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Summer/Fall 2016

THE Motivator

Published by the Multiple Sclerosis Association of America



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SERVICE DOG

Partnership

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COVER STORY

4 The Joys and Challenges of a Service Dog Partnership

By Darbi Haynes-Lawrence, PhD

Dr. Darbi Haynes-Lawrence takes readers along her eventful journey to partner with a service dog, encountering many benefits and hurdles along the way.



Cover photo:
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DEPARTMENTS

- 2 Up Front** *By Gina Ross Murdoch*
Record-breaking outreach, a new online community, and upcoming events are among the exciting topics presented.
- 29 Ask the Doctor** *By Jack Burks, MD*
MSAA's chief medical consultant answers questions sent in by readers.
- 35 Research News** *By Susan Wells Courtney*
Information is given on newly approved Zinbryta™ (daclizumab) and two investigational medications, Ocrevus™ (ocrelizumab) and siponimod.
- 38 Program Notes** *By Peter Damiri*
The return of MSAA's MRI Access Fund, the launch of My MSAA Community, and the updated S.E.A.R.C.H. live webinar are featured.
- 43 Thoughts about Giving** *By Susan Wells Courtney*
MSAA's new Vice President of Development is introduced.
- 44 Spread the Word** *By Susan Wells Courtney*
Three books from MSAA's free Lending Library are featured.



MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA

Improving Lives Today!™

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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Record-Breaking Outreach Funded by Your Generosity

By Gina Ross Murdoch
MSAA President and CEO

Welcome to fall! Thank you all for the warm welcome into the MSAA family. It has been an exciting few months filled with new directions and record-breaking outreach.

Over the last few months, I have had the chance to dive further into the great work that MSAA does – all supported by our donors, event participants, corporate partners, mission partners, and you... our MSAA family. MSAA continues to be a leading resource for the MS community and maintains an excellent reputation as being uniquely responsive to the needs of all those affected by multiple sclerosis.

Over the last few months, we restarted the MRI Access Fund to much excitement. The vital need of this program became even more evident during its short suspension. We heard from many clients and providers about how important this program continues to be. We

are thrilled to have it back. In addition, we broke a record in July, having provided cooling vests and accessories to nearly 1,000 people during the month, illustrating the essential need for this program. These are just two examples of how MSAA is committed to meeting the important needs of our clients.

In August, we launched My MSAA Community at healthunlocked.com/MyMSAA, a new peer-to-peer online community. This forum offers a welcoming and safe haven to all affected by MS, to share their stories and find information and support. In just the first few weeks, members of the forum grew by 500, bringing a voice and support to so many individuals. To learn more about this exciting new service, please see Program Notes on page 38 of this publication.

At the time this issue of our magazine was in production, we held our annual Lone Star Roundup Cattle Drive in Dallas, Texas and our Gary Wallace Memorial Golf Tournament in Cherry Hill, New Jersey. Last year these events

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.

MSAA President and CEO Gina Ross Murdoch prepares for her first ride in MSAA's annual Lone Star Roundup Cattle Drive in Grandview, Texas! This event raises much-needed funding for MSAA's vital programs and services.

raised close to \$100,000 for our mission and the many individuals we serve. As a new member of the MSAA team, I am so happy to take part in both events... from riding the range as a cattle-hand in Texas to driving a ball down the fairway as a golfer in New Jersey.

In addition to the money raised at these types of events, we still need your help to make our vital programs and services possible. I encourage you to keep MSAA in mind as you consider your year-end gifts. Many companies will match your contribution, doubling and even tripling your generosity. To make a donation, please visit support.mymsaa.org/donate, which includes an option for matching gifts. To learn about other ways to give, please visit mysaa.org and view the different options under "Donate." We thank you for your support! ■



**Submit Your
Best Work for
MSAA's 2017**

Art Showcases

MSAA is now accepting submissions for the **MS Ability Showcase** and **Four Seasons Showcase**!

MSAA welcomes paintings in oil, watercolor, and acrylic, as well as pastels and drawings in pencil and ink. MSAA also accepts digital artwork.

Artwork will only be accepted from individuals who have MS. Submitted pieces must be two-dimensional. Sculpture, pottery, fabric, and other types of three-dimensional works cannot be accepted to either showcase. The **MS Ability Showcase** is open to all themes; however, submitted artwork to the **Four Seasons Showcase** must depict a specific season or holiday.

Submissions will be featured on MSAA's website beginning March 2017 in recognition of MS Awareness Month. Each month we will highlight one artist and his or her work.

Submissions will be accepted until December 16, 2016. For submission guidelines, visit support.mymsaa.org/artshowcase

For more information, contact:

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A Panda Named Roni
Susan Russo, Pearland, TX



Keep Cool
Paula Breiner, Tamaqua, PA



by Darbi Haynes-Lawrence, PhD
Edited by Susan Wells Courtney

The Joys and Challenges of a **SERVICE DOG** PARTNERSHIP

© Liz Kaye Photography / ICANdog.org

How a Service Dog Can Help

I was diagnosed with multiple sclerosis in June 2009. Never in a million years did I see a service dog as part of my future. I had absolutely no idea how a service dog would be able to assist me in my daily life.

As my disease progressed, mobility and fatigue became greater issues. In the summer of 2015, my health took a turn for the worst. I always had difficulty with fatigue and balance, as well as issues with my legs. However, I was now having difficulty walking, along with a new tremor that caused me to jerk so powerfully that I would lose my balance and fall. While I did not want to walk with a cane, I had to do so, and started using a wheelchair periodically as well.

My husband asked me if a service dog could be of benefit. I was baffled. A service dog? For mobility issues? I thought service dogs were only for people who are visually impaired. Thus, I began my search for just what exactly a service dog could do, for someone like me who had mobility issues due to MS.

The investigation into “all things service dog” was a double-edged sword. On one hand, the information on the role a service dog could play specifically in *my life* was awesome. I am a college professor and have very ambitious goals. Having MS is not going to interfere with those goals! On the other hand, as noted later, the search for a service dog would prove to be quite disheartening.

At this point in time, my MS had progressed to where I often dropped things, and those of you with balance issues know if something is dropped, you have likely thought, "Do I risk bending over and picking it up, only to land on the floor, or ... just let that item stay right where it has landed?" Now, add the mobility issues into the picture.

Through my research, I found amazing information about the role a service dog could play in the lives of people who have mobility and balance issues, and even issues with fatigue. I discovered information on various organizations' websites about the skills these amazing dogs could perform, such as picking up items that were dropped, opening doors, carrying items, helping people with balance issues to continue walking, and so on. Service dogs can also assist with maintaining independence. My heart was aflutter with joy.

Costs Associated with a Service Dog

While the assistance that service dogs can provide is awesome, what was not awesome was the cost of these dogs. During my search, I learned that some of the organizations charged anywhere from \$25,000 to \$50,000 per service dog. There was no way my husband and I could afford a dog at this price, despite the fact that we are both gainfully employed. It actually made me question how anyone – disabled or not – could afford such a steep fee for a service dog. Some organizations charged less, but only worked with people with specific disabilities, many of which did not include multiple sclerosis. Other organizations limited their clientele by a mileage radius, and unfortunately, I was not within that radius.

Because of that information, I put the search for a service dog on the back burner for a month or two. During that time, my

About this Article

Editor's Note

MCAA's Client Services Specialists have received many inquiries about service dogs, including how they may be able to help someone with MS and how to find a service dog. We were very fortunate that Dr. Darbi Haynes-Lawrence, Associate Professor of Child and Family Studies at Western Kentucky University, generously volunteered to write this article for MCAA, sharing details about her journey of learning about, training for, and embarking on a new relationship with her service dog.

While we hope that this information sheds light on the topic, we also recognize the fact that only a very small percentage of the MS population is able to receive a service dog. Finances, the ability to care for and maintain a service dog, as well as the small number of service dogs available, are all important factors that must be considered. For readers who are either not seeking a service dog or who are unable to obtain one, we hope that you will find this story about Darbi's own challenges and her journey with Jaeger, to be both interesting and heartwarming.

How to Find a Nonprofit Service Dog Organization

During my search for a service-dog program, I kept coming across "Assistance Dogs International" (ADI). I saw that phrasing on some organizations' websites, yet didn't take the time to search the ADI site to look for a specific organization in my state. This was my error. Per their website, **AssistanceDogsInternational.org**,

"Assistance Dogs International (ADI) is a coalition of not for profit assistance dog organisations [sic]. The purpose of ADI is to improve the areas of training, placement, and utilization of assistance dogs, staff and volunteer education, as well as educating the public about assistance dogs, and advocating for the legal rights of people with disabilities partnered with assistance dogs."

In order to assist in searching for a nonprofit organization, ADI is broken into categories. For example, to search in North America, ADI has a North American (NA) section: ADINA. By using this link, **assistedogsinternational.org/members/programs-search/**, you can click on the region in which you live, then continue to narrow your search for a nonprofit service-dog organization in the area in which you live.

mobility decreased further and I began using a wheelchair fulltime. I was scared now. I was limited with my ability to leave the house, go to the grocery store by myself, or take my daughter Sami to the local swimming pool. Independence was quickly slipping away.

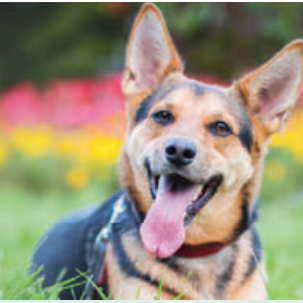
I worried about how my disease progression was impacting my daughter. Thankfully we are a very open and honest family, so we discussed this change in mobility. Our hope was that this was a relapse and things would improve after the relapse passed. Unfortunately, things did not improve as much as we hoped. My life was being detrimentally affected by my decreasing mobility, and some assistance was needed.

I decided one morning to try one more time to search for a service-dog organization. You might be thinking at this point, "Why not train your own dog?" Although this might be a wonderful option for some people, having a disease like MS – with fatigue as one of its major symptoms – made it impossible for me to be able to train a puppy on "all things service dog." Although *it is possible* to train your own service dog, those who follow this path should thoroughly learn about the organizations that train service dogs. Really investigate and obtain an understanding of the *depths of the training* required during the first two years of a service dog's life.

By a fluke, an absolute glorious fluke, I stumbled upon a program called the "Indiana Canine Assistant Network" or ICAN, which provided service dogs in my area. To locate a nonprofit organization in your state, please see the sidebar at left.

Steps Needed...

...when Looking for and Applying to a Service-Dog Organization



Darbi explains the process she needed to follow in the steps shown below:



Confirm Location

ICAN has a radius of clients, so the first step was to confirm that I lived within that radius.



Consider Affordability

ICAN is a nonprofit organization and that is important information to keep in mind. Nonprofit organizations typically do not charge the same prices for a service dog as were previously mentioned. These types of organizations work through fundraising, making it possible for clients like you and me to receive a service dog at a more affordable rate. Service dogs are typically not given to people for free, and for more information, please see the sidebar on page 11.



Complete the Application

I needed to apply to the organization, and the application process is lengthy. For ICAN, the application packet includes answering detailed questions about your health and wellbeing. It also requires letters from medical specialists, colleagues, and friends.

I made it to and then through the interview process and I was put on the waiting list, all by the end of August 2015. Service-dog programs commonly have a waiting list, and the list at ICAN is two-to-four years. I was ready to settle down for that two-to-four-year wait.

Matching and Training for a Service Dog

You can imagine my shock when roughly six weeks after being placed on the two-to-four-year waiting list (as noted in the sidebar above), I was invited for a “matching.” This is

the time when I would be paired with a service dog. At the matching, I met with trainers and worked with six different dogs to determine which dog would be the best fit for me. I cannot express strongly enough that

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Use

COPAXONE® (glatiramer acetate injection) is prescription medicine used for the treatment of people with relapsing forms of multiple sclerosis (MS).

