

MSAA

MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA

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Winter/Spring 2016

THE Motivator

Published by the Multiple Sclerosis Association of America

A photograph of a woman with curly hair, wearing a white turtleneck sweater, hugging a young girl from behind. The girl is also wearing a white sweater and a denim skirt. They are standing in a field of tall, thin grasses. In the background, there is a body of water and a sandy beach under a bright sky.

Making the Most of Our Relationships

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Susan W. Courtney, Senior Writer and Creative Director
Dr. Jack Burks, Chief Medical Officer
Peter Damiri, Contributing Writer
Kimberly Goodrich, Contributing Writer
John Masino, Advertising Manager

MSAA National Headquarters

375 Kings Highway North
Cherry Hill, New Jersey 08034
(800) 532-7667
mysaa.org

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By Susan Courtney

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MSAA

MULTIPLE SCLEROSIS
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*Improving Lives Today!*TM

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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An Unrelenting Passion to Answer the Needs of Others

By Gina Ross Murdoch
MSAA President and CEO

I am delighted and honored to begin my new position here at MSAA. This organization has grown tremendously under the leadership of the recently retired President and CEO Doug Franklin, along with the help of MSAA's Board of Directors and the recently retired Chief Operating Officer Robert Rapp. I look forward to building upon that solid foundation to further support our vital mission of Improving Lives Today for the entire MS community.

My tenure with MSAA is truly a return to my roots. In my previous experience, I spent 14 years with the National MS Society focusing on helping all people affected by

MS. It was those experiences that led me back to the MS community, and to MSAA. In addition, I have dedicated my career to making an impact in people's lives through my time at the Leukemia and Lymphoma Society and American Diabetes Association. These experiences have given me an unrelenting passion to answer the needs of others with a particular commitment to the needs of the MS population.

I officially became MSAA's President and CEO on January 4, 2016... and spared no time before getting started! During my first month, I met with the entire home-office and regional staff, as well as took part in a major MSAA Board Meeting to exchange ideas and develop plans for the future. These include plans for

our vital programs and services, plus important fundraising opportunities to make these programs and services possible.

I am inspired to see so many exciting things happening at MSAA! In February, we launched our newly updated and completely responsive

MSAA had a wonderful opportunity to raise awareness of multiple sclerosis by ringing the Nasdaq Opening Bell on March 11th!



MSAA is very proud to present our 2016

Art Showcase

CELEBRATING THE WORK OF ARTISTS AFFECTED BY MULTIPLE SCLEROSIS

MSAA's **2016 Art Showcase** includes two galleries – **MS Ability** and **Four Seasons** – that each feature various themes and styles. Artwork highlighted in the Four Seasons Showcase depicts a specific season or holiday.

In 2015, we received many wonderful submissions from individuals across the country. We are delighted to now share their work and stories with you!

We invite you to view the complete online gallery of artwork from participants in MSAA's 2016 Art Showcase. Please visit mymsaa.org/artshowcase2016



(mobile-friendly) website at mymsaa.org. This extensive resource enables us to engage our mission across the country, providing the opportunity to educate, support, and empower members of the MS community. March was MS Awareness Month, and in addition to a host of educational programs and other important activities, we focused our attention on managing the symptoms of MS – a critical topic for anyone diagnosed with this challenging disorder. Also in March, we held our “2016 Improving Lives Benefit,” where we honored Susan Russo, MSAA Art Showcase Artist, and Doug Franklin, our past president and CEO, while raising much-needed funds for programs.

Brimming with enthusiasm, I look forward to my tenure here at MSAA. Working together

with our wonderful staff, I will do everything possible to support our mission of Improving Lives Today for the entire MS community! ■

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.

Making the Most of Our Relationships

Helping ourselves and those around us to cope with MS

By Susan Courtney

With contributions from:

Jack Burks, MD

Kimberly Castelo, MS, LMFTA, CIIP

Miriam Franco, PsyD, MSCS

Kathleen A. Taylor, PhD

After the Diagnosis

Relationships and Initial Reactions

From the time we are born, we depend upon relationships to survive and flourish. Unfortunately, circumstances are not always ideal, and different things can complicate relationships. We all know that most relationships are not without their problems, and when a chronic condition such as MS enters the picture, it can make an impact on our interactions with one another. How we choose to address the issues that may arise and how we communicate with one another can make a tremendous difference.

Whom to tell, what to tell, and possible reactions to expect will all differ by how close

you are to the individual and whether the person is an adult or a child. Once those close to you are aware of your MS and the symptoms you may be experiencing, keeping your lines of communication open – and practicing good speaking and listening skills – will help to ensure that your relationships remain positive.

Miriam Franco, PsyD, MSCS, is a psychotherapist and psychoanalyst who specializes in working with individuals coping with chronic illness. She has been an active member of MSAA's Healthcare Advisory Council for many years and has contributed to several articles appearing in *The Motivator*.

Dr. Franco explains, “MS varies with individuals and families. A broad range of symptoms is associated with MS and individuals differ considerably regarding how this disease affects them initially and over the course of time. No two people or families react exactly the same way in responding to an MS diagnosis or in coping with this disease. Everyone, however, remembers the day he or she was diagnosed and what it felt like to receive the diagnosis.

“First reactions can range from shock, disbelief, and anger, to fear and denial. These are all adaptive and predictable responses that you may experience initially. If you had to wait months or years for a definitive diagnosis after living with puzzling, unexplained symptoms, or if you doubted your perceptions, the diagnosis can bring some relief. This is especially true if you’ve been told ‘this is all in your head.’

“Most MS doctors are aware that individuals need time to grasp what is happening, to learn and understand what may be involved, and to find out about what treatment options are available. Time is needed to not only build a treatment plan, but to also develop trust and a supportive relationship with healthcare practitioners.”

Your family will need time as well to adjust to the diagnosis and people react to a diagnosis in different ways. Some want to learn everything they can about MS as soon as possible. Education can come in many forms, from informative websites, publications, and videos, to support groups, educational programs, and one-on-one

discussions with your healthcare professionals. Be sure that you are keeping the amount of information at a reasonable level and are consulting reliable resources, such as MSAA or other major MS organizations.

While some want to get information, others may become upset and “turn off” at the idea of learning more about the disease. They know that getting MS is not fair, that it is not anyone’s fault, but they may still ask, “Why me?” Another common reaction is great concern and over-protectiveness. A spouse or parents (including a parent of an adult with MS) can often feel this way, and in their worry for your safety and health, may infringe upon your independence. Learning about the disease and having open communication about your symptoms, along with the precautions you are taking, can greatly help to reduce the anxiety that your spouse, parents, or others close to you may be experiencing.

Dr. Franco continues, “Grief is a reaction most people don’t expect, probably because it is frequently associated with the death of a loved one. Grief, however, is a natural and often necessary reaction to any significant change that threatens your sense of self or areas of former functioning. You may find yourself grieving over your initial diagnosis or any time you experience an exacerbation of your symptoms, especially during relapses.

“Depressive symptoms are common with MS because the disease itself may trigger these. Depression is also highly treatable and the best strategy is to treat it early before

suffering too long. Anxiety also seems to come along with MS, largely because it is such an unpredictable condition, making it difficult to plan and requiring that you become more flexible and tolerant of the disease.

“Mental health professionals with experience in working with MS can be very helpful here and can help you discern between what is MS and what is not. Treating your depressive symptoms can also help reduce fatigue and stress, which can exacerbate your MS symptoms. Understanding your symptoms and proactively treating them can help you to minimize their impact on your relationships with others.”



Deciding Whom to Tell

According to Dr. Franco, “How you begin to cope with MS and whom you decide to tell are dependent on many variables, such as age, life experiences, presence of social supports, personality-coping style, access to good MS care and resources, and the type of symptoms you are experiencing. For instance, if you are a young adult in college and are not struggling with gait difficulties that others can see, you may opt to only let your academic advisor know of your condition, but not opt to tell most of your peers. You may prefer to

‘blend in with the crowd’ as long as possible to appear that you do not have this condition. You may feel that there is a stigma associated with having a condition and fear you might be treated differently once you disclose your MS.

