Summer is almost here and with it comes the hot temperatures that keep individuals with MS from enjoying outdoor activities for months at a time. Fortunately, MSAA’s **Cooling Distribution Program** is here to help! This program offers free cooling vests and accessories to eligible individuals to provide relief from heat sensitivity and the symptoms it causes.

Eligible clients may receive cooling products from MSAA once every five years. Please visit mymsaa.org/cooling or call **(800) 532-7667** for more information.

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Equipment Distribution Program

Equipment designed for mobility, safety, and comfort can greatly improve quality of life and enhance activities of daily living.

Unfortunately, not everyone has access to the equipment he or she needs, and cost can often play a role. If this is the case, MSAA's

Equipment Distribution Program may be the answer. This program offers products designed to improve safety and mobility while also providing greater opportunities for

exercise and wellness. MSAA distributes these products at no charge to individuals with MS who qualify for assistance, and items are shipped directly to the client.

Products provided through the program range from grab bars, shower chairs, and walkers, to wide-grip utensil sets and yoga mats. MSAA can assist in offering those with MS equipment products every three years. Please visit mymsaa.org/equipment or call **(800) 532-7667** for more information.

MRI Access Program

Do you need financial assistance to help pay for magnetic resonance imaging (MRI) – either in the near future or one already done within the past six months? MSAA's **MRI Access Program** assists with the payment of cranial (brain) and c-spine magnetic

resonance imaging (MRI) scans to individuals meeting eligibility requirements. Assistance is provided to qualified individuals who have no medical insurance or cannot afford their insurance costs and require an MRI to help determine a diagnosis of multiple sclerosis or evaluate current MS disease progression.

For eligible individuals who have no insurance or cannot afford their insurance costs, 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 your 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 your application. MSAA pays the imaging center directly and does not reimburse the client. Please visit mymsaa.org/MRI or call **(800) 532-7667** for more information.

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please visit: mymsaa.org/signup

MSAA's Helpline Offers Timely Information, Supportive Resources, and Needed Reassurance

Do you have questions about MS, its symptoms, or its treatments? How are you and those around you feeling – is sadness, worry, frustration, or other emotion impacting your daily life? Each year, several thousand members of the MS community reach out to MSAA's trained and experienced Client Services Specialists to ask questions and learn about helpful resources. Sometimes callers simply need a sense of comfort and reassurance with whatever challenges or concerns they may be experiencing.

If you are in need of information, resources, support, or any other type of assistance, please contact MSAA's Helpline

via phone or email. Helpline hours are Monday through Friday, 8:30 AM to 8:00 PM (ET). 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@mym saa.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@mym saa.org**. El horario de la línea de ayuda es de lunes a viernes, de 8:30 AM a 8:00 PM, hora del este. ■



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Multiple Sclerosis
Association of America

Honoring Two MSAA Champions for Their Unique Support in a Virtual Age

By Rebecca Mooney,
MSAA Vice President of Development

As MSAA prepared to recognize our 50th Anniversary in 2020, no one could have predicted COVID-19 and the impact it would have on every aspect of the organization. One bright spot in the uncertainty of life during a



Now in its seventh year, MSAA's in-person Improving Lives Benefit will be held in Philadelphia on May 5th. Our virtual Improving Lives Benefit, now in its second year, will take place a week later on May 12th.

pandemic has been the launch of MSAA's unique virtual events, including our Improving Lives Through Art series. For MSAA's 2022 Improving Lives Benefit, we are excited to recognize two MSAA Champions who inspired the art series and have helped it grow every step of the way.

After a necessary cancellation of the 50th Anniversary Improving Lives Benefit, originally set for March 2020, MSAA was faced with determining what to do next. **Alexandra von Plato**, MSAA Board of Directors Member and CEO of Publicis Health, suggested planning a smaller event in the fall at a museum she also works closely with, the Barnes Foundation. As the pandemic unfortunately continued, MSAA once again had to pivot, and we worked closely with Alex, the Publicis Health team, and the Barnes Foundation to launch a virtual art tour – allowing the community to join together safely from the comfort of their homes. Despite a short timeframe to launch, the event was well-received and had more than 120 attendees raising more than

\$80,000 in support of MSAA's mission.

