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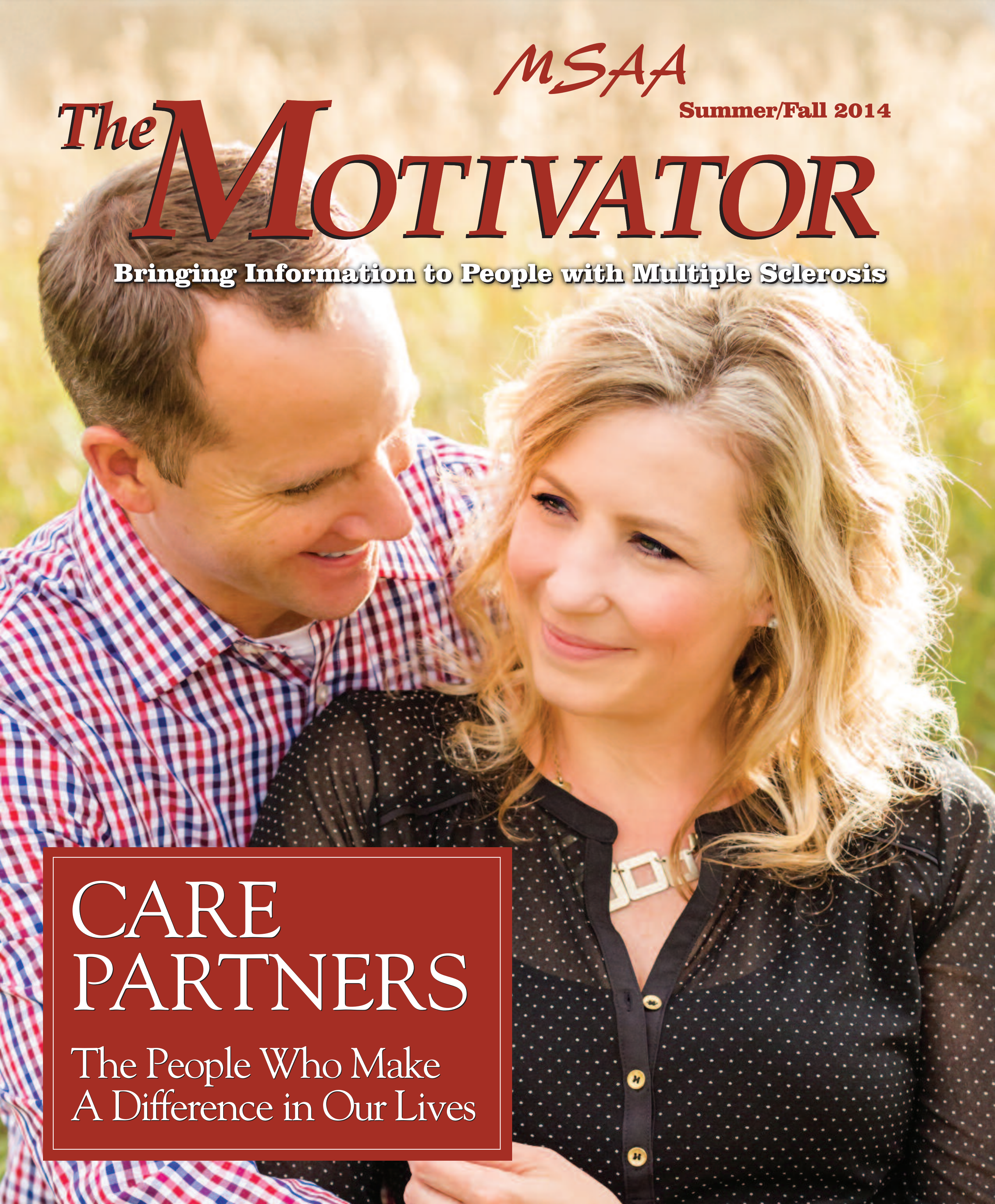