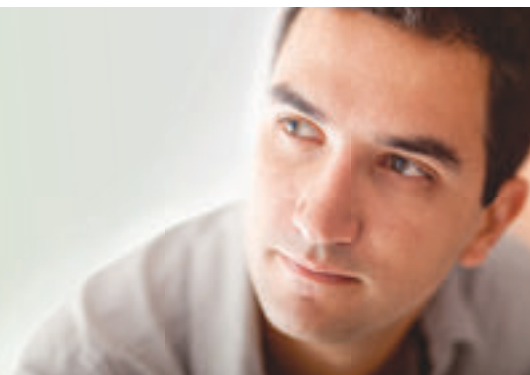
“You may choose not to tell others about your MS, as you may fear that people won’t understand, will exclude you in some way, or will treat you as less capable. You may also not want to be reminded of your condition when you are not experiencing major symptoms as, after all, it takes time to really wrap one’s self around having MS. And it takes time to become a person with MS versus an MS patient.

“In the MS community, the ‘newly diagnosed’ are those who have been coping with the disease for at least the first two years, which implies that the diagnosis and what it may entail takes time to know and to set in. If you are in a committed relationship, it’s common to experience private fears that your partner may leave you. If you have children, you may fear your disease will interfere with your parenting or you may become a burden to others.

“It’s important to keep in mind that if any of your initial reactions to having MS become unmanageable or too uncomfortable, you’ll find that much support is available. Major MS organizations such as MSAA provide resources for support, including hotlines, educational videos and publications, and referrals to psychologists and social workers who are skilled in helping people cope with the emotional and stressful effects of having MS. Support groups can also be very helpful.”

Important Coping Mechanisms for the Newly Diagnosed

By Miriam Franco, PsyD, MSCS



Don't give up HOPE. So much is happening now in the MS world regarding new medications, new treatments, new knowledge, and new research for a cure. Much is possible, but first you need to develop ways to cope with your disease.

Learn as much as possible about MS, because there are so many misperceptions about it. Fatigue is the most common symptom with MS, but not everyone will need a wheelchair in the future. It is very important to learn quickly about the many treatment options available for reducing relapses and delaying disease course for individuals with relapsing forms of MS. The reason is if you start treatment early, you can delay your disease course and reduce relapses considerably. And there are many treatments available for managing MS symptoms. The MS organizations provide much information on this as well.

Most people find that teamwork makes everything easier. Get good MS care. Find the right doctor for you. The neurologist who first diagnosed you may not be the one to see you through your disease course. If you

don't live near a major MS center, a good idea is to find a social worker, psychologist, physical therapist or other rehabilitation professional, or MS nurse who can help you build a team or network of MS practitioners who can work together with you in developing your best treatment plan.

Find good coping strategies to reduce stress and anxiety. These include activities such as yoga, guided imagery, meditation, acupuncture, and neurofeedback. More than 30 percent of people with MS turn to complementary forms of medicine to relieve symptoms of pain, stress, and fatigue. Be sure to consult your physician before participating in these types of activities.

Think about the people you will tell outside of your family. Before disclosing your MS at the office, learn about your rights under the Americans with Disabilities Act (ADA) and consider talking with an expert connected with one of the major MS organizations. Select people who can be the most supportive and helpful to you as you begin your coping process.

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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.

Chest pain may occur either as part of the immediate postinjection reaction or on its own. This pain should

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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)

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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, "Disposal 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



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Product of Israel

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

COP-41059

Daily Life and Family Relationships

The Impact of Symptoms

Specific MS symptoms can easily impact relationships, roles, and family routines. Such symptoms as fatigue, depression, cognitive issues, emotional vulnerability, and pseudobulbar affect (PBA, a condition with sudden, involuntary episodes of crying or laughing) may be particularly challenging. These types of symptoms can create confusion and upset within the family, as the individual with MS may have difficulty performing his or her normal activities or may act inappropriately.

If you are experiencing symptoms of significant fatigue or depression, activities such as housework, running errands, socializing, and even interacting with your children, can become difficult if not impossible at times. Family members need to understand that you are not being lazy, but are rather experiencing some of the most common and debilitating symptoms of MS. Openly speaking with your family members and getting professional help to treat those symptoms are vital.

With the other symptoms mentioned, including cognitive issues, emotional vulnerability, and pseudobulbar affect (PBA), you may be confused or overly emotional at various times. Similarly, family members need to understand that you do not have control over these symptoms and emotional outbursts do not represent your true feelings. In these types of instances, your spouse or other

family member may need to assist you in getting help for these difficult issues. All of these symptoms have management strategies to reduce the severity of the symptom, often using medication in combination with other types of therapies.

Kathleen A. Taylor, PhD is a Professor in the Psychology Department and Chair of the Women and Gender Studies Department at the Sierra College in Rocklin, California. She is also a new member of MSAA's Healthcare Advisory Council.

Dr. Taylor agrees that getting help to treat your symptoms is critical to your health and to your relationships. However, particularly with invisible symptoms – including pain – you need to be your own advocate to make sure you are getting the help that you need.

According to Dr. Taylor, “Managing pain can be difficult and research suggests that, compared to men, women’s reports of pain are more likely to be dismissed and their pain relief protocols less likely to be as aggressive. Although no data directly suggest that women with multiple sclerosis are less likely to be treated for pain than men, it is important that your doctor understands how much pain is being experienced and what interventions work best.”

Because MS has so many symptoms that may not be seen visually by another person, people tend to think that you don’t look sick, even when experiencing difficult symptoms. Often someone with MS may look fine, but he

or she is unable to participate in everyday activities. Those around you may not understand or believe how ill you may be feeling and some may even feel resentful or angry that you are not doing your fair share of work around the house or on the job.

Dr. Taylor continues, “This can be particularly difficult for women due to gender stereotypes about women as non-rational or prone to hysteria. The very nature of MS in terms of ambiguity of early symptoms may play into these gender-biased notions about women’s “inherent” emotionality, leading to the assumption that they are unreliable reporters of their own experience. Combine this with the tendency for women to emotionally take care of their loved ones, and this can become a significant issue. It is essential to be frank about your symptoms and clearly define limitations. This can be difficult, but also expressing when one is having a ‘good day’ versus bad helps people understand that not all MS days are experienced in the same way.”

Particularly when not having a good day, or when experiencing a flare-up of symptoms, having plans in place for redistributing household duties is always a good idea. Knowing that your spouse and older children can pitch in with making a meal, shopping, laundry, and other responsibilities can help to provide some peace of mind. While care must be taken not to ask too much of your children, learning to help someone in need teaches children the importance of having empathy for others and looking beyond their own needs and wants.

Dr. Taylor points out, “Individuals can experience issues around trying to pass things off as ‘life as normal,’ while putting out considerable effort to cover the appearance of illness. Often this can be seen in small ways, such as doing more housework and perhaps even overcompensating in that area – now the house needs to be even cleaner or tidier than it ever was in the past. Although achievement in and of itself can be rewarding, sometimes this new goal or standard creates unnecessary stress and self-criticism if one fails. It can also use precious physical energy that will be in short supply for other pursuits.”

Talking to Children about MS

According to Dr. Taylor, “Exactly what to tell a child about an MS diagnosis clearly depends upon the child’s age and maturity level. There is the issue of how much information and how to tell that information so the child still feels that the parental attachment is secure and that although things might be different, parental commitment and love continues.

“When a parent chooses to not reveal that they are ill, sometimes the children intuit that something is wrong but no one is talking about it. For example, Dad looks angry whenever he drops something when it never used to be a big deal. Who is Dad mad at? For some children, this can be frightening as they fill in the ambiguity with their own invention of what could be wrong.”

In the book *MS and Your Feelings* (Hunter House Inc., 2007), written by Allison Shadday, LCSW (a counselor who also has MS), the

topic of talking to your children about MS is addressed. Just as Dr. Taylor notes, Ms. Shadday advises that you keep your explanation simple and age-appropriate. She notes that to a younger child you might say, “Mommy gets sick sometimes and needs to lie down and rest.” She emphasizes the importance of explaining that you will not die from this illness, but that you will have days where you feel better than on other days. Children need to be reassured that MS isn’t their fault, isn’t contagious, and they will not catch it from you. Ms. Shadday also instructs that you stay calm and confident while talking to your children and encourage them to ask questions.