Important Safety Information

Do not take COPAXONE® if you are allergic to glatiramer acetate or mannitol.

Some patients report a short-term reaction right after injecting COPAXONE®. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain with heart palpitations,

anxiety, and trouble breathing. These symptoms generally appear within minutes of an injection, last about 15 minutes, and do not require specific treatment. During the postmarketing period, there have been reports of patients with similar symptoms who received emergency medical care. **If symptoms become severe, call the emergency phone number in your area.** Call your doctor right away if you develop hives, skin rash with irritation, dizziness, sweating, chest pain, trouble breathing, or severe pain at the injection site. If any of the above occurs, do not give yourself any more injections until your doctor tells you to begin again.

References: 1. IMS Health National Prescription Audit, March 2016. Data proprietary to IMS Health. 2. COPAXONE® (glatiramer acetate injection) prescribing information. Rev. 1/2014. Teva Neuroscience, Inc.



Neuroscience

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Arrange your treatment around your life—not your life around your treatment

Help take control of relapsing MS with 3-times-a-week COPAXONE® (glatiramer acetate injection) 40 mg:

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- Proven clinically effective²
- Demonstrated safety and tolerability profile²
- Injections must be at least 48 hours apart
- The financial support, training and nurse support, and educational resources of Teva's **Shared Solutions**®

*Based on total number of prescriptions for relapsing forms of MS (IMS National Rx Audit, March 2016). All Rights Reserved by IMS.



Chest pain may occur either as part of the immediate postinjection reaction or on its own. This pain should only last a few minutes. You may experience more than one such episode, usually beginning at least one month after starting treatment. Tell your doctor if you experience chest pain that lasts for a long time or feels very intense.

A permanent indentation under the skin (lipoatrophy or, rarely, necrosis) at the injection site may occur, due to local destruction of fat tissue. Be sure to follow proper injection technique and inform your doctor of any skin changes.

The most common side effects in studies of COPAXONE® are redness, pain, swelling, itching, or a lump at the site of injection, flushing, rash, shortness of breath, and chest pain. These are not all of the possible side effects of COPAXONE®. For a complete list, ask your doctor or pharmacist. Tell your doctor about any side effects you have while taking COPAXONE®.

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 brief summary of full Prescribing Information on the following page.

COPAXONE
(glatiramer acetate injection)

shared solutions
support. knowledge. answers.

Patient Information

COPAXONE (co-PAX-own) (glatiramer acetate injection) for subcutaneous use

Read this Patient Information before you start using COPAXONE and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is COPAXONE?

COPAXONE is prescription medicine used for the treatment of people with relapsing forms of multiple sclerosis (MS). It is not known if COPAXONE is safe and effective in children under 18 years of age.

Who should not use COPAXONE?

- Do not use COPAXONE if you are allergic to glatiramer acetate, mannitol or any of the ingredients in COPAXONE. See the end of this leaflet for a complete list of the ingredients in COPAXONE.

What should I tell my doctor before using COPAXONE?

Before you use COPAXONE, tell your doctor if you:

- are pregnant or plan to become pregnant. It is not known if COPAXONE will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if COPAXONE passes into your breast milk. Talk to your doctor about the best way to feed your baby while using COPAXONE.

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

COPAXONE may affect the way other medicines work, and other medicines may affect how COPAXONE works.

Know the medicines you take. Keep a list of your medicines with you to show your doctor and pharmacist when you get a new medicine.

How should I use COPAXONE?

- For detailed instructions, see the **Full Prescribing Information** for complete information on how to use COPAXONE.
- Your doctor will tell you how much COPAXONE to use and when to use it.
- COPAXONE is given by injection under your skin (subcutaneously).
- Use COPAXONE exactly as your doctor tells you to use it.
- Since every body type is different, talk with your doctor about the injection areas that are best for you.
- You should receive your first dose of COPAXONE with a doctor or nurse present. This might be at your doctor's office or with a visiting home health nurse who will teach you how to give your COPAXONE injections.

What are the possible side effects of COPAXONE?

COPAXONE may cause serious side effects, including:

- **Post-Injection Reactions.** Serious side effects may happen right after you inject COPAXONE at any time during your course of treatment. Call your doctor right away if you have any of these post-injection reaction symptoms including:
 - redness to your cheeks or other parts of the body (flushing)
 - chest pain
 - fast heart beat
 - anxiety
 - breathing problems or tightness in your throat
 - swelling, rash, hives, or itching

If you have symptoms of a post-injection reaction, do not give yourself more injections until a doctor tells you to.

- **Chest Pain.** You can have chest pain as part of a post-injection reaction or by itself. This type of chest pain usually lasts a few minutes and can begin around 1 month after you start using COPAXONE. Call your doctor right away if you have chest pain while using COPAXONE.

- **Damage to your skin.** Damage to the fatty tissue just under your skin's surface (lipoatrophy) and, rarely, death of your skin tissue (necrosis) can happen when you use COPAXONE. Damage to the fatty tissue under your skin can cause a "dent" at the injection site that may not go away. You can reduce your chance of developing these problems by:

- following your doctor's instructions for how to use COPAXONE
- choosing a different injection area each time you use COPAXONE. **See Step 4 in the Instructions for Use, "Choose your injection area".**

The most common side effects of COPAXONE include:

- skin problems at your injection site including:
 - redness
 - pain
 - swelling
 - itching
 - lumps
- rash
- shortness of breath
- flushing (vasodilation)

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of COPAXONE. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store COPAXONE?

- Store COPAXONE in the refrigerator between 36°F to 46°F (2°C to 8°C).
- When you are not able to refrigerate COPAXONE, you may store it for up to 1 month at room temperature between 59°F to 86°F (15°C to 30°C).
- Protect COPAXONE from light or high temperature.
- Do not freeze COPAXONE syringes. If a syringe freezes, throw it away in a sharps disposal container. **See Step 13 in the Instructions for Use, "Dispose of needles and syringes".**

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

General information about the safe and effective use of COPAXONE.

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

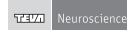
This Patient Information Leaflet summarizes the most important information about COPAXONE. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about COPAXONE that is written for health professionals.

For more information, go to www.copaxone.com or call 1-800-887-8100.

What are the ingredients in COPAXONE?

Active ingredient: glatiramer acetate

Inactive ingredients: mannitol



Marketed by: TEVA Neuroscience, Inc., Overland Park, KS 66211
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Product of Israel

This brief summary is based on COPAXONE FDA-approved patient labeling, revised: January 2014. COP-43414

this short time on the waiting list was an absolute stroke of luck and is quite uncommon.

I fell in love with one specific dog, Jaeger (sounds like “YAY-grrrr”). I cannot tell you what it was about my boy that clicked; it just DID! A few months later, I attended team training with Jaeger, which was two weeks long and concluded with a graduation ceremony. Because I lived some distance from where the training took place, I stayed in a hotel for the two weeks. I was responsible for all costs

including housing, travel, and food. I also needed to take time away from work.

While training, I was taught cues, handling, and how to teach Jaeger new skills. We also worked together to begin the development of our bond. My journey with Jaeger had just begun!

My training with Jaeger extends beyond those first two weeks. I was required to return for “refresher training” twice within our first year together. After that, I can attend refresher trainings anytime I feel they are

Why Service Dogs are Not Given for Free

Service dogs are typically not given to people for free. There is a considerable range in the fee for a service dog, whether that dog is from a not-for-profit or a for-profit program. Nonprofit programs, like ICAN, use fundraising to help offset the cost to the recipient. A reason behind the fee is that service dogs require a lot of care throughout their lives. Remember, they are not pets. The care required includes veterinary visits, quality food, and preventative care, all of which can add up quickly. An added cost for a service dog is insurance, just in case any accidents would occur. For example, if the dog gets hurt while running across the backyard, the person or family he serves is required to pay for any and all injuries.

Part of the program’s interview process includes determining if a person is able to afford and adequately care for a service dog throughout his or her life. A rationale for the fee for a service dog is often a way for the program to help assure that the client will be able to financially care for the service dog. A service dog needs high-quality food, which is expensive, but this is what is best for him. He needs to stay in top working shape, so he can provide amazing care for the person he cares for, and it’s only fair that he is provided with amazing care as well!



needed. The refresher trainings allow me to receive extra assistance with teaching Jaeger a new skill, or refreshing a skill that we haven't used frequently and needs some improvement. I love these refresher trainings!

I am also required to complete an "end of the month" report for as long as I have Jaeger. This report is one method of communication with ICAN, and keeps them abreast of everything Jaeger and I are doing. The reports also allow me to describe any concerns I have with Jaeger. My favorite part of these reports is that it allows me to further celebrate all the successes Jae and I are having together.

How ICAN Trains Service Dogs

ICAN's training program is, quite simply, amazing! ICAN has a dual mission: The training of service dogs, along with the education and rehabilitation of incarcerated adults. ICAN service dogs are cared for and trained in three Indiana Correctional Facilities. Female and male offenders, referred to as handlers, are the trainers of the service dogs. The handlers apply to and are carefully screened by the ICAN program.

At this point, you might be questioning the idea of involving prisoners with the training of service dogs; however, ICAN believes that everyone has the potential to give back to their community. "Although society must hold offenders responsible for their behavior, we also need to provide them opportunities to learn skills that can help them grow into productive and responsible citizens" (Correctional Facility Training, 2015). It is not

uncommon for nonprofit service-dog organizations to use correctional facilities to assist in training service dogs. ICAN is one of three programs where the team training occurs within the prison.

Handlers take classes within the correctional facilities to learn skills that may allow them to get a job once their sentence is complete. During their time in the ICAN Program, "The handlers develop life skills such as responsibility and accountability, compassion, teamwork, pride, self-esteem, unconditional love, discipline, and the use of logic over emotion to achieve goals" (Positive Impact on Offender and Family, 2015). Job skills for the handlers means a decrease in recidivism (re-offending) rates.

The level of hands-on training that is provided by the handlers is priceless. The service dogs live with the handlers for two years, rotating between the correctional facilities and community-based furlough volunteers. The handlers teach the service dog skills, while the volunteers continue the socialization process for the dogs in training. During the two years of training, all dogs are on a rotation of six weeks in prison and three weeks out with volunteers. This rotation assures that the dogs are continually socialized and can perform their skills out in public.

During team training, I felt completely safe with my handler. I actually forgot where I was on most days, as the set up for the training was in a building much like a school – with classrooms, a library, cafeteria, and gymnasium. Working in the ICAN program is

an honor for the handlers, and something in which they take great pride. I am eternally grateful to the handler who trained Jae.

Tasks Performed by a Service Dog

Earlier in this article, I mentioned some of the skills that service dogs can perform. Jaeger was trained on more than 75 basic skills. Even more importantly is the fact that he *is trainable, and so am I!* This means that as he and I go through life together, new skills can be taught at any time. My primary issues are balance, mobility, and fatigue. The skills I am about to describe are only some of the skills that Jaeger performs. It is by no means an exhaustive list!

During team training, I was taught how Jaeger can “brace.” To brace means that if I am on the ground and need assistance getting up, Jae stiffens his body to provide support. I put my left hand on his shoulders,

my right hand on his rump, and use him to help balance and push myself up.

When I was learning this skill, I felt horrible. I’m a larger gal and I did not want to put my weight on Jaeger. I was on the ground a lot during team training (by my choice, so I could be closest to Jae) and every time I got up, I would not have Jae brace for me. An ICAN volunteer who was in the training with me, finally said, “Look – the more you use Jaeger to assist you, the less fatigue you will have. The less fatigue you have means the more energy you will have for your daughter.” Having Jaeger was one thing; using him was another. I was afraid that by using Jaeger, I was being lazy. This guilt quickly subsided as our bond became stronger and I recognized Jaeger’s desire to help me throughout daily living.