MSAA

Summer/Fall 2014

The MOTIVATOR

Bringing Information to People with Multiple Sclerosis

CARE PARTNERS

The People Who Make A Difference in Our Lives

The MOTIVATOR

Published by the Multiple Sclerosis Association of America

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Andrea L. Griesé, Editor
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
706 Haddonfield Road
Cherry Hill, New Jersey 08002
(800) 532-7667
mymsaa.org

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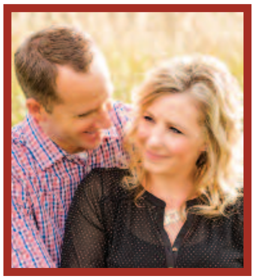

COVER STORY

DEPARTMENTS

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

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By Douglas G. Franklin
MSAA President and CEO


Douglas G. Franklin

New, Vital Programs … Made Possible By Your Support

At MSAA, we are working on several program initiatives to help individuals with MS access timely and vital information. One of these projects, My Health Insurance Guide, is a specific section on our website dedicated to the rules and changes related to the Affordable Care Act (ACA), Medicare, and other insurance options. More details on this web-based initiative can be found in the Program Notes column on page 42 of this issue.

I'm also pleased to report on a collaborative project with the MS Coalition (MSC). All eight member organizations of the MSC, including MSAA, recently developed a paper for healthcare professionals. Titled "The Use of Disease-Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence," this detailed writing summarizes the current evidence supporting the FDA-approved disease-modifying therapies (DMTs) for the long-term treatment of MS. The document was distributed at the recent ACTRIMS-ECTRIMS meeting. A layperson's version of the paper will be available later this year, at which time MSAA will post the article on our website.

And speaking of later this year, we are fast-approaching our annual end-of-year events and activities! Please watch for our fun Thanksgiving eCard election, where individuals may vote online for their favorite electronic greeting card. This is followed by a full selection of free December eCards to send to family and friends.

This is also a time when we depend on special donations to help fund our urgent programs and services. During the upcoming holiday season, please be sure to add MSAA to your gift list. On behalf of everyone at MSAA, I would like to thank you for your generous contributions that enable MSAA to continue improving lives today through vital services and support. ◆

Doug Franklin joined MSAA as President & CEO in 1999. He has a distinguished career in nonprofit leadership and is a former national trainer in strategic planning for the Peter Drucker Foundation. A published international expert in social marketing and corporate social investment, he is a graduate of four universities and holds dual certifications in two professional associations. He currently serves on the National Board of the Key Philanthropic Organizations Committee of the American Society of Association Executives and as President of the Multiple Sclerosis Coalition.

CARE PARTNERS

The People Who Make A Difference in Our Lives

By Maryann B. Hunsberger

Most major life changes come with advance notice. Weddings are preceded by engagements. Births follow pregnancies. Graduations come after education. Disability, however, arrives with no notification. While MS sometimes enters a life in stages, the onset is still a surprise.

Becoming a care partner is the same way. An individual suddenly becomes responsible for another with no notice. Even after years of caring for another's wellbeing, the effort can be daunting, especially without the right direction. The proper resources, however, can both inform and encourage care partners in the task of supporting another.

This article is a resource that care providers and people with MS can use for information and reinforcement. Understanding the responsibilities and subtleties of being a care partner can assist individuals in planning ahead and being prepared for issues that might arise.

Although the demands may be great, being a care partner can be rewarding for all involved, providing essential physical, emotional, and social support for the person with MS. A care partner relationship also allows friends and family members to feel needed and grow closer with the individual receiving care.

Lara Krawchuk, MSW, LCSW, MPH, a therapist, professor, wellness educator, and the founder and owner of Healing Concepts, LLC, points out, "Being a care partner may bring pride and hope and resilience. Care partners realize they are handling something that others might not be able to cope with, helping them feel stronger."