Creating a Positive Relationship with a Child with MS

Just as MS affects adults differently, the same is true for children. Many children with MS may appear to be fine, but in reality, they may be experiencing the same types of invisible symptoms as adults do, including fatigue, cognitive issues, and depression. Others may have symptoms that are more visually evident and affect functions such as mobility, strength, and coordination.

In the book, *The Personal Care Attendant Guide* (Demos Medical Publishing, 2007), written by Katie Rodriguez Banister, several tips are listed for caring for and interacting with a child with a disability and how to keep the relationship positive. To follow is an overview of the main points given in this book.

Children first and foremost need to be loved. They have feelings that always need to

be considered. If the help of an aide is required, he or she should know from the start what the child is capable of doing and what things he or she needs assistance with to complete. If providing physical care for a child, being sensitive and gentle is vital. Be respectful of your child’s privacy; don’t discuss the diagnosis or special needs with everyone. If help is needed with dressing and bathroom details, be sure that doors are closed and privacy is always respected.

All children need to have fun, so make time to play on a regular basis. For a child with MS, giving him or her some space and not fussing over the child all of the time is important. Avoid yelling when a child makes a mistake, and regardless of the level of their

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ability, always show respect to children, which will also help them to learn to give respect back to those around them.

Cognitive ability and degree of physical disability frequently do not correlate. This is particularly true with MS, so while interacting with a child with MS, always communicate well by thoughtfully talking and listening; never talk down to a child (or anyone) with a disability. Keep in mind that children are still learning and have many experiences to go through; don't forget that their concerns, emotions, and thought processes are different from those of an adult. You also need to help prepare your child for a successful life, which includes working with him or her to set personal and academic goals.

Encourage children to be independent and learn to do things on their own. Particularly for children who are disabled, their parents often want to do too much for them. Learning to do things on their own, such as communicating independently and speaking for themselves, instructing others on how to care for them,

and learning positive ways to deal with negative feelings, can all work together to empower them and develop self-esteem.

With or without disabilities, all teens experience the same challenges with hormones and with identity issues. They are continually trying to find themselves. The key is to be patient and try to help them find healthy ways to overcome any confusion, anger, or other emotions they may be feeling. Talking openly about the changes they are experiencing and their emotions can be very helpful, but if they are still struggling, seeing a counselor or therapist is often recommended.

When More Than One Family Member is Diagnosed

Dr. Taylor provides her unique perspective, "Although it is not common, in biological families more than one person may be diagnosed with multiple sclerosis. When this occurs, a range of emotions can be experienced. The symptoms and degree that MS affects each individual may vary, and this may carry with it subtle feelings of guilt about being less affected or conversely, disappointment about being more affected than the other family member.

"Expectations by non-affected family members may change as they begin to wonder if indeed they are also likely to be diagnosed. It is important to remember that there is no genetic test to assure one if he or she will or will not get MS, and the likelihood of more family members becoming ill is not high.

"From my personal vantage point as someone who received a diagnosis of MS

14 years later than my fraternal twin sister's diagnosis, it was important to remember that although we can talk about similarities of our symptoms, each of us are having unique experiences. We find that we can both be supportive for one another, but at the same time, there can also be a tendency to not want to 'burden' the other, since she is already dealing with her own version of MS."

Self-Esteem, Self-Efficacy, and Self-Image

Self-esteem, self-efficacy, and self-image are all communicated either verbally or nonverbally in our relationships. These may be seen in how you carry yourself, whether you refer to yourself in a positive or negative way, and the things you find important about yourself and your relationships.

Dr. Taylor explains, "Self-esteem is the emotional response to self-efficacy. For anyone not familiar with this term, self-efficacy is the ability we believe we have to meet challenges and achieve goals. We have multiple roles we play in life (such as parent, daughter, employee, singer, athlete, etc.) and self-efficacy will relate to any particular role.

"One of the greatest difficulties is considering that you only have one role in life that matters. Hence, when you lose the ability to meet all the actions and goals important to you within that one role, your self-esteem suffers. This lowering of your self-esteem can improve as you adapt to being in that role differently by adjusting personal expectations and creating achievable goals.

"Additionally, you need to keep in mind that you play multiple roles in life, each with

their particular goals and challenges.

Focusing on expanding the complexity of the role in which you view yourself can be particularly helpful, as there are countless ways to make contributions in life."

Multiple Sclerosis: The Questions You Have, The Answers You Need (Demos Health, 2012), written by Rosalind C. Kalb, PhD, covers a wealth of MS topics. In her book, Dr. Kalb explains that your self-image has been built up slowly over your lifetime and is made up of many components, including personality, skills, and life experiences. When MS interferes with your ability to do something that is important to you, or forces you to do something differently, you will find that these types of changes will cause you to mourn over the loss of the "old you." However, this will allow you to become more comfortable with the "new you," as your self-image shifts to incorporate these changes.

Dr. Kalb points out, "As you confront the challenges of everyday life with MS and learn alternative ways to do things, you will begin to identify strengths and talents you never knew you had." She suggests that as you give up an activity, experiment with others that may turn out to be equally satisfying. Most importantly, find an aspect of yourself that MS is unable to touch, such as your sense of humor, religious beliefs, or love of music. This "MS-free zone" will help you to retain a sense of who you are, and can also be an important source of emotional energy. When drained or overwhelmed by the challenges of everyday life, you can refuel by tapping into the things you enjoy through your "MS-free zone."

For adults
with MS-related
walking
difficulties



**THE 7:16 WAS ON TIME
BUT MY LEGS WERE
BEHIND SCHEDULE**

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.

ampyra®

(dalfampridine) 10 mg
EXTENDED RELEASE TABLETS



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.

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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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Relationships at Work

In *The Everything Health Guide to Multiple Sclerosis* (Adams Media, 2009), written by Margot Russell with Allen C. Bowling, MD, PhD, as the title states, virtually every major topic of importance to an individual with MS is addressed. To follow is an overview of some of the information given on employment and MS.

After diagnosis, many may question if they will be able to stay at their job – and some might immediately assume that they will need to discontinue their career. However, no one knows the course his or her MS will take, and particularly with today's treatment options, many are experiencing fewer and less-severe relapses and are able to stay at their job. Also, if and when symptoms interfere with one's ability to perform a job, accommodations can frequently be made. These may include easy changes such as getting a closer parking spot or modifying one's office space, or more significant modifications, such as changing one's job duties and schedule. Various types of assistive technology are also available. However, accommodations must be reasonable, and not cause undue hardship to your employer.

The big question that individuals with MS are faced with is whether or not to divulge that they have MS to their employer and coworkers. They may feel that doing so will impact their relationships at the office. Fears may be that coworkers will treat them differently, that they may miss out on promotions, or that they may even lose their job.



The Americans with Disabilities Act (ADA) has been protecting individuals with disabilities from discrimination since 1990, and this has served to prevent people from wrongfully losing their job, being demoted, or taking a cut in pay. This law, which applies to employers of 15 or more people, also specifies that reasonable accommodation be made to modify one's position, schedule, or work environment, to enable a person with a disability to continue his or her employment. Please note that state or local laws may apply to smaller companies, helping to prevent discrimination and allow for reasonable accommodations in those circumstances.

Under the ADA, people do not need to divulge their specific diagnosis. However, if you need to request an accommodation, you need to establish that you have a disability. A disability is an impairment that affects one or more major life functions such as sight, hearing, mobility, etc. If you request an

accommodation, the employer must determine whether or not you have a disability that would affect your ability to perform your job and requires some type of modification.

Sometimes medical documentation is needed for your employer if your disability is not obvious. While you do not need to divulge a specific diagnosis, you do need to give some type of reason for your disability, and saying that you have a “neurological condition” may be adequate – and this can be stated in your medical documentation from your doctor as well, rather than specifically saying that you have MS, should you prefer to keep your diagnosis private.