As previously mentioned, balance is a major issue for me. Jaeger assists me with my balance

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Darbi demonstrates how Jaeger provides support and helps to maintain her balance as she pushes herself up from the floor.



while I walk. He wears a “balance harness” (pictured) that I grip with my left hand while I walk. If I experience a strong tremor, I grab ahold of the balance harness. Jaeger will “counter-pull” if I begin to fall backwards (he will pull forward). This can happen in a split second. I am absolutely amazed that he was trained to recognize this very slight, but frightening movement. I could easily fall when these tremors occur.



Jaeger assists with walking up and down stairs. At home, the stairway is odd and doesn't have a full handrail. Jaeger assists me up these stairs by walking slowly by my left side, while I have my hand on his shoulders. This allows me to maintain my balance going up and down the stairs. I am in awe with how he waits for me to maneuver up and down the stairs, moving at my pace. We frequently use this skill in public, especially when no elevator is available.

When fatigue is at its worst and I'm resting on the couch, I have trained Jaeger to get a blanket for me from our cabinet. He opens the cabinet door by pulling on a rope that has been tied to the handle. He pulls the blanket out with his paw, picks it up, and brings it to me. He then returns to the cabinet, and using his nose, pushes the door shut. I cannot stress strongly enough that I would not have been able to teach him this skill, if he didn't have such an amazing foundation of learning, and had I not been trained how to teach him.

The handler trained him to open the refrigerator door by tugging on a rope tied to the refrigerator. He then gets a bottle of water, shuts the door, and brings the bottle of water to me. Most drawers, the dishwasher, the refrigerator, and door handles all have small ropes tied to them so he can pull them open for me. He uses his nose to close things.

He assists with removing the sheets from the bed on laundry day. I use the “tug” command when asking him to remove the sheets. He will pull the sheets with his mouth. He'll then drag the sheets to the laundry room for me and put them in the washing machine.





One of my favorite things to watch Jaeger do is to drag the laundry basket full of clean clothes over to me. The laundry basket has a rope attached to it, and Jaeger uses this rope to “tug” the basket to me. He is so silly when he is executing this skill and prances all the way to me. While training, I was told Jaeger loves to work, and it’s true!

While we are at my job on campus, Jaeger assists me by carrying things to the classroom and picking up what I drop. Most frequently I drop my keys and my phone. He is quite adept at picking up my phone and handing it to me. It’s interesting to me that he was taught to pick up my phone by the edges, and not put his teeth on the screen of the phone. When I’m in my wheelchair, closing my office door is difficult. Jaeger pulls my door shut by tugging on a rope that has been tied to the door handle.

During long days on campus, I tend to use my wheelchair as my tremors increase as I become fatigued. I do not like lecturing from my wheelchair, so I use a tall chair in my classrooms. Jaeger assists me in transitioning from my wheelchair to the tall stool by

“pulling” me from my chair by tugging on a rope that I am holding horizontally. He then pushes my wheelchair over to the corner of the room. When I’m ready to go back into my wheelchair, he pulls the chair to me by pulling on a rope tied across the wheelchair frame. He assists me in transitioning back to the wheelchair. He also opens and closes the classroom door for me as well.

When we are at home, lying on my legs is a physical skill that Jaeger performs to assist with pain management. On occasion, the spasticity in my legs is quite painful. By lying on my legs, his body weight puts pressure on those muscles and it feels phenomenal!



For adults
with MS-related
walking
difficulties



**HE WAS GETTING
FASTER BUT I WAS
GETTING SLOWER**

Actor portrayal

AMPYRA® (dalfampridine) Extended Release Tablets, 10 mg, is the only product indicated to improve walking in patients with MS. This was demonstrated by an increase in walking speed.

AMPYRA does not work for everyone, and people experience different levels of response to the medication. Ask your doctor if AMPYRA may be right for you.

IMPORTANT SAFETY INFORMATION

Do not take AMPYRA if you

- have ever had a seizure,
- have certain types of kidney problems, or
- are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA.

Take AMPYRA exactly as prescribed by your doctor.

Before taking AMPYRA, tell your doctor if you

- have kidney problems or any other medical conditions
- are taking compounded 4-aminopyridine
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby.

- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.
- are taking any other medicines

Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA. You could have a seizure even if you never had a seizure before. Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50. Your doctor may do a blood test to check how well your kidneys are working before you start AMPYRA.



THAT'S WHEN I ASKED FOR THE WALKING PILL

Today is the day to ask your doctor about a **FREE* 60-day trial**. Find out more at AmpyraFreeTrial.com

*Limitations and restrictions apply.

IMPORTANT SAFETY INFORMATION continued...

AMPYRA should not be taken with other forms of 4-aminopyridine (4-AP, fampridine), since the active ingredient is the same.

- AMPYRA may cause serious side effects, including
- severe allergic reactions. Stop taking AMPYRA and call your doctor right away or get emergency medical help if you have shortness of breath or trouble breathing, swelling of your throat or tongue, or hives;
 - kidney or bladder infections.

The most common adverse events for AMPYRA in MS patients were urinary tract infection, trouble sleeping,

dizziness, headache, nausea, weakness, back pain, problems with balance, multiple sclerosis relapse, burning, tingling, or itching of your skin, irritation in your nose and throat, constipation, indigestion, and pain in your throat.

Please see the Patient Medication Guide on the following page.

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.

To learn more at an educational event near you, visit AmpyraEvents.com.

MEDICATION GUIDE FOR AMPYRA® (am-PEER-ah) (dalfampridine) Extended Release Tablets

Read this Medication Guide before you start taking AMPYRA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

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

AMPYRA can cause seizures.

- You could have a seizure even if you never had a seizure before.
- Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50.
- Your doctor may do a blood test to check how well your kidneys are working, if that is not known before you start taking AMPYRA.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See “How should I take AMPYRA?”

Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA.

What is AMPYRA?

AMPYRA is a prescription medicine used to help improve walking in people with multiple sclerosis (MS). This was shown by an increase in walking speed.

It is not known if AMPYRA is safe or effective in children less than 18 years of age.

Who should not take AMPYRA?

Do not take AMPYRA if you:

- have ever had a seizure
- have certain types of kidney problems
- are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA

What should I tell my doctor before taking AMPYRA?

Before you take AMPYRA, tell your doctor if you:

- have any other medical conditions
- are taking compounded 4-aminopyridine (fampridine, 4-AP)
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. You and your doctor will decide if you should take AMPYRA while you are pregnant.
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins and herbal supplements.

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

How should I take AMPYRA?

- Take AMPYRA exactly as your doctor tells you to take it. Do not change your dose of AMPYRA.
- Take one tablet of AMPYRA 2 times each day about 12 hours apart. Do not take more than 2 tablets of AMPYRA in a 24-hour period.
- **Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you cannot swallow AMPYRA tablets whole, tell your doctor.**
- AMPYRA is released slowly over time. If the tablet is broken, the medicine may be released too fast. This can raise your chance of having a seizure.
- AMPYRA can be taken with or without food.
- If you miss a dose of AMPYRA, do not make up the missed dose. Do not take 2 doses at the same time. Take your next dose at your regular scheduled time.
- If you take too much AMPYRA, call your doctor or go to the nearest hospital emergency room right away.
- Do not take AMPYRA together with other aminopyridine medications, including compounded 4-AP (sometimes called 4-aminopyridine, fampridine).

What are the possible side effects of AMPYRA?

AMPYRA may cause serious side effects, including:

- serious allergic reactions. Stop taking AMPYRA and call your doctor right away or get emergency medical help if you have:
 - shortness of breath or trouble breathing
 - swelling of your throat or tongue
 - hives
- kidney or bladder infections

See “What is the most important information I should know about AMPYRA?”

The most common side effects of AMPYRA include:

- urinary tract infection
- trouble sleeping (insomnia)
- dizziness
- headache
- nausea
- weakness
- back pain
- problems with balance
- multiple sclerosis relapse
- burning, tingling or itching of your skin
- irritation in your nose and throat
- constipation
- indigestion
- pain in your throat

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of AMPYRA. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store AMPYRA?

- Store AMPYRA at 59°F to 86°F (15°C to 30°C).
- Safely throw away AMPYRA that is out of date or no longer needed.

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

General Information about the safe and effective use of AMPYRA

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

This Medication Guide summarizes the most important information about AMPYRA. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about AMPYRA that is written for health professionals.

For more information, go to www.AMPYRA.com or call 1-800-367-5109.

What are the ingredients in AMPYRA?

Active ingredient: dalfampridine (previously called fampridine)

Inactive ingredients: colloidal silicon dioxide, hydroxypropyl methylcellulose, magnesium stearate, microcrystalline cellulose, polyethylene glycol, and titanium dioxide.

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Ardsley, NY 10502

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This Medication Guide has been approved by the U.S. Food and Drug Administration.

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Jaeger can get my shoes for me. I say, “Jaeger, get shoe!” When I need something that hasn’t been named, I point to the object and say, “Jaeger, get!” He can retrieve pens, pencils, and even pick up a debit card straight from the floor!

The Challenges of Being Partnered with a Service Dog

Extra Care Required

Service dogs require more care than a pet. I had never given much thought to the care a service dog requires until team training. Service dogs must be exercised 30 minutes a day, or have access to a large, fenced in yard so they can exercise – such as running after a

ball. Jaeger’s weight is carefully watched for health reasons.

They must be groomed frequently, teeth brushed twice a week or more, ears cleaned and nails trimmed once a week or more, plus they need to be bathed more frequently than the average pet, and so on. It is imperative that a service dog is well cared for, as they are highly trained dogs that in order to continue working, they must be healthy!

Continuing with care, a service dog’s training never ends. Jaeger and I work on “cognitive” training every day, for a minimum of 30 minutes. We play games that promote thinking and problem-solving, practice skills that aren’t used daily, and review those cues or skills that I notice he isn’t performing well. I teach him new assistive skills constantly.

Finally, if you have a disease such as MS, and your MS brings with it a good deal of fatigue, you need to know if you are able to provide this daily care for your service dog. What happens if I experience fatigue or even a relapse? Jaeger’s care needs to be provided by someone if I am unable to care for him, because of my MS. That is where my family steps in.

During the interview process, I was asked who would help me care for a service dog if I was sick or having an exacerbation. I have a great “team,” which is made up of my husband, Greg, and my daughter, Sami. They



Jaeger has been taught commands to pick up any item Darbi requests, which is very helpful both at home and at the store.

are my “immediate-assistance” team. My “extended-assistance” team includes my parents. All of these people are around Jaeger frequently.

Unwanted Attention

I am often asked, “Isn’t it the coolest thing to have a service dog?” and told, “I wish I could take my dog everywhere, too! My dog is so smart!” While it is absolutely amazing to have Jaeger, I caution readers to think long and hard about obtaining a service dog. The attention you will receive – warranted or unwarranted, wanted or unwanted – from the public, does not stop.

It might seem really neat at first, but after a few months, a quick trip to the store is no longer a quick trip. My family and I joke that the community responds as if they are seeing a unicorn, not a dog. Finally, laws are in place to assist and protect those of us with service dogs that allow us to enter public businesses. However, not everyone in these public businesses is aware of the laws with regard to having our dogs with us in public, and has difficulty seeing past “*a dog in the store!*”

During our team training, we were educated that having a service dog means we will receive unwarranted attention. At first, my family and I were so excited to have Jaeger with us when traveling together in public.