Please note that individuals with MS who don't have care partners can also make use of the information provided in this article.

Part 1: THE ROLE OF THE CARE PARTNER

Care Partner Responsibilities

Since each person in a care partner relationship is unique, needs and responsibilities can vary. Some care partners may be required to handle household responsibilities, such as cleaning, cooking, laundry, errands, grocery shopping, or meal preparation. Others might need to drive children to school and activities, or take their loved one to appointments with hairdressers or medical professionals. Sometimes, care partners must learn to use newer technology – and they might teach these skills to the person with MS. Handling business, legal, or insurance issues can also fall within the duties of a care partner.

A care partner may need to learn some basic medical skills, depending on the care recipient's level of need. All care partners should practice infection-controlling skills, such as using surgical gloves, washing hands frequently, disinfecting the home, providing good nutrition, ensuring proper personal hygiene, and promoting good general health.

A care partner might need to learn to monitor vital signs (respiration, temperature, pulse, and blood pressure). Providing assistance with a treatment regimen and medications, as well as assisting with medical appointments, may also be necessary.

If the person with MS needs help walking, a medical professional or physical therapist should be consulted on the best way to provide assistance. This might involve helping to select the proper assistive equipment; assisting with instructions on pace, posture, turning, and climbing stairs; and guiding or supporting the individual.

Sometimes, assistance may be needed when using a wheelchair. A physical therapist or medical professional can help a care partner learn the correct procedure for transferring, locking brakes, moving footrests, and placing the individual's feet on the footrests.

Learning these new skills can often be challenging, yet care partners can experience a sense of sufficiency as they master these new proficiencies.

Care partners invest large amounts of energy, time, and emotion in caring for another. Phil Sisser, from North Carolina, has been a care partner for his wife Shelley, now 57, for the 13 years she has had MS. The Sissers have no outside help. They moved to North Carolina from Pennsylvania in 2009, seeking better weather. However, they haven't made any friends in the area and their children are scattered in different states.

Phil Sisser has cared for his wife Shelley for 13 years. The couple moved from Pennsylvania to North Carolina seeking better weather.

Phil, who stopped working in 2006 due to his own disabilities, handles 90 percent of the household responsibilities. On days when Shelley feels well enough, she handles the other 10 percent.

For Diana Hill, 55, a woman with MS from New Jersey, care partnering is a team effort. While husband Joe is at work, their grown children pitch in to help. Their daughters Jennifer and Christina take turns picking up Diana from physical therapy three days each week and taking her out to eat afterward. Their son Eric provides help with lifting and transferring when necessary. When they drop Diana off at home, Diana's father, Alex, walks to her house, staying with her until her husband comes home from work. Husband Joe then takes over, handling all of the household responsibilities and his wife's care. "Everyone pitching in makes it work," says Jennifer. "Everyone has their job to do and everyone does it."

The Importance of Communication

Dr. Miriam Franco, MSW, PsyD, a professor at Immaculata University's sociology department in Immaculata, Pennsylvania, and a member of MSAA's Healthcare Advisory Council, states that learning to talk openly is essential for effective problem solving. "Bringing up difficult topics is never easy. Discussing issues frequently is best, especially as living with MS involves fluctuating adaptations over time. MS extends over a lifetime, so coping with the disease requires adjusting to life transitions and the disease course. The lack of predictability is one of the hardest issues for people with MS and for their care partners."

As a long-term care partner, Phil finds communication especially important in light of the unpredictability of MS. "I like to be sure I'm heard correctly and vice versa. I need to know up front when my wife can do things instead of my always having to ask, so I'll know when she needs help and when she doesn't. When Shelley has more energy, she tells me not to do things for her. She wants to do some things herself, since always depending on someone is scary for her. But her cognitive skills are sometimes impacted, and I don't know when this is happening. If I remind her of something, she might say, 'I know. You don't need to remind me.' While another time, she will say, 'Oh, I forgot.' That unpredictability can make it difficult, so communicating is of the utmost importance."