Individuals may feel the need to divulge that they have MS, or some type of disability, when their symptoms may be easily observed and can no longer be hidden – such as when experiencing changes in mobility. They may also want to tell their employer when having to take extra days off from work and are having trouble keeping up with their duties. Another reason may be to request modifications to their work environment, job description, or schedule. Examples of schedule changes may include such options as flexible hours, job-sharing, changing from fulltime to part-time hours, and working from home.



If you do tell your employer about your diagnosis, you may feel some relief as you no longer need to hide symptoms that you are experiencing. Keeping your symptoms hidden from others can be very stressful. Additionally, if you choose to tell your coworkers, they may become more understanding of your needs as various challenges arise. However, you need to be prepared for the possibility that some people may have misperceptions about the disease and not be as open-minded.

When telling your employer that you have MS – or something less specific, such as a “neurological disorder” – planning what you want to say in advance is important. Ideally, you should be familiar with the laws that protect you from discrimination, and the size of your company can affect which laws apply. By doing so, you will know what types of modifications to your job and work environment may be possible. You should



For Further Reading...

All books mentioned in this article are available through **MSAA’s Lending Library**, a free program that includes shipping to and from your home. Please see **page 48** for ordering information.

think about your limitations and what aspects about your job are or may become difficult for you. Some people may consult a job or career coach to learn about their options.

Approach your conversation with your employer in a business-like manner, trying not to become overly emotional or give too much personal information. When you talk about the symptoms that you want to disclose, explain how they may affect you and what types of reasonable accommodations will help you in your job. Be prepared to give solutions for any challenges you may anticipate, so your employer will know that you have strategies in place to continue at your present level of work.

If you decide to disclose that you have MS to your employer and possibly to your coworkers as well, giving details about the disease is important. Be sure to clearly state that it is not contagious, so no one would have that worry. You may want to describe

some of the symptoms you experience, and if you have a relapsing form of MS, explaining how symptoms will flare up and then remit after a period of time will help those around you understand why some days are more difficult than others. Talking about any invisible symptoms you may experience, such as fatigue or vertigo, will let others know that while you may appear to be fine, you may be challenged to complete certain tasks. Doing so may also help reduce someone's suspicions that you are taking advantage of your disability.

In regard to interviewing for a new job, potential employers are not allowed to ask whether or not you have a disability. However, they may ask if you have any concerns with your ability to be proficient at the job. If a medical exam is required, it must be one that is required for all individuals applying for similar positions and must also be related to the work at that company.

ONLINE RESOURCES FOR EMPLOYMENT ISSUES

CertifiedCareerCoaches.com	Website to help find a job or career coach
AskJan.org	Job Accommodation Network, to explore accommodation options and assistive devices
ADA.gov	Americans with Disabilities Act (ADA)
EEOC.gov	United States Equal Employment Commission, which enforces the ADA laws
dol.gov/whd/fmla	Family Medical Leave Act (FMLA), which protects employee jobs during unpaid leave for medical reasons

The Importance of Communication in Your Relationships

Improving Communication

Kimberly Castelo, MS, LMFTA, CIIP is a Licensed Marriage and Family Therapist Associate and Certified Integrated Intimacy Professional in Seattle, Washington. She is also an inspiring speaker at MSAA's educational programs.

Ms. Castelo explains, "It is hard to communicate. We do it all the time, but truly it is a hard task. Everyone has feelings, we hear each other differently, and we bring our fears, joy, and histories into our conversation. When talking with others and the talk is getting tense, it's okay to say that the conversation is getting heated... emotional... stressful... and can we take a break and reconvene in 20 minutes? Taking that break can help people self-soothe and regroup for another try at communication.

"Sometimes you may have a need to improve communication at home, work, school, or with friends. A good strategy is to identify what you would like to accomplish from a conversation, and if you want to, write your thoughts on paper. Consider how you can communicate while being self-reflective and not pointing fingers or blaming. Being self-reflective and non-blaming opens dialogue that is helpful.

"Being honest about MS can be scary; you wonder how people are going to respond. You may ask yourself, 'How am I going to put my diagnosis into words?' It's okay to be nervous. You can also say, 'This is a really hard topic to

talk about, but what I need is...' and then state what you are in need of or hoping for from your talk.

"Clearly defining what you are expecting or needing from people can help to open the lines of communication. Always trying to be overt with communication can strengthen bonds between people. Try to avoid assumptions or 'mind-reading.' You can be curious... for example, 'I am sensing that you are feeling a certain way' (note what emotions you think another may be feeling); then ask if you are correctly picking up how the other person is feeling. Asking a person to respond to your perception – and allowing the individual to tell you if you are right or wrong – will help to enhance communication.

"Listening is such a powerful tool in communication. Many times we overlook the power of hearing each other's stories. Listening involves our whole body and how we engage someone else. Are we making eye contact, does our body say we are engaged and interested, are we talking less than the other person? Often times slowing down a conversation and saying 'I am hearing you say... did I get that right?'

Slowing down a conversation to make sure you are taking in all of the details helps people feel heard and loved. When someone truly listens to us, it can be healing to our mind and body... releasing tension and providing the realization that we are not alone."



Communicating with Children

Ms. Castelo notes, “Communicating with children can be upsetting because parents worry if their children can handle difficult topics. Being open with your children in an age-appropriate manner is always helpful. Talking to young children about a parent having MS needs to be addressed at their level, but should not be hidden. What this reflects is how the family can join together and overcome whatever life brings their way.

“Look for books for children that talk about a parent having MS or a parent being sick. MSAA offers two books for parents talking to younger children about MS, titled *Mommy’s Story* and *Daddy’s Story*. These types of books can help begin the dialogue.

“For older children, sharing fears and talking about some of the issues of MS – while trying not to overwhelm them – is always helpful. Naming our fears to our loved ones and being overt about what we are afraid of can help reduce the fear and take away the heaviness from these types of difficult topics.”

Communicating with Parents

According to Ms. Castelo, “For an adult with MS, talking with your own parents can have its own challenges. Similar to talking to older children, you’ll find that being honest

with fears, hopes, and dreams is always important. Using ‘I’ statements that are self-reflective can help communication.

“Try to avoid defensiveness, blame, or guilt. Also avoid using words such as ‘always’ and ‘never,’ as these are rarely 100-percent accurate and tend to close a conversation rather than open it. Being self-reflective and talking about your personal feelings tends to open a deeper and more meaningful conversation.”

In her book, *When the Diagnosis is Multiple Sclerosis* (The Johns Hopkins University Press, 2009), author Kym Orsetti Furney, MD talks about the challenges she felt when having to tell her parents that she was diagnosed with MS. Dr. Furney notes that while she is very close with her parents emotionally, they did not live nearby and were not aware of her recent symptoms. She didn’t want to create new issues for them until she knew what was wrong.

Once her diagnosis was confirmed, Dr. Furney took a day or two before telling her parents. She explains, “While my husband had seen all the tears, my mom heard a calm daughter reporting the facts like the physician I was trained to be... I never shed a tear on the phone and neither did my mother. As silly as it may have been, I felt that I had to be strong for her. I am sure she felt the same for me. Yet, I felt great relief in telling both my

mother and my father and in hearing their words of love and encouragement.”

Communicating with Your Significant Other

Ms. Castelo points out, “With regard to communication with a spouse or significant other, talking openly is very important for romantic relationships. Allowing fears and joys to be heard enables each other to draw closer and create a deeper intimacy. To be touched, to feel loved, to be heard, and to feel

safe with a significant other, all helps our moods and helps us face difficult situations. Drawing close to a person who makes us feel safe can reduce anxiety and even reduce physical pain.”

In the book *MS and Your Feelings* (noted earlier), a great deal of helpful information is provided on improving your communication skills with your spouse or partner. Author Allison Shadday, LCSW starts by explaining that

continued on page 29

Develop Better Communication Skills

Improving both speaking and listening skills will lead to better communication. Below are some of the main points from *MS and Your Feelings*, written by Allison Shadday, LCSW.