Most people are fascinated by service dogs, but we learned very quickly that a lot of people in the community don’t seem to have



Service-dog Jaeger watches as Darbi and her daughter Sami calculate their purchases. Time alone is rare when in public, as people often try to pet and even taunt Jaeger.

boundaries when it comes to Jaeger. It was as if he was inviting people to “pet and speak to me.” The first time we went to the local store, we were bombarded by people trying to touch Jaeger as he walked by, with people barking and making noises at him, and others saying, “Look, a DOG!” People wanted to tell us about their dogs, when all we wanted to do was grab a gallon of milk!

Jaeger and I have been matched for a year now, and the public response has yet to go away. We had been trained how to respond to people who wanted to pet him, by saying, “No thank you, he is working.” We are asked constantly by strangers if they could pet Jaeger. I have been told I was “mean” by

more people than I can count, simply because I would not allow them to pet my service dog. This is all despite the fact that Jaeger has two patches on his gear that say, "Working dog, do not pet!" But regardless of how those around us were acting, I was always friendly and polite in my responses, even when I didn't want to be.

On one occasion, we were eating dinner at a restaurant and an older couple came over and sat down at our table. The gentleman said to me, "What is so wrong with you that you need a service dog?" This kind of thing is more commonplace than I had ever realized. Is it ok? Absolutely not, but it hasn't all been negative. We've also enjoyed talking to many children about Jaeger and how he helps me.

Teaching the Community about Service Dogs

As an educator, I just knew something could be done about the responses from our community, toward Jaeger and my family. My primary concern wasn't for us, but for those people who live with other conditions where stress can trigger a negative health response, such as a seizure.

First, I needed to learn to ignore people who barked at us or made other noises at Jaeger as we walked by them. I'll be honest; it is a terrible feeling to have this happen. I would love to say that the group we have the most difficulty with is children, but it is not; it's adults. Parents encourage their children to bark at Jaeger, and as parents, Greg and I are simply astonished by this behavior. We've learned from experience that if we ask them

to stop, they typically bark louder. Adults get very vocal with their anger toward me because I won't allow them to pet Jaeger while we are working.

Second, being a person who believes that education is very important, we decided to develop a small program to educate the public about how to behave around service dogs, starting with children. We selected three educational points that we wanted children to learn from our presentations on service dogs, and designed pencils with puppy paws to give to attendees. I contacted the elementary school where Sami attended, and Jaeger and I began giving presentations to each classroom, from kindergarten through fifth grade.

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So far, we have educated 614 elementary-age students and 20-plus teachers about service dogs. The children love the pencils and are eager to learn about Jaeger. Our plan is to expand our educational program to other elementary schools during the next academic year. Our hope is that the young people will educate their parents on appropriate behavior around service dogs.

The Americans with Disabilities Act

Earlier I mentioned how many people comment about the “coolness” of having a service dog. The growing number of people with “fake” service dogs is astounding. I understand that people love their pets and want to take them everywhere. However, the service dogs who are not “real” are a big problem.

First, according to the Americans with Disabilities Act (ADA), in order to have a service dog, *you must have a disability*, and the task(s) trained will be specific to the person’s disability. For example, when Jaeger is wearing a walking harness, he assists me with walking and balance.

Second, Jaeger is not with me because I like having my dog around. He performs a service similar to what I gain from my medical equipment, which allows me to walk safely.

A service dog is able to go into stores, restaurants, and other locations not because he is a service dog, but because he is with a person who has a disability. Now, if my husband Greg took Jaeger into a grocery store, and I was not there, Jaeger would not be allowed in the store. Jaeger is allowed *accessibility* to locations because he is with me, providing a service similar to the assistance that durable medical equipment would provide to a person with a disability.

Continuing with accessibility, and I have thankfully not experienced this yet, people with service dogs cannot be denied entry into public places, such as stores, malls, and restaurants. A proprietor of a location, or its employees, can ask a person with a service dog two specific questions only. According to the ADA’s publication, *Service Animals*,



Practicing their skills in the classroom, Darbi asks Jaeger to retrieve her cane for her. Jaeger knows to pick up the cane by a small rope tied near the handle, and these types of small ropes are tied to many door and cabinet handles throughout Darbi’s house.

© Liz Kaye Photography / ICANdog.org

“When it is not obvious what service an animal provides, only limited inquiries are allowed. Staff may ask two questions: (1) is the dog a service animal required because of a disability, and (2) what work or task has the dog been trained to perform. Staff cannot ask about the person’s disability, require medical documentation, require a special identification card or training documentation for the dog, or ask that the dog demonstrate its ability to perform the work or task.”

With regard to “fake” service dogs who are not professionally trained and serving an individual with a disability, one clue that this may not be a real service dog is if the owner indicates that his or her dog is a “certified service dog.” There is no such thing as a certification for service dogs. Unfortunately, a few online companies will, for a fee, provide a “certification” for your dog to be viewed as a service dog. Many companies will also sell service-dog vests. *I dislike these companies; it is a disservice to real service dogs and to the individuals with disabilities who rely on their vital assistance.*

How Jaeger Has Changed My Life

During team training, I shared with my graduating ICAN class members – who were also each receiving a service dog – how I found that being partnered with a service dog can be bittersweet. On the one hand, how amazingly exciting to begin this journey! Having a service dog, like Jaeger, allows me to be more independent, assist with my balance, have someone to get those pesky things I drop, and help me conserve energy

that I can thankfully spend with my daughter.

However, on the other hand, throughout this exciting journey of applying for the ICAN program, interviewing, home visiting, and matching, I could no longer hide from the changes I was experiencing. Getting a service dog also means, for me, my disease has progressed. I now need assistance. Many people with MS have experienced this loss of their “old self.” And like those people, I have learned to adjust, and appreciate my new normal, which includes an amazing new partner.

If we reflect on the reasons why those of us were fortunate enough to receive a service dog, I hope that each of us can see how the “new you” is better than the “old you.” My new me is invested in the MS community, how we can help parents with MS become the best parents they can be, access services needed to live successful lives, and to parent their children to the best of their abilities.

I am also an advocate for service dogs. My new me, although not as athletic, is still able to share my humor with my daughter; model perseverance through times of challenge, and let me just say my favorite part is – I can love my daughter just as much, if not more, than the old me could ever imagine.

Since bringing Jaeger home, I have noticed changes. I no longer sit at home, waiting for someone to go with me to specific locations. I actually exercise a little more, because I have someone to help me walk (YAY for JAE!). The exercise has actually aided in the decrease of my ever-present fatigue. My spirits have been lifted. I am

much more engaged in the community now.

Ever the educator, I feel strongly that young people need to be educated on service dog awareness, and how to behave around service dogs. Because of the assistance Jaeger provides, I am no longer fearful of the grocery store, and the worry of falling – while walking across campus or during a lecture – is gone.

Yes, Jaeger helps me with things such as mobility and picking up what I have dropped, but it's more than that. It's independence. It's

strength. All of those things that I had lost were returned to me when I embarked upon getting help... and this help was packaged in the body of a pup named Jaeger. ■

References

www.icandog.org/our-training-partners
Correctional facility training

www.icandog.org/indiana-offenders
Positive impact on offender and family

www.ada.gov/service_animals_2010.htm
ADA's publication, *Service Animals*



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About the Author

Darbi Haynes-Lawrence, PhD is an Associate Professor at Western Kentucky University in the Child and Family Studies unit. She uses her experiences as a researcher and a person living with MS to educate as many people as possible about the disease. As well as conducting, publishing, and presenting research, she is passionate about teaching.

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INDICATION GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

IMPORTANT SAFETY INFORMATION You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or warning stroke, or certain types of heart failure. Do not take GILENYA if you have an irregular or abnormal heartbeat (arrhythmia), including a heart finding

called prolonged QT as seen on an ECG, or if you take medicines that change your heart rhythm. Do not take GILENYA if you are allergic to fingolimod or any of the other ingredients.

*GILENYA can result in a slow heart rate when first taken. You will be observed by a health care professional for at least 6 hours after you take your first dose. You may need to repeat this monitoring if you miss a dose.

Please see additional Important Safety Information on the next page and Brief Summary of Important Product Information on the following pages.



Talk to your health care professional to see if GILENYA is right for you.

gilenya.com



IMPORTANT SAFETY INFORMATION

GILENYA® may cause serious side effects such as:

- Slow heart rate, especially after first dose. You will be monitored by a health care professional for at least 6 hours after your first dose. Your pulse and blood pressure will be checked hourly. You'll get an ECG before and 6 hours after your first dose. If any heart problems arise or your heart rate is still low, you'll continue to be monitored. If you have any serious side effects, especially those that require treatment with other medicines, or if you have certain types of heart problems, or if you're taking medicines that can affect your heart, you'll be watched overnight. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor, or seek immediate medical attention if you have any symptoms of slow heart rate, such as feeling dizzy or tired or feeling like your heart is beating slowly or skipping beats. Symptoms can happen up to 24 hours after the first dose. Do not stop taking GILENYA without consulting with your doctor. Call your doctor if you miss 1 or more doses of GILENYA—you may need to repeat the 6-hour monitoring.
- Increased risk of serious infections. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test before you start GILENYA. GILENYA may decrease the way vaccines work in your body, especially the chicken pox vaccine. Increased risk of infection was seen with doses higher than the approved dose (0.5 mg). Two patients died who took higher-dose GILENYA (1.25 mg) combined with high-dose steroids. Call your doctor right away if you have fever, tiredness, body aches, chills, nausea, vomiting, or headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion. These may be symptoms of meningitis.
- Progressive multifocal leukoencephalopathy (PML). PML 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. It is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days, including problems with thinking, eyesight, strength, balance, weakness on 1 side of your body, or using your arms and legs.
- Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. If it happens, macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA; 3 to 4 months after you start GILENYA; and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- Swelling and narrowing of the blood vessels in your brain. A condition called PRES (Posterior reversible encephalopathy syndrome) has occurred rarely in patients taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated, it may lead to a stroke. Call your doctor right away if you experience any symptoms, such as sudden headache, confusion, seizures, loss of vision, or weakness.
- Breathing problems. Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.
- Liver problems. Your doctor should do blood tests to check your liver before you start GILENYA. Call your doctor right away if you have nausea, vomiting, stomach pain, loss of appetite, tiredness, dark urine, or if your skin or the whites of your eyes turn yellow.
- Increases in blood pressure (BP). BP should be monitored during treatment.
- A type of skin cancer called basal cell carcinoma (BCC). Talk to your doctor if you notice any skin nodules (shiny, pearly nodules), patches or open sores that do not heal within weeks. These may be signs of BCC.

GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or planning to become pregnant. Women who can become pregnant should use effective birth control while on GILENYA, and for at least 2 months after stopping. If you become pregnant while taking GILENYA, or within 2 months after stopping, tell your doctor right away. Women who take GILENYA should not breastfeed, as it is not known if GILENYA passes into breast milk. A pregnancy registry is available for women who become pregnant during GILENYA treatment. For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by e-mailing gpr@quintiles.com, or by going to www.gilenyapregnancyregistry.com.

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; heart problems; a history of repeated fainting; a fever or infection, or if you are unable to fight infections due to a disease or are taking medicines that lower your immune system, including corticosteroids, or have taken them in the past; eye problems; diabetes; breathing or liver problems; or uncontrolled high blood pressure. Also tell your doctor if you have had chicken pox or have received the chicken pox vaccine. Your doctor may test for the chicken pox virus, and you may need to get the full course of the chicken pox vaccine and wait 1 month before starting GILENYA.

If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.

Tell your doctor about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines, called live attenuated vaccines, while taking GILENYA and for at least 2 months after stopping GILENYA treatment.

The most common side effects with GILENYA were headache, abnormal liver tests, diarrhea, cough, flu, sinusitis, back pain, abdominal pain, and pain in arms or legs.

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 additional Important Safety Information on previous page.



Please see Brief Summary of Important Product Information on next pages.