Sometimes family roles can change due to

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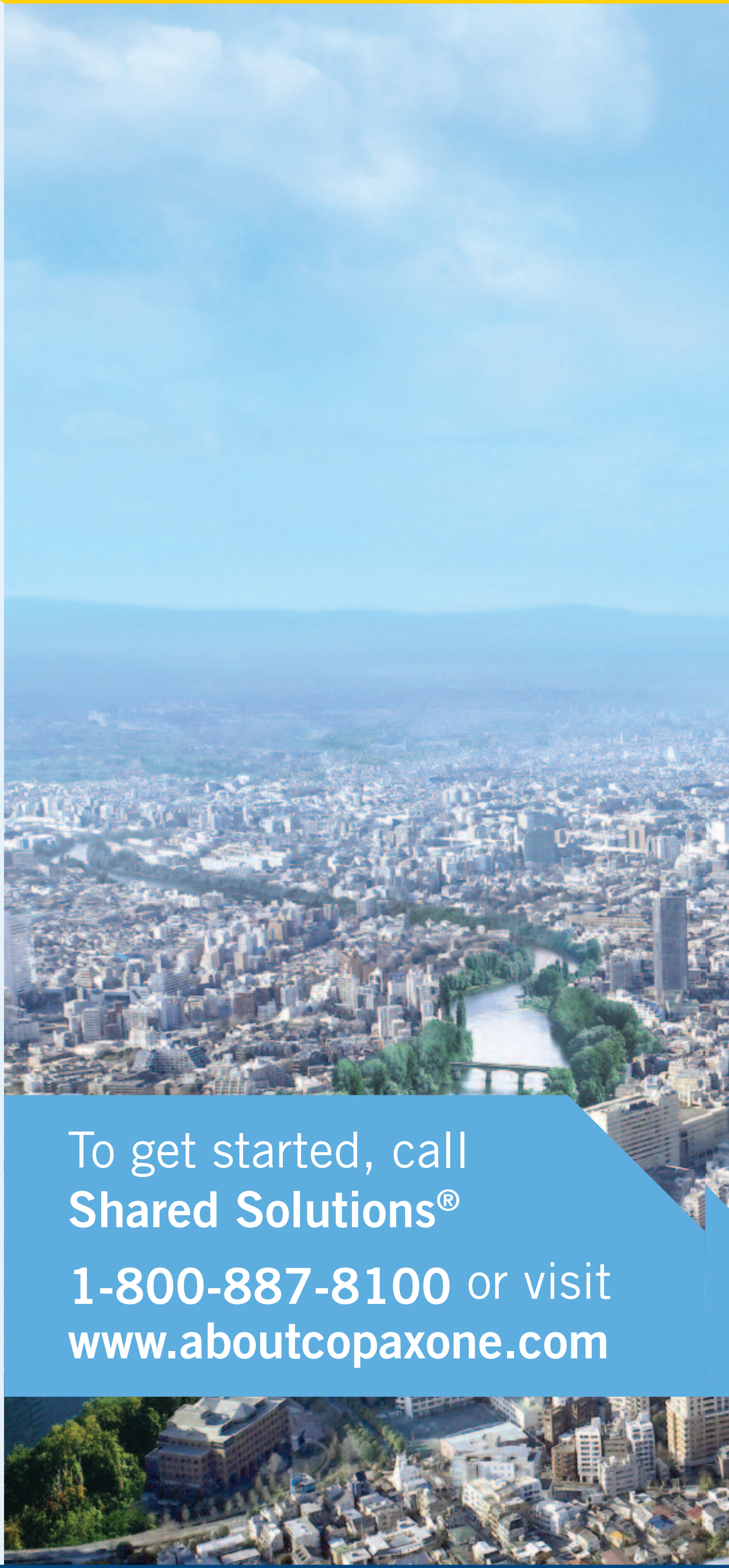
EXPERIENCE



COPAXONE® (glatiramer acetate injection) is indicated for the treatment of patients with relapsing forms of multiple sclerosis.