After that success and the incredible attendee feedback, we knew we had to keep the momentum going. Tying in MSAA's long standing tradition of recognizing artists with MS through the MSAA Art Showcase, the team quickly worked to pull together a series

of events featuring another virtual art tour and an interactive paint-along. When faced with whom to ask to support these virtual events, longtime contributor **Hannah Garrison** was an immediate suggestion. As fate would have it, Hannah had personally hosted past paint-and-sip events, both virtually and in-person,



IMPROVING LIVES BENEFIT 2022

Corporate Honoree

ALEXANDRA VON PLATO

CEO, Publicis Health

Chief Executive Officer of Publicis Health, Alexandra von Plato joined the MSAA Board of Directors in 2019. Across Publicis Health's network of 11 agency brands, a key focus is connecting healthcare and wellness brands with the people who need them. That's what drew Alex to MSAA – the idea of working hand-in-hand with an organization with a history of bringing that focus to life was a perfect fit. In her time with MSAA's Board, Alex has led the Communications and Marketing Committee, providing key insights from her vast professional experience. In addition, her team has financially supported a range of events and initiatives, including the Improving Lives Through Art series, the Improving Lives Benefit, MSAA's Anniversary Challenge, and key MSAA Golf Classic events in both New Jersey and Pennsylvania. Beyond that, her team has a strong commitment to build connections that make sense – expanding MSAA's corporate reach one introduction at a time.

and was excited to bring that experience to MSAA. Joe Caliva, a docent and tour guide from the Barnes Foundation, also proved to be another key connection. Joe

graciously offered to build custom art tours for MSAA and to host the new series. In total, these art initiatives have raised more than

“The art series is INCREDIBLE. It’s perfect for all ages – I do them with my 8-year-old. It’s fun and informative. I thank you for hosting them and highly recommend for all to join!”

– Meryl Ravitz, MSAA Board Member

\$250,000 to date, with a fall series planned for 2022. None of this would have been possible without the leadership of Alex and Hannah, and MSAA is proud to have the honor of

recognizing them both as our Corporate and Mission Honorees for the 2022 Improving Lives Benefit.

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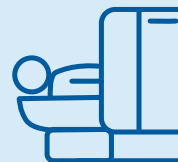
\$10/month provides shower chairs for two individuals with MS



\$15/month provides a wheelchair for an individual with MS



\$25/month provides a cooling vest for two individuals with MS



\$60/month provides an MRI exam of the brain for an individual with MS

MSAA will host our second annual virtual event, “Together at Home,” on May 12 at 7:00 PM EST, as well as an in-person event in Philadelphia on May 5. Both of these events will be hosted by Tyler Campbell, along with running a peer-to-peer fundraising campaign to raise

funds to directly support the Mission Auction portion of the event. To start your own virtual viewing party or to join MSAA in honoring Alexandra von Plato and Hannah Garrison at the 2022 Improving Lives Benefit, please visit: engage.mysaa.org/benefit2022. ■



IMPROVING LIVES BENEFIT 2022 Mission Honoree

HANNAH GARRISON

A long-time visual artist from Texas, Hannah Garrison was diagnosed with multiple sclerosis in 2017 and used her painting as a safe space for exploration, mindfulness, and a chance to practice self-love when she needed it the most. For her, healing has always started with mental health.

While she sometimes makes adjustments to the way she creates art to accommodate difficulty holding tools or other physical issues related to her MS, Hannah maintains a focus on creating art for her personal wellbeing and sharing that with others. In addition to contributing to the MSAA Art Showcase each year, she serves as a volunteer and community leader bringing the arts to people facing life-altering health challenges. She truly believes her continued focus on art has helped her mind overcome some of the damage done to her neural pathways due to MS.

Hannah significantly helped drive the success of the Improving Lives Through Art series from its inception – her infectious smile, simple directions, and an ability to help people make art their own has hooked participants from the first event. The best part? Members of the MS community who have participated alongside Hannah consistently provide feedback that they feel more empowered to not let MS get in their way.

MS and Me

By BeLynda “Bea” Davis

I remember it as if it were yesterday, my spirit was moved while attending the funeral of one of my husband’s distant family members. I didn’t know much about his family member, but I did know of her battle with cancer.

At the service, loved ones spoke about her medical diagnosis, her physical hardships, AND all that she was still able to accomplish. I felt a strong connection to her and I began to cry, uncontrollably. As if we were best friends, I wept from the depths of my soul and, at the same time, I was inspired. I believe I was divinely “inspired to inspire!”

I was born in Madisonville, Kentucky, but I spent most of my formative years as an “Army Brat.” This allowed me to travel to Hawaii, Germany, and many other places around the world. Although I moved every few years to a different military base, I learned to be flexible and adapt very quickly.