BRIEF SUMMARY
GILENYA® (je-LEN-yah)
(fingolimod)
capsules

Read the Medication Guide before you start using GILENYA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your health problem or treatment.

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

GILENYA may cause serious side effects, including:

1. **Slow heart rate (bradycardia or bradyarrhythmia) when you start taking GILENYA.** GILENYA can cause your heart rate to slow down, especially after you take your first dose. You will have a test to check the electrical activity of your heart (ECG) before you take your first dose of GILENYA.

You will be observed by a healthcare professional for at least 6 hours after you take your first dose of GILENYA.

After you take your first dose of GILENYA:

- Your pulse and blood pressure should be checked every hour.
- You should be observed by a healthcare professional to see if you have any serious side effects. If your heart rate slows down too much, you may have symptoms such as:
 - dizziness
 - tiredness
 - feeling like your heart is beating slowly or skipping beats
- If you have any of the symptoms of slow heart rate, they will usually happen during the first 6 hours after your first dose of GILENYA. Symptoms can happen up to 24 hours after you take your first GILENYA dose.
- 6 hours after you take your first dose of GILENYA you will have another ECG. If your ECG shows any heart problems or if your heart rate is still too low or continues to decrease, you will continue to be observed.
- If you have any serious side effects after your first dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. You will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA the next day.
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight after you take your first dose of GILENYA.

Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA. Call your doctor or go to the nearest hospital emergency room right away if you have any symptoms of a slow heart rate.

If you miss 1 or more doses of GILENYA you may need to be observed by a healthcare professional when you take your next dose. Call your doctor if you miss a dose of GILENYA. See **“How should I take GILENYA?”**

2. **Infections.** GILENYA can increase your risk of serious infections and decrease the way vaccines work in your body to prevent certain diseases, especially the chicken pox vaccine. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping treatment. Your doctor may do a blood test before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection:

- fever
- tiredness
- body aches
- chills
- nausea
- vomiting
- headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion (these may be symptoms of meningitis)

3. **Progressive multifocal leukoencephalopathy (PML).** PML 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. It is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days, including problems with:

- thinking
- eyesight
- strength
- balance
- weakness on 1 side of your body
- using your arms and legs

4. **A problem with your vision called macular edema.** Macular edema can cause some of the same vision symptoms as an MS attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 3 to 4 months after you start taking GILENYA. Your doctor should test your vision before you start taking GILENYA and 3 to 4 months after you start taking GILENYA, or any time

you notice vision changes during treatment with GILENYA. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye called uveitis.

Call your doctor right away if you have any of the following:

- blurriness or shadows in the center of your vision
- a blind spot in the center of your vision
- sensitivity to light
- unusually colored (tinted) vision

What is GILENYA?

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

It is not known if GILENYA is safe and effective in children under 18 years of age.

Who should not take GILENYA?

Do not take GILENYA if you:

- have had a heart attack, unstable angina, stroke or warning stroke or certain types of heart failure in the last 6 months
- have certain types of irregular or abnormal heartbeat (arrhythmia), including patients in whom a heart finding called prolonged QT is seen on ECG before starting GILENYA
- are taking certain medicines that change your heart rhythm
- are allergic (hypersensitive) to fingolimod or any of the other ingredients of GILENYA listed at the end of this medication guide. Allergic reactions, which could include symptoms of rash or itchy hives, swelling of lips, tongue or face, are more likely to occur on the day you start GILENYA treatment but may occur later. If you think you may be allergic, ask your doctor for advice.

If any of the above situations apply to you, tell your doctor.

What should I tell my doctor before taking GILENYA?

Before you take GILENYA, tell your doctor about all your medical conditions, including if you had or now have:

- an irregular or abnormal heartbeat (arrhythmia)
- a history of stroke or warning stroke
- heart problems, including heart attack or angina
- a history of repeated fainting (syncope)
- a fever or infection, or you are unable to fight infections due to a disease or taking medicines that lower your immune system. Tell your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a blood test for chicken pox virus. You may need to get the full course of the vaccine for chicken pox and then wait 1 month before you start taking GILENYA.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes
- breathing problems, including during your sleep
- liver problems
- high blood pressure
- a type of skin cancer called basal cell carcinoma (BCC).
- Are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.
 - Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
 - If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and for at least 2 months after you stop taking GILENYA.

Pregnancy Registry: There is a registry for women who become pregnant during treatment with GILENYA. If you become pregnant while taking GILENYA, talk to your doctor about registering with the GILENYA Pregnancy Registry. The purpose of this registry is to collect information about your health and your baby's health.

For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by sending an email to gpr@quintiles.com, or go to www.gilenyapregnancyregistry.com.

- Are breastfeeding or plan to breastfeed. It is not known if GILENYA passes into your breast milk. You and your doctor should decide if you will take GILENYA or breastfeed. You should not do both.

Tell your doctor about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Especially tell your doctor if you take medicines that affect your immune system, including corticosteroids, or have taken them in the past.

Know the medicines you take. Keep a list of your medicines with you to show your doctor and pharmacist when you get a new medicine.

Using GILENYA and other medicines together may affect each other causing serious side effects.

Especially tell your doctor if you take vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines, called live attenuated vaccines, while you take GILENYA and for at least 2 months after you stop taking GILENYA. If you take certain vaccines, you may get the infection the vaccine should have prevented. Vaccines may not work as well when given during GILENYA treatment.

How should I take GILENYA?

- You will be observed by a healthcare professional for at least 6 hours after your first dose of GILENYA. See **“What is the most important information I should know about GILENYA?”**
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- Call your doctor right away if you miss a dose of GILENYA. You may need to be observed by a healthcare professional for at least 6 hours when you take your next dose. If you need to be observed by a healthcare professional when you take your next dose of GILENYA you will have:
 - an ECG before you take your dose
 - hourly pulse and blood pressure measurements after you take the dose
 - an ECG 6 hours after your dose
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight by a healthcare professional in a medical facility after you take your dose of GILENYA.
- If you have serious side effects after taking a dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. If you were observed overnight, you will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA. See **“What is the most important information I should know about GILENYA?”**

What are possible side effects of GILENYA?

GILENYA can cause serious side effects.

See **“What is the most important information I should know about GILENYA?”**

Serious side effects include:

- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior reversible encephalopathy syndrome) has occurred rarely in patients taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated it may lead to a stroke. Call your doctor right away if you have any of the following symptoms:
 - sudden headache
 - confusion
 - seizures
 - loss of vision
 - weakness
- **breathing problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.

- **liver problems.** GILENYA may cause liver problems. Your doctor should do blood tests to check your liver before you start taking GILENYA. Call your doctor right away if you have any of the following symptoms of liver problems:
 - nausea
 - vomiting
 - stomach pain
 - loss of appetite
 - tiredness
 - your skin or the whites of your eyes turn yellow
 - dark urine
- **a type of skin cancer called basal cell carcinoma (BCC).** Talk to your doctor if you notice any skin nodules (e.g., shiny pearly nodules), patches or open sores that do not heal within weeks (these may be signs of BCC).

The most common side effects of GILENYA include:

- headache
- abnormal liver tests
- diarrhea
- cough
- flu
- sinusitis
- back pain
- abdominal pain
- pain in arms or legs

Tell your doctor if you have any side effect that bothers you or that does not go away.

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

General information about GILENYA

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

This Brief Summary contains the most important information about GILENYA. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about GILENYA that is written for health-care professionals.

For more information, go to www.pharma.US.Novartis.com or call 1-888-669-6682.

What are the ingredients in GILENYA?

Active ingredient: fingolimod

Inactive ingredients: gelatin, magnesium stearate, mannitol, titanium dioxide, yellow iron oxide.

GILENYA is a registered trademark of Novartis AG.

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East Hanover, New Jersey 07936

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Can There Be a Genetic Predisposition to Multiple Sclerosis?

By Dr. Jack Burks

MSAA's Chief Medical Consultant



Q: I've had RRMS for 20 years and I do okay with my issues, but now my son has been diagnosed with MS. He was originally diagnosed with trigeminal neuralgia more than a year ago. My question is that while I know MS is not hereditary, I understand that there is some kind of predisposition in the genes... what exactly does that mean? I don't know of anyone else in my family who had MS. Your thoughts on this matter are greatly appreciated.

A: I am sorry to hear that your son has also been diagnosed with multiple sclerosis. The risk for this happening is about 2 percent. The causes of MS are not fully understood, but genetic factors have been implicated. Many genes that influence the immune system have been identified as being “over represented” in MS patients.

The risk for MS in the general population is about one in 1,000 in the United States. The risk for a close, blood relative (your son) increases to about 2 percent. The MS risk for a non-identical twin of a person with MS is about 5 percent. The risk for an identical twin

is about 30 percent. Therefore, a family history of MS may increase the risk – or “predispose” someone in the family to MS. If MS were a hereditary disease, the risk might be 50 percent for any close, blood relatives (versus about 2 percent) and we would likely be able to identify the specific genetic link. However, that is fortunately not the case in MS.

In an earlier issue of *The Motivator*, MSAA featured a cover story titled “Family Genes & MS.” This may be accessed by going to mymsaa.org/ws11cs. This article defines certain genetic terms and provides a good overview of genetics and MS, along with noting the direction of future research. The article explains, “What can be said at present is that genes have some role in susceptibility to MS but exact mechanisms remain unclear. Nevertheless, genetic epidemiological studies in MS have clearly shown that the increased frequency of MS seen within families is a result of relatives sharing DNA and not the common family environment.” I hope this information will be helpful to you.

Q: I was diagnosed with RRMS in December 2014 at the age of 28. I have been taking Gilenya® (fingolimod), and seem to be doing pretty well. My doctor also increased my dosage of Topamax® (topiramate) and started me on Cymbalta® (duloxetine delayed-release capsules) for depression.

Since the age of 12 I have suffered with chronic migraines and nothing really helps. I am now taking all of these drugs for MS, depression, and migraines. In addition, I have spasticity in my legs. I have major problems with cognition and fatigue. I recently completed a neuropsychological exam and my scores were "consistent with disability." I am very concerned that my cognition has declined in such a short period of time.

My questions and concerns are:

1. Is there a way to improve memory, cognition, and fatigue without medicine?
2. Could medical marijuana help with migraine relief and spasticity?
3. Why don't neurologists talk about diet and lifestyle changes?

A: Decreased memory/cognition, fatigue, migraine, headache, and spasticity are all frequent with MS. I am pleased that Gilenya is helping. However, I am concerned that you are still having many problems, including memory and cognition issues, after being diagnosed less than two years ago. I suggest you seek help for your multitude of problems from a comprehensive MS center, where experts can

provide help in several areas, including disease-modifying therapies, symptom management, rehabilitation (including cognitive rehabilitation), wellness, nutrition, and lifestyle.

For cognition specifically, exercise has been shown to improve cognitive performance. In one study, walking on a treadmill appeared to have the greatest effect. Swimming is another good option. Computer programs designed to help with cognition retraining have also proven to be effective. Your neurologist or a physical or occupational therapist may have more information on where to get this type of computer program.

For more information on cognition and MS, please refer to our cover story from the Winter/Spring 2015 issue of *The Motivator*, "Cognitive Issues with Multiple Sclerosis: Research, Strategies, and Support," found at mymsaa.org/ws15cs. In this article, you'll find a good deal of information and additional resources on this topic.

As for marijuana, I have concerns about long-term cognitive problems with daily marijuana. Some marijuana research shows troubles with cognition. While marijuana may help your headache and spasticity, other better-researched treatments might be tried first. As for specific diets or wellness lifestyle strategies, many neurologists do not feel qualified, unless specifically trained. However, as I noted earlier, comprehensive MS centers are likely to have MS experts in these areas.