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.**

Please see additional Important Safety Information and brief summary of full Prescribing Information on the following pages.

To get started, call **Shared Solutions®**

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(glatiramer acetate injection)

Important Safety Information (cont'd)

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 COPAXONE® (glatiramer acetate injection) 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.

Patient Information

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

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

What is COPAXONE?

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

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

Who should not use COPAXONE?

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

What should I tell my doctor before using COPAXONE?

Before you use COPAXONE, tell your doctor if you:

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

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

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

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

How should I use COPAXONE?

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

What are the possible side effects of COPAXONE?

COPAXONE may cause serious side effects, including:

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

  If you have symptoms of a post-injection reaction, do not give yourself more injections until a doctor tells you to.
- **Chest Pain.** You can have chest pain as part of a post-injection reaction or by itself. This type of chest pain usually lasts a few minutes and can begin around 1 month after you start using COPAXONE. Call your doctor right away if you have chest pain while using COPAXONE.
- **Damage to your skin.** Damage to the fatty tissue just under your skin's surface (lipoatrophy) and, rarely, death of your skin tissue (necrosis) can happen when you use COPAXONE. Damage to the fatty tissue under your skin can cause a "dent" at the injection site that may not go away. You can reduce your chance of developing these problems by:
  - following your doctor's instructions for how to use COPAXONE
  - choosing a different injection area each time you use COPAXONE. **See Step 4 in the Instructions for Use, "Choose your injection area".**

The most common side effects of COPAXONE include:

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

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

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

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

How should I store COPAXONE?

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

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

General information about the safe and effective use of COPAXONE.

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

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

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

What are the ingredients in COPAXONE?

Active ingredient: glatiramer acetate

Inactive ingredients: mannitol

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Product of Israel

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

COP-41059

MAKING CONNECTIONS

Care partners looking for ways to connect with other people can go to the MSAA website at **mymsaa.org** and click “Calendar of Events” to find activities such as educational programs where others with an interest in MS will be.

MSAA also offers an interactive one-on-one chat feature that allows care partners to ask questions while browsing MSAA’s website. MSAA’s Client Services Specialists can help identify or explain programs offered by MSAA or refer individuals to helpful resources. Please go to **mymsaa.org/mschat** to learn more.

MSAA’s Networking Program is an option for people who are interested in finding peer support and corresponding through email exchange. For more information, please go to MSAA’s website at **mymsaa.org** and select “Networking” under “How MSAA Can Help.”

Individuals may also be interested in connecting with others via MSAA’s social media platforms and blog, *MS Conversations*, found at **blog.mymsaa.org.**

continued from page 5

MS. Ms. Krawchuk stresses the need for communicating about what has changed and what each person’s specific needs are. “The care partner should not feel that she or he has to do and take on everything. The person with MS may still be able to provide emotional care for the other family members. The person with MS may still be able to read books to the child at bedtime, call the school about problems, or help with homework. Finding out what everyone can do and splitting responsibilities is best.”

When Diana goes out to lunch with her daughter Jennifer each week, she enjoys playing with Jennifer’s baby (and Diana’s grandson), Colin, and helping him eat while he sits in his high chair. This allows the two to bond and gives Jennifer time to eat her meal.

Connecting with Others

Megan Weigel, DNP, ARNP-c, MSCN, an advanced registered nurse practitioner at Baptist Neurology, Beaches Division in Jacksonville, Florida, recommends meeting other care partners to get support. “Events such as educational meetings, aquatic exercise or aquatic therapy classes, and various support groups are the types of programs that connect not only people with MS, but care partners as well.”