I was diagnosed with multiple sclerosis at the age of 15 while still in high school. Try to imagine an extremely active teenager who loved running track, who was just beginning to think about the future, and who had the world ahead of her! Now imagine that same teenager fighting to make other people understand the “real” pain she was in, fighting to keep her faith in God, and fighting to hold on to the hopes that having a great life was still possible.



Enjoying family time together, author “Bea” Davis is joined by husband Steven, a United States Army Officer, and their two children, DJ and BriAna.



I can remember always being in pain. I also remember feeling like my eyeball was going to pop out of its socket. But my pain was misunderstood and my cries fell on deaf ears. It was difficult for me to explain what I was feeling. I was still a young girl and MS was new to me. At times, my doctors didn’t even understand my pain.

Forever changed, but still fighting, I found solace in attending church. After joining the choir, I discovered my passion and gift... singing. I love to sing and, as I'm often told, people love to listen. I also always knew I'd make people "look and feel good," and I did so by graduating from Ogeechee Technical College in Statesboro, Georgia. I accomplished my childhood dream by receiving my certificate and working as a cosmetologist.

I was so inspired, I continued to pursue higher education. I received my certification as a medical records specialist in 2016, but I didn't stop there!

I've just published my first book, *Let's T.A.L.K.: Your 4-Step Guide To Getting Beyond The Pain Of Loss And The Uncertainty Of Illness So You Can Live Your Best Life Now*.^{*} I never knew God planned for me to be an author, let alone a bestselling author!

I would have never imagined the many hardships in my life, the chronic symptoms of MS, and the death of a woman I hardly knew, would inspire me during my darkest moments.

I would have never imagined I would be called upon to continuously inspire others to never give up and keep moving forward.

And I would have never imagined that the many doctor appointments, the medications, and the many lifestyle changes I've had to make over the years, would inspire me to stand up to MS and keep on LIVING!

Simply put, MS is life-altering! When you've experienced life-changing situations and

**Available through Amazon and AmazonSmile.com.*

circumstances due to a chronic illness, it's important to learn to TRUST again. You may need to ACCEPT that your life is changed, but it's NOT over! You may need to learn to LOVE yourself in a new way OR continue to cherish loved ones even when they don't understand what you're going through. Last, but not least, you may need to KNOW you are loved and "more than a conqueror!"

Now when I wake up, I give thanks to God for another day. After prayer, I review my goals and daily schedule. Then, I focus on the family that I've been blessed with – my two beautiful children, DJ and BriAna, and my husband, Steven (a United States Army Officer). Despite MS, my life has meaning and it will not cause me to lose sight of the love and life I still have.

So, the next time someone tells you he or she has MS, you better know that you're looking at a warrior who is fighting every day to live, laugh, and love. So, give him or her a smile, and tell this MS warrior to "keep on fighting!" ■

Share Your Story to Inspire!

If you have an inspirational story that you would like to share with readers of The Motivator, please submit your story to editor@mymyaa.org for consideration. "Stories to Inspire" articles are typically 600 words in length and include one or two photos. MSAA does not pay for these articles and those submitting a story will need to sign a release form.

MSAA is very
proud to
present our
2022-2023

ART SHOWCASE

Each year, MSAA features the work of artists affected by multiple sclerosis in the annual **MSAA ART SHOWCASE**, highlighting one artist each month as our Artist of the Month.

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

View the complete gallery by visiting mymsaa.org/artshowcase2022



Connect with others and find support on **My MSAA Community**

Join more than 7,000 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



TEAM MSAA

ANNIVERSARY CHALLENGE

RUN - WALK - BIKE



06 — 08 — 19.70

In honor of serving the MS community for more than 50 years,
Team MSAA is bringing back the **Anniversary Challenge**.

Complete your challenge during the month of June by:

RUNNING

6 miles

WALKING

8 miles

BIKING

19.70 miles

Or take on **ALL THREE** options for the **Triple Challenge!**

Register now and get started on your challenge at
engage.mysaa.org/anniversary2022

We need your help...

**Please tell us
more about
yourself.**

MSAA would like to know more about our readership of *The Motivator* and the larger MS community that we serve. This will help us better tailor our programs and services to meet the various needs across all demographics of individuals affected by MS.

Please spend a few minutes and take our online survey today.

mymsaa.org/tellus-ws22

¿Hablas español?

Cuéntenos más sobre usted respondiendo nuestra encuesta en línea. Visite

mymsaa.org/tellus-ws22-espanol