To improve SPEAKING skills...

Make sure you **have the time available** for your conversation; don't start something if short on time

Avoid discussions when your emotions are running high; approach delicate subjects when calm

If you have a few important points to make, you may want to **write these down in advance**

Avoid all-or-nothing statements that include “never” and “always”

Openly **explain how you feel**; don't expect someone to read your mind

Maintain eye contact for at least 15 seconds at a time

Reduce any distractions by turning off the TV and avoiding other things that may interrupt the conversation

Select a place where you are comfortable to talk; some may be able to talk more easily while sitting outside or taking a walk

Avoid insults, be courteous, and maintain an open mind

Ask the other person **if he or she understands** what you are saying and if you need to explain anything

To improve LISTENING skills...

Try not to interrupt while the other person is speaking

Ask questions to better understand what the other person is saying

If you are not sure how to respond, tell the other person that you want to **take time to think about** what he or she has said

Give full attention to the one speaking, turning your body toward them, making eye contact, and not crossing your arms

Try not to be distracted and don't multitask during the conversation

Avoid giving advice, making assumptions, or expressing criticism

FOR RELAPSING FORMS OF MULTIPLE SCLEROSIS (MS)



**ONE PILL
ONCE A DAY***

**HALF THE
MS RELAPSES**

WE'RE FIGHTING BACK WITH GILENYA, the only once-a-day pill* that reduced the number of relapses by 52% in a 1-year study vs Avonex® and by 54% in a 2-year study vs placebo.

Everyone here is fighting back against their relapsing MS with GILENYA. They are compensated for their time.

Join the more than **125,000** people who have been treated with GILENYA worldwide. This includes people in clinical trials and those prescribed GILENYA by their doctors—and every one of them is saying **"HEY MS, Take This!"**

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.

*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 doctor 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.

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 breast-feed, 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, you can contact the GILENYA Pregnancy Registry by calling Outcome at 1-877-598-7237, by sending an e-mail to gpr@outcome.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; 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. Especially tell your doctor if you take medicines that affect your immune system, including corticosteroids, or have taken them in the past. 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.

MEDICATION GUIDE
GILENYA® (je-LEN-yah)
(fingolimod)
capsules

Read this 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
- chills
- tiredness
- nausea
- body aches
- 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
- strength
- eyesight
- 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

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
- 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 Outcome at 1-877-598-7237, by sending an email to gpr@outcome.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

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.

How do I store GILENYA?

- Store GILENYA in the original bottle or blister pack in a dry place.
- Store GILENYA at room temperature between 59°F to 86°F (15°C to 30°C).
- Keep GILENYA and all medicines out of the reach of children.

General information about GILENYA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. 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 Medication Guide summarizes 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 healthcare 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.

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

GILENYA is a registered trademark of Novartis AG.

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lack of communication is one of the biggest problems that can occur in a relationship. Additionally, when a chronic illness such as MS comes along, good communication becomes an even bigger challenge.

Ms. Shadday notes that the most frequent cause of misunderstanding among her clients is a result of what she refers to as “The Mind-Reading Trap.” This is when someone with an illness has the unrealistic expectation that a partner should automatically know his or her wants, needs, or emotions. However, this is an unrealistic expectation that leads to disappointment and hurt feelings.

She explains, “Living with our illness day-in and day-out, we become intimately aware of how we’re feeling moment-to-moment, so shouldn’t our loved one be aware as well? We desperately want them to be able to read our moods and physical abilities because so often we feel alone in our struggle.”

Especially with an illness such as MS, where symptoms such as fatigue, pain, and vertigo are invisible to others, expecting your partner to know what you’re feeling and how much it is affecting you at that time is not reasonable. For example, you might be looking for help and feeling upset because your partner isn’t pitching in, while your partner might be misinterpreting how you feel, thinking that you are angry and want to be left alone. Whether you’re looking to be comforted, to have help with dinner or housework, in need of some rest, or wanting to have some space, you need to openly communicate these types of feelings to your partner so he or she knows what to do.

Learning to accept help from others is another issue that can interfere with relationships. Often people with an illness or disability do not want to burden those around them, so they may avoid asking for assistance. However, in most instances, people enjoy helping others. Doing so allows people to feel needed and appreciated, along with building their self-esteem.

Ms. Shadday points out that men and women often communicate differently and are looking for different results when a problem arises. She explains that women with a problem want to be heard, and feel a sense of relief and comfort simply by telling their feelings to another. They are looking for understanding and for someone to say they are not alone. Men on the other hand want to fix and protect, so they will offer a solution without recognizing the woman’s feelings or providing any comfort. As a result, a woman may feel hurt and as if her emotions and concerns are unimportant. Things only get worse as men misinterpret how women react to their advice, becoming confused and frustrated that a woman isn’t happy to get his help.

In instances where the wife has MS, a husband may feel helpless when trying to fix the issues that his wife is experiencing with the disease. And she may be hurt that he isn’t providing enough comfort and understanding. These types of miscommunication can be resolved by learning to listen to one another and to be more supportive. Specifically asking how each of you is feeling and how you can help one another is a good way to avoid these types of problems.

Finding Support

Ms. Castelo inquires, “Why is asking for help so hard to do? Is it because we are told never to show weakness? Is it because we are having a hard time accepting help, and if so, why? Take time to reevaluate what is stopping you from asking for help. Find that asking for help – even from people who you do not know well – is a strength! It is also a way to allow yourself to feel loved and cared for.

“Withdrawing is very common when we are feeling overwhelmed. However, reaching out to others helps with our mood and outlook on life. While our tendency might be to withdraw, the goal would be to fight that urge and try something new. You’ll find that staying involved with others can add more happiness to your life. Try doing the kinds of things that you used to enjoy, such as going to a movie, or getting together with an old friend.

“Support groups are great! They help us feel like we are not alone. We can also learn about new ways of coping with MS that we hadn’t thought of before. In addition, we can meet new friends who we can connect with and expand our network of people with whom we can engage and share our thoughts.

“Look for a group where your voice can be heard and where you can learn from the others. Hopefully being heard and learning new ideas is what you can expect from every group. Take some time to decide if a group is right for you... because as with all relationships, getting to know the other members takes time. Give some time to find

the rhythm of the group and how you might add to that rhythm.”

In *Multiple Sclerosis: The Questions You Have, The Answers You Need*, Dr. Kalb talks about the variety of support groups that are available. She notes that groups may be large, with 20 to 200 people, and tend to be educational and feature invited speakers. Groups may be small, with a consistent membership of 8 to 10 people who meet regularly to share problems and support.

Support groups may be led by professionals, peers, or have no leader. Groups range from those aimed at people who are newly diagnosed, to those coping with the disease for several years, to those who are more significantly disabled. Groups may be formed for couples, spouses, or children of someone with MS. Employment groups, to discuss job-related topics, may be available, as well as singles groups for men and women to meet others who share the same challenges.

To find support groups in your area, you may call the National MS Society at **(800) 344-4867** or visit the MS Foundation’s website at **msfocus.org/support-groups.aspx**. Dr. Kalb notes the importance of finding the group that is the most suitable for you. She suggests that if one does not seem to meet your needs, try another. If you try several but still haven’t found the right fit, you can start a group of your own! The two organizations mentioned above can help you get started.

An Added Note from Jack Burks, MD

MSAA's Chief Medical Officer Dr. Jack Burks has been helping individuals with MS for more than 40 years. He has seen many people experience conflicts in their relationships.

According to Dr. Burks, "You should try to plan time in a private, quiet place for discussions with family and friends. Before starting a difficult conversation, to avoid offending anyone, think of a polite phrase to use in case you need to end the conversation and reconvene later. You might say, 'I hope you don't mind, but I need to take a break and collect my thoughts.'

"Taking time away from a conversation can be very helpful when you've reached an

impasse. Sometimes only a short time is needed for everyone to recollect their thoughts and plan a more supportive approach.