Phil was active with an MS group in Pennsylvania before moving to North Carolina. He found them to be a valuable support. “Belonging to the MS group let me observe people with MS and how they coped. I noticed that sometimes a person with more severe symptoms had a better attitude than one with fewer symptoms. This showed me the importance of keeping a good attitude. I need an attitude check whenever I project into future scenarios and begin to feel helpless. Bringing it back into the here and now provides perspective.”

Part 2: CARING FOR THE CARE PARTNER

Care Partner Health

Phil, who had left hip replacement surgery in 2011, now has problems with his right hip. "Shelley's health was better the last time I needed surgery and she was able to care for herself. I can't get the other hip fixed because I can't go to the hospital and leave Shelley alone."

This isn't an unusual situation. The Family Caregiver Alliance reports that one-in-10 care partners has experienced a decline in physical health due to caregiving. Care partners are less likely to engage in preventive-health behaviors. However, care partners need to care for their health needs, or they can find themselves unable to provide care to the person with MS.

In addition to maintaining a healthy weight and exercising, care partners can protect their health by getting enough sleep, maintaining social interaction, seeing their doctors and dentists for regular checkups, and getting any routine medical screening necessary. This can include tests such as cholesterol blood panel, mammograms, PAP tests, prostate exams,

CARE PARTNER HEALTH

Our bodies are meant to move. Movement keeps bones strong, aids in keeping muscles sturdy and flexible, and helps alleviate stiffness in joints. People with MS and their care partners who want to maintain or gain strength and flexibility while enjoying time together may be able to join an exercise class. This should be done under a doctor's guidance. This is also a good way to meet new friends.

The Swim for MS online Aquatic Center at **SwimForMS.org** helps individuals learn about important factors to consider when selecting an appropriate pool and understand how to assess a qualified aquatic fitness instructor. This site features MSAA's latest webinar with physical therapist and aquatics expert Linda Csiza. A series of inspirational videos can also be viewed at this site. The videos feature individuals with MS who incorporate swimming and aquatic exercise into their healthy lifestyle.

To locate a local community-based aquatic exercise program, go to My MS Resource Locator at **resources.mymsaa.org**. This MS-specific database allows individuals to search for an array of targeted information and services, including content on aquatic exercise and community pools.

In addition, the Arthritis Foundation has exercise, Tai Chi, and aquatic exercise classes that encourage social interaction. For individuals with MS, please ask if the pool temperature is less than 86 degrees F. to help reduce the risk of overheating. Learn more at **www.arthritis.org/resources/community-programs** or call **(800) 283-7800**.

Some people with MS and their care partners might want to improve their fine motor skills and strengthen finger and hand muscles while having fun together. One idea is to search for local pottery and clay-making studios to find one that best meets the individual's needs. Some studios even have adaptive pottery-making for individuals with disabilities.

blood pressure checks, colonoscopies, and similar screenings.

Since having the strength needed for lifting is so important for care partners, they should take steps to remedy injuries as soon as possible by visiting their physician. They may also need to go for tests, such as x-rays, MRIs, and CT scans. They should follow any direction given by their physician. This could include some form of corrective procedure and possibly seeing a physical therapist to increase their strength.

Some physical therapy centers have programs allowing clients to move into a supervised exercise plan after completing therapy. These programs cost a fraction of what is charged for physical therapy and can be an excellent way for care partners to maintain their strength. Such programs also give care partners the opportunity to work out in a different environment, chat with other people, and have time away from the home.

Care Partner Burnout

According to the Family Caregiver Alliance, studies consistently report higher levels of depressive symptoms among care partners than among their non-caregiving peers. They report that more than one-fifth (22 percent) of care partners are exhausted when they go to bed at night, and many feel they cannot handle all of their caregiving responsibilities.

Ms. Krawchuk states that experiencing a variety of emotions is normal. “Emotions vary from person to person. Exact road maps don’t exist. Loss brings grief, so any emotion can be expected, and all emotions are normal.” She explains that people with MS and their care partners should ask each other about their emotional wellbeing if one notices that the other seems depressed. “Ask without pressuring or judging. Use compassion.”