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Q: After 11 years on different disease-modifying therapies, I was not able to tolerate the side effects. After discontinuing these treatments, I have been on 3 mgs of Low Dose Naltrexone (LDN) for the last four years. I have several symptoms, but no major exacerbations. MSAA's *MS Research Update* listed 32 medications and not one mention of LDN. Why is there no research on this drug?

A: This is a great question that involves many facets related to MS research. First, LDN may have some positive effects on some MS symptoms, according to various small pilot research trials. However, it is not believed by most MS experts to have significant disease-modifying effects in MS.

Economics play a role in decisions to test drugs. Since clinical trials in MS leading to FDA approval may take five to 10 years at a significant cost, the risk of failure or only marginal symptom relief with LDN is not likely worth this costly investment to the pharmaceutical companies. Some pilot MS research on LDN several years ago was encouraging for some symptoms, but it did not appear to have the “blockbuster” effect to risk a huge financial investment.

Patent issues and other factors also play a role in the decisions to pursue clinical trials for any drug. Therefore, LDN is not FDA-approved and is only used by a small percentage of patients, most with progressive forms of MS, where no FDA-approved drugs are available at this time. My experience is that some people feel better and some do not.

It is not expensive and does not appear to be harmful, although unknown risks might appear with closer scrutiny.

MSAA's *MS Research Update* reports on current clinical trials. The update covers recently published research in neurology journals with data presented at major MS meetings. LDN research data has been lacking in recent MS meetings and no new LDN research is available to discuss. In the meantime, I'm pleased that you are benefitting by taking LDN and hope that these positive effects continue for you. ■

Jack Burks, MD is the chief medical consultant for MSAA. He is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies and advises patients, families, MS organizations, and healthcare groups. Dr. Burks is a Professor and Director of the MS Program at Nova Southeastern University in Davie, Florida and has authored textbooks, chapters, and articles on MS.

PLEASE SUBMIT YOUR QUESTIONS TO:

MSAA
Questions for Ask the Doctor
c/o Dr. Jack Burks
375 Kings Highway North
Cherry Hill, New Jersey 08034

Questions may also be emailed to askdr@mymsaa.org. Please be sure to include “Ask the Doctor” in the subject line.

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*Christine, Paul, Maby, and Katrina
Acthar patients who share
their MS relapse stories*

USES

H.P. Acthar® Gel (repository corticotropin injection) is indicated for the treatment of acute exacerbations of multiple sclerosis in adults. Controlled clinical trials have shown Acthar to be effective in speeding the resolution of acute relapses of multiple sclerosis. However, there is no evidence that it affects the ultimate outcome or natural history of the disease.

IMPORTANT SAFETY INFORMATION

You should not take Acthar if you have:

- A skin condition called scleroderma
- Bone density loss
- Any infections
- Eye problems, such as ocular herpes simplex
- Had recent surgery
- Stomach ulcers or a history of ulcers
- Heart problems
- High blood pressure
- Allergies to pig-derived proteins
- Been recently given a vaccine or are about to take one
- A condition where your adrenal glands produce either too much of certain hormones (as with Cushing's syndrome), or not enough (adrenal insufficiency)

Never inject Acthar directly into a vein, and always take Acthar as prescribed by your doctor.

Never stop treatment suddenly unless your doctor tells you to. Try not to miss any scheduled doctor's appointments, as it is important for the doctor to monitor you while taking Acthar.

Acthar can cause side effects similar to those with steroid treatments. Tell your doctor if you have any of the symptoms listed here.

- **Increased risk of infections.** You may be more likely to get new infections. Also, old infections may become active. Signs of infection are fever, cough, vomiting, or diarrhea. Other signs may be flu or any open cuts or sores
- **Adrenal gland changes.** Taking Acthar long term may cause symptoms of Cushing's syndrome, such as upper body fat, rounded "moon" face, bruising easily, or muscle weakness
- **Increased blood pressure, body salt, and fluid.** Your doctor may recommend changes to your diet
- **Unpredictable response to vaccines.** Talk to your doctor about which vaccines are safe to use when taking Acthar

- **Masking other conditions.** Tell your doctor if you have any infections, changes in weight, excessive tiredness, increased thirst, fast heart rate, or difficulty breathing
- **Stomach or intestinal problems.** Acthar may put you at increased risk for bleeding from the stomach or getting stomach ulcers. Tell your doctor if you have any pain in the stomach area, vomiting, or bloody or black stools
- **Changes in mood or behavior.** You may be irritable, have mood swings, be depressed, or have trouble sleeping
- **Worsening of other medical conditions,** including diabetes
- **Eye problems,** such as cataracts, glaucoma, or optic nerve damage
- **Allergic reactions.** Tell your doctor if you have a skin rash, swelling, or trouble breathing
- **Bone density loss.** Acthar may cause osteoporosis at any age
- **Potential harm to unborn baby.** Tell your doctor if you are pregnant or plan on becoming pregnant

The most common side effects are similar to those of steroids. They include:

- Fluid retention
- Changes in blood sugar
- Increased blood pressure
- Behavior and mood changes
- Changes in appetite and weight

Specific side effects in children under 2 years of age include:

- Increased risk of infections
- Increased blood pressure
- Irritability
- Symptoms of Cushing's syndrome
- Cardiac hypertrophy (thickening of the heart muscle)
- Weight gain

The above side effects may also be seen in adults and children over 2 years of age.

These are not all of the possible side effects of Acthar. Tell your doctor about any side effect that bothers you, or that does not go away.

You may report side effects to the FDA. Call 1-800-FDA-1088 or visit www.fda.gov/medwatch. You may also report side effects by calling 1-800-778-7898.

Please see adjacent page for Brief Summary of Acthar full Prescribing Information.



Important information about H.P. Acthar® Gel.

Please read this summary carefully and ask your doctor about Acthar. No advertisement can provide all of the information needed to determine if a drug is right for you or take the place of careful discussions with your healthcare provider. Only your healthcare provider has the training to weigh the risks and benefits of a prescription medicine.

What is the most important information I should know about H.P. Acthar Gel?

Acthar can cause serious side effects, including:

- Increased risk of infections.** Acthar affects your immune system. Therefore, patients may be more likely to get new infections, or inactive infections may become active. Tell your doctor right away if you have any signs of infection, such as fever, cough, vomiting, diarrhea; or sign of illness or flu; or any open cuts or sores.
- Adrenal gland changes.** Acthar has effects on the adrenal gland. When a patient is taking Acthar, their adrenal gland may produce too much of a hormone called cortisol. This can cause symptoms of Cushing's syndrome (upper body fat, rounded face, thin skin), which is more common in patients who take this medicine for a long time. When a patient stops taking Acthar after a long time, the body may not produce enough cortisol on its own (adrenal insufficiency). The doctor may prescribe a steroid medicine to protect the body until the adrenal gland recovers. Do not stop administering Acthar without talking to your doctor first.
- Blood pressure changes.** Blood pressure should be checked during treatment; your healthcare provider may instruct you to make some dietary changes. Acthar may cause an increase in blood pressure.
- Increased amount of water in the body, increased body salts, and low potassium in the blood.** Acthar may cause your body to have an increased amount of body salts and water that stays in the body, and may lower the amount of potassium in the blood. Your doctor may instruct you to make some dietary changes.
- Vaccine eligibility.** Patients should not receive certain vaccines during Acthar treatment. Talk to your healthcare provider about which vaccines are safe for you.
- Undetectable conditions.** Acthar may hide (or mask) symptoms of other conditions or diseases, making it more difficult for your healthcare provider to diagnose other conditions or diseases in you during treatment.
- Stomach bleeding or ulcers.** You may have an increased risk for bleeding from the stomach or having a stomach ulcer. Report any pain in the stomach area, vomiting or bloody vomit, bloody or black stools, excessive tiredness, increased thirst, difficulty breathing or increased heart rate.
- Changes in mood or behavior.** Irritability, depression, or trouble sleeping may occur.

What is H.P. Acthar Gel?

Acthar is a prescription medication used to treat acute relapses or flares in adults with multiple sclerosis (MS). Studies have shown H.P. Acthar Gel to be effective in speeding recovery from an MS relapse. However, there is no evidence that Acthar affects the ultimate outcome or natural history of the disease.

What should I tell my healthcare provider before using H.P. Acthar Gel?

Tell your doctor about all of your health conditions, including if you have:

- A skin condition called scleroderma
- Bone density loss (osteoporosis)
- Infection throughout your body
- Eye problems such as ocular herpes simplex
- Recently undergone surgery
- History of or a current stomach ulcer
- Heart problems
- High blood pressure
- Allergies to pig-derived proteins
- Diabetes
- Kidney problems
- Thyroid problems
- Liver problems
- Neuromuscular problems
- Convulsions or seizures
- Had exposure to someone with tuberculosis (TB)
- Recently been vaccinated

Tell your doctor if you are pregnant or plan on becoming pregnant.

Tell your healthcare provider about these and any other health problems you may have or medicines you are taking, including prescription and non-prescription medicines, vitamins, and herbal supplements.

How is H.P. Acthar Gel given?

Acthar should never be given intravenously (into a vein).

Acthar is given as an injection into the muscle or under the skin. Do not inject it into a vein, or give it by mouth.

- Inject Acthar exactly as your doctor tells you. Your doctor will tell you where to give the injection, how much to give, how often and when to give yourself the injection.

Refer to the full Prescribing Information for additional information on how Acthar is given.

What are the possible side effects of H.P. Acthar Gel? See "What is the most important information I should know about H.P. Acthar Gel?"

Acthar can cause side effects similar to those that can happen with steroid treatments. Tell your healthcare provider right away if you have any of the symptoms listed below while taking Acthar. Not all of the following side effects have occurred with Acthar, but they might be expected. *Before beginning any treatment, you should discuss with your healthcare provider the potential benefits and risks associated with Acthar.*

Acthar can cause serious side effects. Acthar may make certain other medical conditions worse such as diabetes (may increase blood sugar); cause eye problems such as cataracts, increased pressure in the eye (glaucoma), and possible damage to the optic nerve; and cause allergic reactions to Acthar (seen as skin rash, swelling of the face, tongue, lips, or throat, and trouble breathing). Acthar may affect growth and physical development after long-term use. Long-term use of Acthar may cause an increase in the size of the heart, but this condition usually goes away after Acthar is stopped.

Tell your doctor if you have any of the side effects listed above.

What are the most common side effects of H.P. Acthar Gel?

The most common side effects of Acthar in infants include: infections, increased blood pressure, irritability and changes in behavior, changes in appetite and weight, diarrhea, and vomiting. Other adverse reactions reported in adults and children over 2 years of age included abdominal bloating, anxiety, asthma, chest discomfort, congestive heart failure, dizziness, shortness of breath, redness of the face, fluid retention, flushing, headache, injection site pain, tiredness, muscle weakness, nervousness, rapid heart rate, and lack of energy.

Report side effects to your healthcare provider. The side effects listed here are not all of the side effects possible with Acthar. Ask your healthcare provider for more information. Tell your healthcare provider if there is any side effect that bothers you or that does not go away.

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.

How should I store H.P. Acthar Gel?

- Store vials of H.P. Acthar Gel in the refrigerator between 36°F to 46°F (2°C to 8°C).
- Throw away any vials after the expiration date printed on the label.

What are the ingredients in H.P. Acthar Gel?

Active ingredient: Corticotropin.

Inactive ingredients: gelatin, phenol, cysteine, sodium hydroxide and/or acetic acid to adjust pH, and water for injection.

General information about H.P. Acthar Gel.

Medicines are sometimes prescribed for purposes other than those listed in the Prescribing Information. Do not use H.P. Acthar Gel for a condition for which it has not been prescribed. Do not give H.P. Acthar Gel to other people, even if they have the same symptoms. It may harm them.