"After restarting the conversation, make sure both parties feel understood by acknowledging the other person's perspective with respect. Listen to one another with empathy, and when appropriate, say things such as, 'I agree' and nod your head. When done, restating what has been discussed can reinforce areas that you agree upon and establish a plan. Thanking the other person for understanding, while showing positive signs – such as a smile and hug – will convey the love and support that you have for one another." ■

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The Role of Gut Bacteria, Parasites, and Antibiotic Therapy in MS Treatment

By Dr. Jack Burks

MSAA's Chief Medical Officer

Q: Upon reading MSAA's MS Research Update, I was surprised at the omission of a treatment that hundreds of MS patients have undertaken. It has to do with the eradication of a bacterium, believed by many microbiologists and scientists to be the cause of MS and other diseases. I often recommend going to the website, Cpnhelp.org for people looking for more information. It involves following a protocol of certain antibiotics for a period of time. Some people adhere to this protocol for years. I just wanted to draw your attention to this, since many people with MS (in all stages) are involved with this.

A: This subject is complex and poorly understood, but recent research findings will stimulate more studies. As reported earlier by MSAA and others, one area is called microbiome or macrobiotics, which is looking at the flora (living bacteria) of the gastrointestinal tract.

It appears that both "good" bacteria and "bad-for-MS" bacteria exist in the gut. MS medications and probiotics can change the ecosystem of the gut and may help people

with MS. As we learn more, watch for updates from MSAA. However, research is at a relatively early stage of development, and answers will require years of rigorous studies.

In addition to bacteria, certain parasites may play a protective role in MS. Research has discovered that parasite infection may reduce the risk and the severity of MS. These parasites appear to modify the immune system in a positive way to reduce disease activity. As mentioned earlier, as more news becomes available, MSAA will work to provide updates.

Q: Everything I hear or read states that fatigue and pain are serious issues for many people who have MS. I am fortunate to have excellent insurance coverage through my former employer. However, my insurance refuses to cover any of the medications that I have used in the past for fatigue and pain. I have used Nuvigil® (armodafinil) and Provigil® (modafinil) for fatigue and Lidoderm® (lidocaine patch) for pain, all with wonderful results. These were all covered by my previous insurance company. But with the insurance I have now, regardless of how much

I work to follow their procedures for appeal, I have not been able to obtain any of these medications. The reason for the denial is that they are not FDA-approved with a specific indication for MS.

Can all of the agencies associated with MS come together to get FDA approval for some of the drugs that are proven effective and even recommended by authorities for those of us with MS?

A: You have hit on a major impediment to “Access to Care” for people with MS and other diseases. MSAA along with other MS Coalition members have previously teamed with the American Academy of Neurology to address many issues in your question. We all share your concerns.

In terms of your own situation, you may want to consider switching insurance companies to an insurer who will cover your physician-prescribed medications – if you are able to do so and if the new coverage would fit all of your needs. If you are looking at other insurance companies, be sure to examine the medicines they cover before switching. Since insurance companies make yearly decisions to change coverage, check each year before deciding on your insurance company.

Additionally, prescription assistance program information for symptom-management medications can be found on www.needymeds.org or by calling **(800) 503-6897**. NeedyMeds is a national nonprofit organization that provides online information to help people who can't afford medications and healthcare costs.

You may also want to stay active in the fight for coverage of these types of symptom-management medications. You could continue to appeal the denial through your doctor and the medical director of your insurance plan. Other ideas include calling your state insurance commissioner and your congressman's healthcare staff person, and possibly telling your story to the media. Be your most-vocal advocate.

Q: Years ago and recently, I experienced incredible fatigue and tingling. An MRI revealed a lesion on my spinal cord back in 2002, and my doctor started me on Avonex. A more-recent MRI showed another lesion in a different area of my spinal cord. My B-12 was and continues to be very low and blood tests revealed a deficiency in Vitamin D. I tested negative for neuromyelitis optica. I do not have protein bands in my spinal fluid. Since there isn't a definitive test for MS, what is required for a diagnosis and what else would cause spinal cord lesions?

A: Your question brings up a number of complex issues when trying to diagnose and treat MS. Many MS experts spend an extra one-to-two years in additional training after their neurology residency to better understand these issues. Your questions are excellent, but you need to continue to meet with an MS expert to fill in the gaps. I expect your efforts will lead to more specific treatment recommendations.

Concerning an MS diagnosis, many diseases may mimic MS. For example,

Vitamin B-12 deficiency may cause “subacute combined degeneration of the spinal cord” and pernicious anemia (a condition that occurs as a result of the body not making enough healthy red-blood cells). The origin is related to a lack of a protein in the gut (intrinsic factor) that should allow for B-12 absorption. Have your doctors considered this possibility? You need to continue to monitor and treat your low vitamin B-12.

In addition, your low Vitamin D level (of 23) may be linked to an increased risk for MS. If you haven’t done so already, you should ask your doctor about taking supplemental Vitamin D. I would also continue to monitor your blood levels of Vitamin D. Recommended levels vary; many MS doctors aim for higher levels of 60 to 75 ng/ml, while others may recommend a lower range.

Concerning your possible MS diagnosis, 85 percent of MS patients start with relapsing-remitting MS (RRMS), where patients typically experience neurological relapses followed by recovery. Your lapse in symptoms for more than 10 years may be related to the effectiveness of Avonex for you, but other possibilities must be considered.

With MS, the spinal-fluid test for protein “bands” is often positive, but not always. Tests to measure the speed of impulses to the brain (evoked potential tests) are usually positive, but not always. Eye tests are usually positive, but again, not always. The MRI usually shows “lesions in time and space” with multiple lesions at multiple times, but not always.

This is why I talk about “complex issues” in diagnosing MS. While you listed spinal cord

lesions but not brain lesions, I will assume that these did not show on an MRI. If the diagnosis was MS, I would expect multiple MRI lesions in the brain, not just in the spinal cord.

If you lack significant brain lesions on your MRI, “Recurrent Transverse Myelitis” (lesions in the spinal cord, only) may be a possibility. If so, this may require a different treatment than what is used to treat RRMS. Therefore, you need an expert with more information to make the diagnosis of your problems. I suggest a second opinion at an MS center in your area. MSAA’s Helpline Specialists, at (800) 532-7667, extension 154, can help you to locate an MS center. ■

Jack Burks, MD is the chief medical officer 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

Readers may also send in questions via email to askdr@mymxaa.org. Please be sure to write “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.



H.P. **Acthar**® GEL
(repository corticotropin injection) 80 U/mL

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.



Research News

By Susan Courtney

Reviewed by Dr. Jack Burks

Expedited Review of Ocrelizumab for PPMS

In February, the United States Food and Drug Administration (FDA) granted “Breakthrough Therapy Designation” for ocrelizumab, an experimental medication presently under investigation for the treatment of primary-progressive multiple sclerosis (PPMS). At this time, no treatments are available for this less-common form of MS. With this designation, the FDA affirms: (1) the medication would be used to treat a serious condition; (2) preliminary clinical evidence indicates that the drug may demonstrate substantial improvement over existing therapies; and (3) the review process would be expedited to within 60 days. Please note that ocrelizumab has not yet been submitted to the FDA for approval.

Genentech, a member of the Roche group, is developing ocrelizumab. They have submitted the brand name Ocrevus™ to the FDA for this investigational medication, noting it is the first drug for MS that has been designated as breakthrough therapy by the FDA.

Ocrelizumab is an investigational, humanized monoclonal antibody designed to selectively target CD20-positive B cells. These are a specific type of immune cell thought to be a key contributor to myelin and axonal damage, which can result in disability in people with MS. In Phase III trials, ocrelizumab

was given every six months in two, 300-mg intravenous (IV) infusions. These two infusions were separated by two weeks.

According to Genentech, the breakthrough designation is based on positive results from the pivotal Phase III ORATORIO study. The trial met its primary endpoint, showing that treatment with ocrelizumab in PPMS significantly reduced the progression of clinical disability sustained for at least 12 weeks compared with placebo. Walking speed, as measured by the timed 25-foot walk, was improved by 29 percent. The incidence of adverse events associated with ocrelizumab was similar to placebo; the most common adverse events were mild-to-moderate infusion-related reactions. Additionally, MRI hyper-intense T2 lesions were reduced by ocrelizumab, and brain-volume loss as viewed on MRI was reduced by 17.5 percent.