Please see the full list of warnings, precautions, and adverse events in the full Prescribing Information for Acthar. Discuss this information with your healthcare provider.

Find out more. Ask your healthcare provider or pharmacist, go to www.acthar.com, or call 1-800-778-7898 to learn more about Acthar.



FDA Approval and Review of MS Medications

Editor's note: The information provided in this column is a brief overview of a few of the major news items occurring since the previous issue of *The Motivator*. For additional news plus national and international meeting updates, please refer to the "Latest News" section of MSAA's homepage at mymsaa.org.

FDA Approves Zinbryta™ (Daclizumab) for Relapsing Forms of Multiple Sclerosis

On May 27, 2016, the United States Food and Drug Administration (FDA) announced the approval of Zinbryta™ (daclizumab) for adults with relapsing forms of multiple sclerosis (RMS). This monoclonal antibody is self-administered subcutaneously (under-the-skin) once per month and has been shown to reduce the number of relapses as well as new or newly enhancing lesions, as compared to Avonex® (interferon beta-1a) and to placebo, in two separate studies. Zinbryta is co-promoted in the United States by Biogen and AbbVie.

While the FDA approved Zinbryta because they determined that the benefits outweigh the potential for adverse events, this medication does carry safety risks, which include liver injury and immune conditions. Monthly liver-function tests are required with Zinbryta, and it is available only through a restricted distribution program under a Risk Evaluation and Mitigation Strategy.

Daclizumab (Zinbryta) is a genetically engineered monoclonal antibody that binds to CD25, a receptor on T cells that is thought to become activated in response to MS.

Daclizumab is believed to work by selectively targeting these activated T cells without causing general T-cell depletion.

For more information, please contact Biogen's Above MS™ program at **(800) 456-2255** or visit www.zinbryta.com.

FDA Accepts Review of Application for Ocrelizumab

On June 27, 2016, Genentech, a member of the Roche group, announced that the Biologics License Application (BLA) for ocrelizumab had been accepted for review by the FDA. This is the first time that an investigational medication is being reviewed for the treatment of both relapsing forms of MS (RMS) and primary-progressive MS (PPMS). A decision for approval will be made on or before December 28, 2016. Genentech has submitted the brand name Ocrevus™ for use with ocrelizumab.

Ocrelizumab is an investigational, humanized monoclonal antibody designed to selectively target CD20-positive B cells. These are a specific type of immune cell that is an important contributor to the MS-disease process. In Phase III trials, 600 mgs of ocrelizumab were given via intravenous (IV) infusion every six months.

Positive results were seen in three Phase III trials with ocrelizumab, including reductions in annualized relapse rates and reductions in disability progression that was sustained for time periods of at least three and at least six

months. Genentech reports that the most common adverse events were mild to moderate infusion-related reactions and infections.

Eligible People with PPMS May Receive Ocrelizumab

Also announced in late June, the experimental medication ocrelizumab is available for eligible individuals with PPMS through an Expanded Access Program (EAP). Please note that only people with PPMS, not with RMS, are able to participate in this program. This program is a nontraditional study that has no placebo group and follows a strict protocol developed through consultation with the FDA.

To take part in ocrelizumab's EAP, individuals must be 18 to 55 years of age, have a PPMS diagnosis, and have an Expanded Disability Status Score (EDSS) of 2.0 to 6.5 points. Women of child-bearing potential will need to check with their program doctor about birth-control options. For more information please call Genentech's **Trial Information Support Line** at **(888) 662-6728**.

Experimental SPMS Medication Shows Positive Results

On August 25, 2016, Novartis announced that siponimod, an experimental oral treatment for MS, is showing positive results for individuals with secondary-progressive MS (SPMS). Novartis, the pharmaceutical company developing siponimod, announced that the Phase III EXPAND study met its primary endpoint, which was to reduce the risk of confirmed disability progression at three months, versus a placebo.

Siponimod, also known as BAF312, is in a class of immunomodulatory drugs called "S1P-receptor modulators," which also includes Gilenya® (fingolimod). The structure of these medications is similar to a naturally occurring component of cell-surface receptors on white blood cells, and block potentially damaging T cells from leaving lymph nodes. They may reduce damage to the central nervous system (CNS) and enhance the repair of damaged nerves within the brain and spinal cord. ■

For more information on these and other topics, please go to mymsaa.org/news.

For any MS-related questions, please contact MSAA's Client Services Specialists via email at MSquestions@mymsaa.org, via phone at **(800) 532-7667, extension 154**, or via our interactive one-on-one chat feature, at mymsaa.org/chat.

By Susan Wells Courtney

Reviewed by Dr. Jack Burks

Portions reviewed by Barry A. Singer, MD

Introducing My MSAA Community

Join others who have similar experiences with multiple sclerosis (MS) in an online HealthUnlocked community



- Get advice, support and connect with people affected by MS
- Communicate directly with others who have MS
- Feel more confident managing your own health and your family's health
- Solve day-to-day challenges
- Have your voice heard about important MS issues

Join My MSAA Community today

www.healthunlocked.com/msaa

HealthUnlocked, the world's largest social network for health

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100% Made in America (even the zippers!)



The Steele Cool-UnderVest[™]



Original Tan Steele Cooling Vest

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Email: steelevest@gmail.com

**Proud participant in the
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MRI Access Fund Returns

By Peter Damiri

Vice President of Programs and Services

MSAA is thrilled to report we are currently processing applications for our longstanding and highly requested MRI Access Fund Program. Through recent support from Teva Neuroscience and Sanofi Genzyme, MSAA has reopened the program to provide cranial MRIs for MS diagnostic and follow-up exams until the limited funds are exhausted.

It is important to note that MSAA has adjusted certain aspects of the program to balance the anticipated high demand from our clients. Under the current program's guidelines, MSAA will process qualified applicants who are uninsured or unable to meet their current insurance deductible

balance. Unfortunately, MSAA is unable to process co-insurance payments at this time.

The MRI Access Fund application has been updated to reflect these changes and can be accessed at mymsaa.org/mri or by calling **(800) 532-7667, ext. 120**.

Applications will be processed on a first-come, first-serve basis; no emergency situations apply; and specific documentation is required.

MSAA is extremely pleased to resume this critically important service to the MS community and will continue to seek additional funding to help meet increasing client demand. If you have any questions, please call **(800) 532-7667, ext. 120**. ■

MSAA Launches My MSAA Community

MSAA is proud to announce the recent launch of a new peer-to-peer online platform titled My MSAA Community. This program gives people living with multiple sclerosis (MS), care partners, and family members a way to connect with others going through the same challenges, as well as to receive valuable and relevant information and support. Powered by HealthUnlocked, this free online portal is a safe, supportive, and friendly community where people can post questions and comments, reply to ongoing conversations, share messaging through social media platforms, and have the option to participate in occasional polling questions about important MS issues.

With 900 followers joining since the launch, My MSAA Community has already made quite an impact on people visiting the site and joining the conversation. Among the many positive comments MSAA has received since launching the site is this post from one of our current community members: *"This message board is fantastic! I've gotten much helpful advice here. Good luck and best wishes."*

MSAA greatly appreciates all of the supportive feedback we've received so far and encourages everyone to visit our new online community. To learn more, please visit healthunlocked.com/MyMSAA. ■

Register Now for MSAA's updated S.E.A.R.C.H.™ Webinar

While having more than a dozen FDA-approved treatments for relapsing MS is encouraging, the safety, effectiveness, and tolerability of any given medication varies from one person to another. As doctors try to encourage patients to take an active role in selecting a disease-modifying therapy (DMT), it can be challenging to learn about the treatments and know what questions to ask. Recognizing this challenge, MSAA created the S.E.A.R.C.H.™ initiative to help the MS community better understand DMT medications and be prepared with key questions to discuss with their doctor when selecting or switching treatments.

Through support from EMD Serono and Sanofi Genzyme, MSAA has been able to update

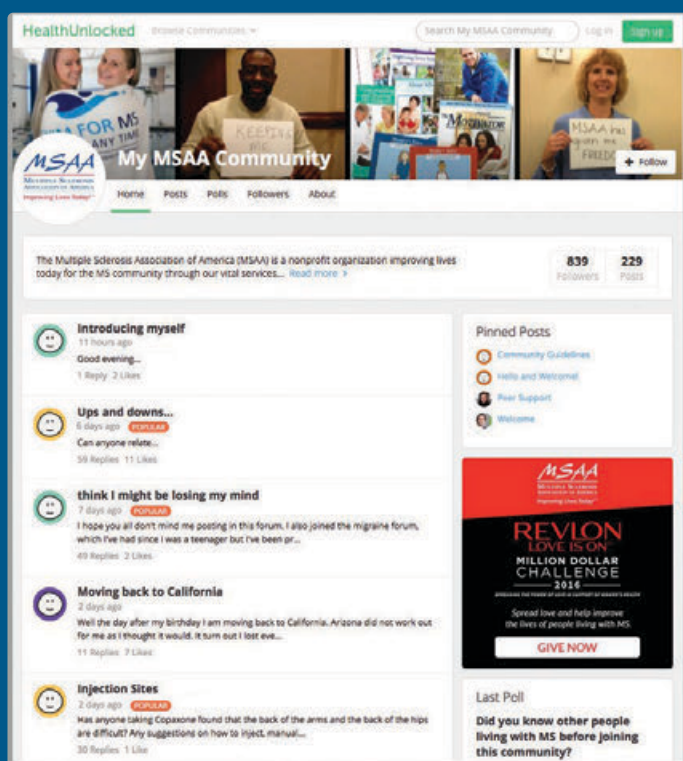


Carrie Hersh, DO, MS will present the October 19 webinar and answer questions submitted through a live chat feature.

our SEARCH tools, including the comprehensive booklet, handy workbook, and the upcoming live webinar scheduled for Wednesday, October 19, 2016 from 8 pm to 9 pm ET. For anyone unable to participate on October 19th, the webinar will be archived and available for viewing on MSAA's website at **mymsaa.org**. In this live webinar, MS expert Dr. Hersh will:

- Review the current landscape of MS therapies and those on the horizon
- Discuss the importance of having a good doctor-patient relationship
- Explain the S.E.A.R.C.H. acronym and how it helps people remember the six key topics to discuss with their physician when deciding on a treatment
- Provide effective strategies for staying on treatment

Following the presentation, participants can engage in a Q & A session with Dr. Hersh from questions submitted through the webinar's live chat feature. To register for the free webinar as well as order the updated SEARCH booklet and workbook, please visit **mymsaa.org/search**. ■



Glatopa[®]
(glatiramer acetate injection)

Your routine stays routine.

Glatopa[®] (glatiramer acetate injection) 20mg/mL is the first FDA-approved, substitutable generic for Copaxone[®] (glatiramer acetate injection) 20mg/mL

Indication

Glatopa[®] (glatiramer acetate injection) 20mg/mL is indicated for the treatment of patients with relapsing-forms of multiple sclerosis.

Important Safety Information

Do not take Glatopa[®] if you are allergic to glatiramer acetate or mannitol.

Some patients report a short-term reaction right after injecting glatiramer acetate. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain with heart palpitations, anxiety, and trouble breathing. These symptoms generally appear within minutes of an injection, last about 15 minutes, and do not require specific treatment. During the postmarketing period, there have been reports of patients with similar symptoms who received emergency medical care.

If symptoms become severe, call the emergency phone number in your area.

Call your doctor right away if you develop hives, skin rash with irritation, dizziness, sweating, chest pain, trouble breathing, or severe pain at the

injection site. If any of the above occurs, do not give yourself any more injections until your doctor tells you to begin again.

Chest pain may occur either as part of the immediate postinjection reaction or on its own. This pain should only last a few minutes. You may experience more than one such episode, usually beginning at least one month after starting treatment. Tell your doctor if you experience chest pain that lasts for a long time or feels very intense.