This breakthrough designation with the expedited review period has only been granted by the FDA for the one indication, which is for the long-term treatment of PPMS as studied in the ORATORIO trial. Genentech is also studying this medication for the long-term treatment of relapsing forms of MS in the OPERA I and OPERA II trials. They plan to submit data from all three of these Phase III studies to the FDA in the first half of 2016, seeking approval for ocrelizumab in both PPMS and relapsing forms of the disease. ■

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MSAA Launches Redesigned Website

By Peter Damiri

Vice President of Programs and Services

While MSAA's website, mymsaa.org, has been mobile-ready for several years, we recently transformed the site into a fully responsive-designed web platform. For those who may not be aware, responsive design allows website content and the end-user experience to look and work the same on ANY device (desktop, tablet or smartphone).

The newly revised site still includes all of the same detailed information about multiple sclerosis for the MS community you have come to depend on, but is now more compatible with today's browsers and mobile devices. Notable highlights of the newly redesigned website include:

- An updated homepage with enhanced graphics and links to essential resources, including our sections on MS relapses and health insurance, as well as our MS Conversations blog and our top videos.
- MSAA's comprehensive MS Information section has been revised for easier navigation and to include more details about MS, its symptoms, long-term treatments, and important topics for individuals who are newly diagnosed.

- A new section, titled My MSAA Community, includes links to information on our educational programs, the My MS Manager™ mobile app, and the latest news from MSAA.
- Enhanced sections on ways to support MSAA - highlighting exciting ways to contribute your time or donations to the MS community.
- More ways to engage with MSAA and share our content on your social networks and more!

Please visit mymsaa.org to see all of these enhancements and let us know your thoughts at CommDept@mymsaa.org. ■



More Ways to Stay Informed

As you can imagine, MSAA is very excited about the launch of our new website, which will enable the MS community to better connect to our information and resources. You may benefit even more by becoming a part of our growing email membership, giving you the opportunity to stay updated with the latest news on MS and MSAA activities.

If you have an email address and have an interest in sharing it with MSAA, you will be able to receive:

- Invitations to MSAA's educational programs in your local community
- Timely updates on late-breaking MS news and treatment information

- Access to MSAA's digital edition of *The Motivator* magazine
- Free subscription to My MSAA Today – MSAA's new bimonthly e-newsletter available through email only
- Easy, online ordering of equipment and cooling products
- Access to MSAA's My MS Resource Locator® and many more online services

Members can opt-out of receiving emails at any time. To register with MSAA and take advantage of these online opportunities, please visit mymsaa.org and select "Receive Email Updates" on MSAA's homepage. ■

MSAA Produces New Video on PBA

With the goal of shedding light on a lesser-known but very impactful symptom of multiple sclerosis, "Why Do I Cry or Laugh Inappropriately?" is MSAA's latest on-demand educational video that discusses pseudobulbar affect (PBA). PBA is a distressing condition marked by sudden, involuntary episodes of crying or laughing.

Supported by Avanir Pharmaceuticals, this latest video features MS expert and MSAA Healthcare Advisory Council member Dr. Daniel Kantor. In this video, Dr. Kantor offers valuable insights into understanding PBA, learning about its cause, and knowing the differences between PBA, depression, and



other mood disorders. Dr. Kantor also provides guidance on discussing PBA with your doctor and ways to evaluate and treat the condition. To watch this video, plus 40 additional video programs available on the Multiple Sclerosis Information (MSi) webpage, please visit mymsaa.org/videos. ■

A Fitting Tribute

By Kimberly Goodrich

Vice President of Development

Finding the perfect gift for an occasion or the right words to say to someone experiencing loss is often a difficult situation. We can spend hours wondering, what is the appropriate way to express my condolences? Or, how can I truly show my appreciation of a person's accomplishments? How do I give a meaningful, lasting gift that serves as a "fitting tribute" to that person?

Often members of the multiple sclerosis (MS) community will take the guesswork out for you, by asking expressly that in lieu of flowers or gifts, you make a donation to MSAA. And for that we are grateful. For every person we have assisted through our vital programs and services, we know there are many more people affected by MS who urgently need these same programs and services as well – and your gifts are what make this possible.

Even if such a gift isn't asked for, this is a wonderful way to honor someone you respect, admire, or love. A memorial gift is a beautiful testimony to the life of a friend or family member, which also helps to make a difference in the lives of those affected by MS.

Gifts sent to MSAA can have a lasting impact and serve as a testimony to the life of a loved one. MSAA will send a personalized card to the family of the person in whose name the donation was made. Please note,



Honor a graduate with a thoughtful tribute gift to help the MS community.

MSAA does not disclose the amount of the gift to the recipient but simply lets them know of your thoughtfulness.

Tribute gifts can also be a terrific way to celebrate the special people and joyous events in your life. Do you know someone who works tirelessly to advocate for those living with MS, or who must personally manage this complex disease on a day-to-day basis? Honor that person and his or her indomitable spirit with a gift in this person's honor. You may also celebrate the birthday of a friend, acknowledge a milestone achievement, rejoice in the commitment of a newly wedded couple – all while giving the gift of hope to others in the MS community.

As the weather begins to warm and we embrace the spring, there are numerous occasions approaching where we can pay tribute to family and friends. What better way

to honor a mother or father in your life on their special day than with a gift that helps others? Will there be any graduates in your life this spring? Send them into their future with a thoughtful gift that salutes their hard work and instills a philanthropic spirit.

For larger events such as birthdays and anniversaries, you may want to get everyone involved. MSAA has the ability for you to create a personalized tribute page on our website. You can download your own photos and messages and share these with your family and friends, encouraging them to help you in your tribute. This can also be a

pleasing way to share your memories of someone and ask others to include theirs. Funds raised through these methods help ensure more people get the assistance they are seeking, whether it be resources for the newly diagnosed, cooling vests, wheelchairs, much-needed information and much more.

For additional information on how to create a fitting tribute to someone you love, visit our website at support.mymsaa.org/tributepage. Thank you for helping MSAA to fulfill its mission of being a leading resource for the entire MS community and for improving lives today! ■

THE

PRESIDENT'S *Circle*

The following thoughtful corporations, foundations and individuals have contributed generously to MSAA to improve lives today for the entire MS community. Those providing gifts of \$10,000 or more during the current fiscal year are shown in this listing.

CHAMPIONS (*\$100,000 and up*)

Acorda
Bayer HealthCare
EMD Serono, Inc. and Pfizer Inc.
Mallinckrodt Pharmaceuticals
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Genzyme Corporation, A Sanofi Company
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Estate of Katherine Payne
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Barbara Kouris
Town Pump Corporate Fund Management

Challenged Yet Charming

By **Mary C. Krapez**

I live a challenged yet charming life. In my younger years, things were going pretty well for me. I was married to my husband Michael and we had bought our second home. Michael was a church deacon and I worked for a local parish as the director of religious education.

In 2000, my husband and I had a wedding to go to out of town. While at the reception, I noticed that something was not quite right; my vision in my left eye was faded and fuzzy. I was also walking a little strange, which I blamed on my shoes.

The next day, I called into work and went to find an ophthalmologist. I was smart enough to see a specialist... after all, my grandmother was a nurse and she instilled in me the importance of seeing the right doctor. After some testing, the ophthalmologist said that I had MS. I then went to see both my family doctor, who confirmed the diagnosis, and a neurologist.

“No big deal,” I thought. I was still walking, working, and driving at this point. Everything was okay until I became overwhelmed with stress. At that time, I began moving slower and had to depend on a cane. My husband had been diagnosed with lung cancer and passed away in 2002. My oh my, how life had changed.



Accompanied by her friends (from left to right) Dr. John Tricou, Ken Tsui, and Claire Chang, Stories to Inspire author Mary Krapez enjoys a ride on “Scootch.” Owned by Barbara and Tim Mulry, Scootch is part of the riding program at the Sojourn Therapeutic Riding Center.