A permanent indentation under the skin (lipoatrophy or, rarely, necrosis) at the injection site may occur,





due to local destruction of fat tissue. Be sure to follow proper injection technique and inform your doctor of any skin changes.

The most common side effects in studies of glatiramer acetate injection 20mg/mL are redness, pain, swelling, itching, or a lump at the site of injection, flushing, rash, shortness of breath, and chest pain. These are not all of the possible side effects of glatiramer acetate. For a complete list, ask your doctor or pharmacist. Tell your doctor about any side effects you have while taking Glatopa.

To report SUSPECTED ADVERSE REACTIONS, contact Sandoz Inc. at 1-800-525-8747 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

Please see brief summary of full Prescribing Information on the following page.

Copaxone is a registered trademark of Teva Pharmaceutical Industries Ltd.

Eligible patients may pay

\$0 Co-Pay*
per month for Glatopa

To learn more about the Glatopa Co-Pay Program, call GlatopaCare® at **1.855.GLATOPA** or visit **glatopa.com**.

***Glatopa Co-Pay Program Eligibility**

The Glatopa Co-Pay Program provides up to \$9,000 in annual Co-Pay support for Glatopa prescriptions. This program is not health insurance. This program is for insured patients only; uninsured cash-paying patients are not eligible. Patients are not eligible if prescriptions are paid, in whole or in part, by any state or federally funded programs, including but not limited to Medicare (including Part D, even in the coverage gap) or Medicaid, Medigap, VA, DOD, or TriCare, or private indemnity, or HMO insurance plans that reimburse you for the entire cost of your prescription drugs, or where prohibited by law. Card may not be combined with any other rebate, coupon, or offer. Sandoz reserves the right to rescind, revoke, or amend this offer without further notice.

GlatopaCare Supports Your Treatment Routine

GlatopaCare personalized support services include:

- **24/7 Support From a GlatopaCare Nurse Trainer**
- **Personalized Injection Training**
- **Insurance and Benefits Information**

To learn more about GlatopaCare, call **1.855.GLATOPA** or visit **glatopa.com**.

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S-GLA-1332901 07/2016

SANDOZ A Novartis Division

Patient Information

Glatopa® (glatiramer acetate injection) for Subcutaneous Use

Read this Patient Information before you start using Glatopa and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is Glatopa?

Glatopa is prescription medicine used for the treatment of people with relapsing forms of multiple sclerosis (MS).

It is not known if Glatopa is safe and effective in children under 18 years of age. Glatopa is supplied as a 1 mL single dose glass syringe with attached 1/2 inch length and 29 gauge needle.

Who should not use Glatopa?

- Do not use Glatopa if you are allergic to glatiramer acetate or mannitol.

What should I tell my doctor before using Glatopa? Before you use Glatopa, tell your doctor if you:

- are pregnant or plan to become pregnant. It is not known if glatiramer acetate will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if glatiramer acetate passes into your breast milk. Talk to your doctor about the best way to feed your baby while using Glatopa.

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

Glatopa may affect the way other medicines work, and other medicines may affect how glatiramer acetate works.

Know the medicines you take. Keep a list of your medicines with you to show your doctor and pharmacist when you get a new medicine.

How should I use Glatopa?

- For detailed instructions, visit www.glatopa.com for complete information on how to use Glatopa.
- Your doctor will tell you how much Glatopa to use and when to use it.
- Glatopa is given by injection under your skin (subcutaneously).
- Use Glatopa exactly as your doctor tells you to use it.
- Since every body type is different, talk with your doctor about the injection areas that are best for you.
- You should receive your first dose of Glatopa with a doctor or nurse present. This might be at your doctor's office or with a visiting home health nurse who will teach you how to give your Glatopa injections.

What are the possible side effects of Glatopa?

Glatopa may cause serious side effects, including:

- **Post-Injection Reactions.** Serious side effects may happen right after you inject Glatopa at any time during your course of treatment. Call your doctor right away if you have any of these post-injection reaction symptoms including:
 - o redness to your cheeks or other parts of the body (flushing)
 - o chest pain
 - o fast heart beat
 - o anxiety
 - o breathing problems or tightness in your throat
 - o swelling, rash, hives, or itching

If you have symptoms of a post-injection reaction, do not give yourself more injections until a doctor tells you to.

- **Chest Pain.** You can have chest pain as part of a post-injection reaction or by itself. This type of chest pain usually lasts a few minutes and can begin around

1 month after you start using Glatopa. Call your doctor right away if you have chest pain while using Glatopa.

- **Damage to your skin.** Damage to the fatty tissue just under your skin's surface (lipoatrophy) and, rarely, death of your skin tissue (necrosis) can happen when you use Glatopa. Damage to the fatty tissue under your skin can cause a "dent" at the injection site that may not go away. You can reduce your chance of developing these problems by:
 - o following your doctor's instructions for how to use Glatopa.
 - o choosing a different injection area each time you use Glatopa.

The most common side effects of Glatopa include:

- skin problems at your injection site including:
 - o redness
 - o pain
 - o swelling
 - o itching
 - o lumps
- rash
- shortness of breath
- flushing (vasodilation)

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of Glatopa. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store Glatopa?

- Store Glatopa in a refrigerator between 36°F to 46°F (2°C to 8°C).
- When you are not able to refrigerate Glatopa, you may store it for up to 1 month at room temperature between 59°F to 86°F (15°C to 30°C).
- Protect Glatopa from light or high temperature.
- Do not freeze Glatopa syringes. If a syringe freezes, throw it away in a sharps disposable container.

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

General information about the safe and effective use of Glatopa.

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

This Patient Information summarizes the most important information about Glatopa. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about Glatopa that is written for health professionals.

For more information, go to www.glatopa.com or call Sandoz GlatopaCare® at 1-855-452-8672.

What are the ingredients in Glatopa?

Active ingredient: glatiramer acetate

Inactive ingredient: mannitol

Marketed By: Sandoz Inc., Princeton, NJ 08540

Distributed By: Sandoz Inc., Princeton, NJ 08540

Product of the USA

This brief summary is based on Glatopa FDA-approved patient labeling, revised: 01/2016

Continuing Our Opportunities to Give

By Susan Wells Courtney

After several years of dedicated service, former MSAA Vice President of Development Kimberly Goodrich has moved on to a new career opportunity. We wish her much success in her new position! We now welcome new Vice President of Development Kristine Magnifico to MSAA's Development team. In addition to her business background, Ms. Magnifico has extensive experience in special events, grant submission, and other areas of donor development. She comes to MSAA following 10 years of work with the American Diabetes Association. Ms. Magnifico will be instrumental in ensuring that necessary funds are raised for MSAA's vital programs and services, all aimed at Improving Lives Today for the entire MS community.

Among the many different avenues Ms. Magnifico will be addressing in an effort to provide as much funding as possible to MSAA's valuable services, MSAA's new Vice President of Development will also be continuing many of the current initiatives for raising money. To follow are a few giving opportunities that have been featured in recent issues of *The Motivator* in our Thoughts about Giving column.

Tribute Gift: This can be the perfect gift to honor a special occasion or someone's important achievement. Whether it's a birthday, anniversary, graduation, or other special time, a tribute gift is a wonderful way

to honor someone you respect, admire, or love. Similar to a tribute gift, a memorial gift is a beautiful testimony to the life of a friend or family member.

Sustaining Gift: A sustaining gift is a donation automatically given at regular intervals, such as monthly, quarterly, or annually. These gifts can be set up in advance and given directly via electronic funds transfer (EFT) or credit card. A big advantage of sustaining gifts is that MSAA can plan ahead and count on these contributions when ordering equipment and provides significant savings in postage and administrative costs.

Leaving a Legacy: This type of giving is often called "planned giving" because of the careful consideration taken when making such a gift, or "deferred giving," because of the gift's timing. Legacy gifts are easily made and can be as simple as naming a charity as the beneficiary of your savings, checking, or retirement account; or listing a charity in your will.

And don't forget about matching gifts! If you are making a contribution to MSAA, please be sure to check with your employer. Many companies will double the dollar amount of the donation as part of their **Matching Gift** program.

For more information about these opportunities to support MSAA and other ways to give, please visit our website at mymsaa.org or call **(800) 532-7667, ext. 101.** ■

MSAA's Lending Library Selections

The Power of Wagging Tails: A Doctor's Guide to Dog Therapy and Healing

by Dawn A. Marcus, MD

Demos Health | MSAA Book #386



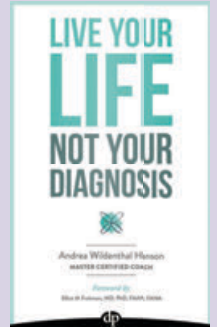
Research has consistently shown that dogs have both therapeutic and healing influences on individuals with a wide range of health issues. Although aimed at medical professionals, this book is appropriate for anyone looking for more information on how a dog may be able to help someone with a chronic condition such as MS, and includes many personal stories of healing and photos from dog owners throughout North America.

Live Your Life, Not Your Diagnosis

by Andrea Hanson

Difference Press

MSAA Book #388

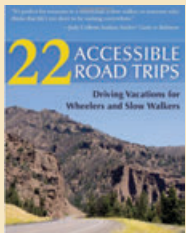


Author Andrea Hanson was

diagnosed with MS in 2000 and uses her experience as a master certified life coach to help readers develop a customized plan to living well with MS. Covering topics such as stress management, diet, and exercise, this book promotes self-awareness and self-healing, while providing direction for strengthening relationships and gaining confidence. *Live Your Life, Not Your Diagnosis* was previously published as *The Inside Guide to MS*.

MSAA's Lending Library

To borrow books featured in this column or any other book in MSAA's Lending Library, please visit mysaa.org/library to view a list of books available and to complete a form. When ordering a book, please reference the book number listed. Readers may also call MSAA at **(800) 532-7667** for more information. MSAA and its clients greatly appreciate any donations made to help build the Lending Library. Please send your book donations to: **MSAA Lending Library, 375 Kings Highway North, Cherry Hill, NJ 08034.**



22 Accessible Road Trips: Driving Vacations for Wheelers and Slow Walkers

by Candy B. Harrington

Demos Health | MSAA Book #456

Author Candy Harrington has a wealth of experience with accessible travel, having completed several books on the topic, along with writing for magazines, speaking at conferences, and conducting workshops. This book talks about the advantages of road travel and provides numerous road trip tips and resources. The chapters cover road travel within different regions of the United States, highlighted by helpful details and many beautiful (black and white) photos.



Do You Experience Spasticity or Muscle Tightness?

The Multiple Sclerosis Association of America, along with the National Stroke Association, United Spinal Association, United Cerebral Palsy, and the Brain Injury Association of America recently formed the Spasticity Alliance in an effort to raise awareness and provide help for people experiencing spasticity.



Please visit [SpasticityAlliance.org](https://www.SpasticityAlliance.org) for valuable information and resources.

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Multiple Sclerosis Association of America

375 Kings Highway North
Cherry Hill, NJ 08034 USA

CHANGE SERVICE REQUESTED

Shopping this Holiday Season?

Support MSAA every time you shop!

MSAA has partnered with several businesses who donate a portion of their proceeds back to MSAA. This is a great way to support MSAA's mission of Improving Lives Today without any added cost to you. Please register with the following businesses so a contribution can be made to MSAA whenever you make a qualifying purchase!

AmazonSmile

Here you'll find gifts for everyone, so please register MSAA as your charity

eBay for Charity

This program donates a percentage of your eBay sales and purchases to MSAA

Yankee Candle

Support MSAA through our 5th Annual Yankee Candle Holiday Fundraiser

CafePress

Purchase customized apparel and accessories in support of the MS community

To get started, please visit
mymsaa.org/ShopAndSupport