I went from a cane, to a walker, to a manual wheelchair. I found that it is hard to wheel on carpeting! Moving to another home was not an option, so I had to make a few changes to the floors and stayed out of the carpeted living room...on the positive side, you don't have to clean a room if you're never in there! I finally returned to the living room after two years – once I got my power chair.

My MS took so much from me, such as my walking, clear talking, driving, and singing. It took away my work, both at the church and as

a licensed beautician. But at the same time, it gave me things in return. It gave me unplanned time, with more time to pray and more time to ponder. I especially have more time to think before I act, as I used to be impulsive and found I would act first and apologize later. These changes all brought balance to my life.

I now even have time to pursue my passion for riding horses – a love that I inherited from my father. I used to ride horses back in high school, and in more-recent years, I have begun therapeutic riding. This is horsemanship for individuals who may have some type of physical, emotional, or other disability. By having more time to ride, I am able to get to know the individual horses better, adapting to the different horses on different days.

Here is my advice. Get on a medication that you are comfortable with and be your own advocate. Question everything that doesn't sound right. And stay off the river called "Denial." Try to stay positive!

My father used to say, "Don't sweat the small stuff," and these are certainly words to live by! How funny that one's goals change along with

his or her situation. My main goal in life has gone from dancing and singing to staying healthy. I try to do this by eating well, planning my physical activities, and praying a lot.

The people around me are important too, and I am so fortunate to have so many wonderful people in my life. These include my partner – he also has MS – and my many caregivers and friends who are too numerous to mention by name. I am thankful to the members of my support group and to the people involved with the riding center where I go for therapeutic riding. I also have a cousin who was just diagnosed with MS; he too is very important to me, and we share our sense of humor. I am grateful to so many people – and feel blessed because I have them in my life.

As you can see, I have led a pretty full life so far! What will the future bring? As we all do, I hope to see a cure someday for MS. One area I may look into is stem-cell research, the kind that uses my own stems cells. And I know that more treatments for MS are right around the corner. In the meantime, I enjoy thinking about a cure, praying for it, and in this story, writing about it! ■



MSAA's 2014-2015

Annual Report

Check out MSAA's latest **Annual Report** highlighting recent program developments, achievements, and recognition of our supporters.

Please visit mymsaa.org/AR to access this publication.

What is Glatopa[®]?

YOU HAVE QUESTIONS...



WE HAVE ANSWERS.

GlatopaCare[™]

Comprehensive suite of patient support services is available.

Glatopa[®] (glatiramer acetate injection) 20mg/mL is indicated for the treatment of patients with relapsing-forms of multiple sclerosis. Eligible people switching to Glatopa[®] or starting it upon diagnosis can receive comprehensive support services through the patient support services center hub, GlatopaCare[™]. GlatopaCare[™] representatives can assist eligible patients to understand insurance benefits. A Nurse Trainer is also available 24/7 to answer non-medical questions and provide injection training in home or by telephone.

Glatopa Important Safety Information (continued on next page)

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

For more information on these support services,
visit: www.glatopacare.com or call **1-855-GLATOPA**.

Glatopa[®]

Important Safety Information (continued)

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 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.

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.

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 the 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 disposal 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 Leaflet 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 Glatopa Care at 1-855-452-8672.

What are the ingredients in Glatopa?

Active ingredient: glatiramer acetate

Inactive ingredients: 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: 06/2015

continued from page 37

Trial Results Presented for Oral Ozanimod

Also in February, the 72-week Phase II results were presented from the RADIANCE trial, which studied the effectiveness of ozanimod treatment in individuals with relapsing-remitting MS (RRMS). Previously known as RPC1063, this investigational medication is now under development by Celgene Corporation.

Ozanimod is a selective S1P 1 and 5 receptor modulator. It was given as a once-daily pill in the Phase II RADIANCE trial and was compared at two different doses (0.5 mg and 1 mg) with placebo. A total of 258 RRMS patients were studied in this double-blind trial, which ran for 24 weeks and was then followed by a 48-week blinded-extension period. After

the initial 24 weeks, individuals taking the placebo were randomized to either dose of the medication.

At the conclusion of the 72-week study, patients in groups taking either dose of ozanimod showed a significant decrease in the mean number of gadolinium-enhanced (GdE) lesions. A significant number of participants were also free of GdE lesions, and relapse rates were reduced as well. The most common side effects reported were minor infections, back pain, and headache. Elevated liver enzymes were seen in 3 to 4 percent of the participants. No serious cardiac events were reported. Ozanimod is now being studied in two Phase III trials, SUNBEAM and a two-year portion of RADIANCE. ■

Ibudilast Receives Fast Track Designation

In March, MediciNova, Inc., the biopharmaceutical company developing ibudilast (MN-166), announced that this investigational medication for progressive forms of MS has received Fast Track designation from the United States Food and Drug Administration (FDA). This designation makes the drug eligible for a quicker review period, possibly leading to an accelerated approval. It is intended for drugs under development for treating serious diseases and with the potential to address unmet medical needs for such diseases.

Once Phase III trial data are available for ibudilast, these may be submitted to the FDA (along with its New Drug Application) and the Fast Track designation would become effective.

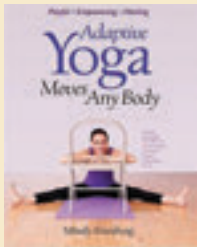
Please note that the Phase II trial will not be completed until the end of 2016, so Phase III data – needed to submit ibudilast for approval – will not be available until a much later time.

Ibudilast is an oral agent with novel immune-modulating and potential neuroprotective properties. It is being studied in both secondary-progressive MS (SPMS) and primary-progressive MS (PPMS). ■

For more information on these and other topics, please go to mymsaa.org and select “News from MSA.”

For any MS-related questions, please contact MSA’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.

MSAA's Lending Library Selections



Adaptive Yoga Moves Any Body

by Mindy Eisenberg

Orange Cat Press | *MSAA Book #361*

This user-friendly instructional guide is written for people with MS and neuromuscular conditions, as well as for students, yoga instructors, and therapists. Chapters cover such topics as basic yoga principles, breathing and posture, warm up, adaptive poses, and even yoga through hand gestures. The author's uplifting messages, along with photos and descriptions of the poses, are all very helpful for people looking to improve their body and mind through yoga, regardless of their level of physical ability or experience.

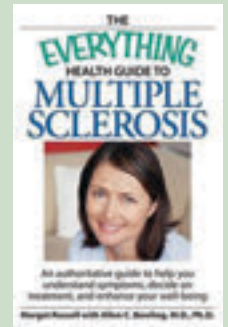
The Everything Health Guide to Multiple Sclerosis

by Margot Russell
with Allen C.

Bowling, MD, PhD

Adams Media

MSAA Book #320



As the title implies, this book offers a wealth of information on countless topics of great interest to the MS community. Written by a communications professional who was diagnosed with MS, along with a top MS specialist, this valuable resource covers everything from diagnosis, symptoms, and treatments, to wellness strategies, employment, family life, creating a support network, and more.

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Healing Conversations: What to Say When You Don't Know What to Say

by Nance Guilmartin

Jossey-Bass | *MSAA Book #392*

This hard-bound publication is quite unique and may be of tremendous help when talking with anyone about a loss, illness, or other life-changing event. Providing direction and heartfelt stories, this book addresses difficult conversations – including those appropriate for individuals asking for help or needing to talk about their own challenges, as well as for those wishing to comfort someone experiencing a difficult event, from changes in employment to health matters and even the loss of a loved one.

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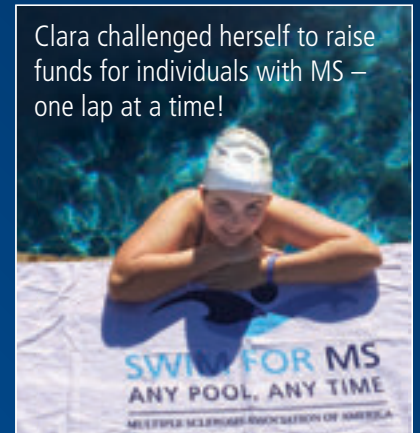
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