Dr. Franco points out some signs of care partner burnout. “The mix of physical and emotional exhaustion hits a care partner at one time or another. You know this is happening when changes in behavior occur. For instance, you may feel furious one minute and helpless the next, or you can’t eat or you eat too much, or you’re still exhausted after a full night of sleep. Perhaps your brain is foggy and you lack taking pleasure in things. Catching every virus that comes around is a sign that your immune system is down. Your body is telling you to take better care of yourself. If you’re becoming easily irritable or over-reactive, you need a time out.”

She suggests not setting expectations too high, and when needed, voicing concerns to someone outside of the home. “Learn to take breaks – not to run another errand – but to see a friend, read a book, or write in your journal. And if you are the person everyone goes to for help, you will need to learn to delegate to others and to receive assistance from others. Many professionals and programs are available in the MS community that can help make your job easier.”

Dr. Franco cautions that untreated depression or anxiety is serious, but also notes that these conditions are highly treatable. She recommends checking in with your doctor and asking to see a therapist or counselor, if appropriate. For more information on depression and anxiety, please refer to the

STRESS-REDUCTION RESOURCES

Miriam Franco, MSW, PsyD, emphasizes the importance of learning quick and effective means of stress reduction for both the care partner and the individual with MS. "Care partners are known to increase their risk of illness because they neglect their own health, don't take time to exercise, or don't take breaks. Stress-reduction techniques can easily be practiced at home, waiting in a doctor's office, or together at the end of the day." She cites the following strategies and resources:

1) Guided Imagery (GI): This is a fast and effective way to learn both relaxation skills and sensory imaging. These techniques work to reduce stress, anxiety, muscle strain, and fatigue, while also improving sleep. Dr. Franco teaches GI workshops and provides GI training over the phone. She also has a CD/MP3 called "DeStress 101" for relaxation and GI to assist in stress reduction. Another CD/MP3 called "Imagery to Relieve Caregiver Stress" is designed specifically for care partners. (Please note that the CD/MP3 programs are available for purchase.) For more information, readers may visit Dr. Franco's website at **www.imagerywork.com.**

To find a trained GI practitioner locally, individuals may search by going to **www.imageryinternational.org**. This professional site lists certified GI practitioners in the United States and abroad.

MSAA also has an article that provides information on the topic. Titled, "An Introduction to Guided Imagery and Its Potential Benefits for Individuals with MS," this may be found by going to: **mymsaa.org/publications/motivator/winter-08/cover-story**.

2) Meditation: Individuals may search for meditation programs on the internet to find local or online workshops. For general information on meditation, please visit the National Center for Complementary and Alternative Medicine (NCCAM) website at **http://nccam.nih.gov/health/meditation/overview.htm**. Also, Sharon Salzberg, one of the top meditation teachers in the country, has a website with information at **www.sharonsalzberg.com**.

3) Care Partner Resources: The National Alliance for Caregiving offers many helpful tips and information about caregiving, caregiving stress, and caregiving resources. Please visit **www.caregiving.org** for more information.

The Well Spouse Association provides support and education for spouses and partners of people with chronic illnesses and disabilities. The association coordinates a national network of support groups, among other services. Please visit **www.wellspouse.com** for more information.

Available through MSWorld, the Caregivers Chat Room is an online support group for care partners of individuals with MS. It has a chat and message board for care partners. Please visit **www.msworld.org** for more information.

cover story of the Winter/Spring 2014 issue of *The Motivator*, "Managing the Emotional and Psychological Symptoms of MS," found at **mymsaa.org/publications/motivator/winter-spring14/cover-story**.

When problems arise, Dr. Franco says counseling can help. "Family or couples' counseling is an ideal way to get lines of communication open and to get help identifying issues, feelings, and expectations. The ability to address difficult, authentic feelings and issues can increase with practice, and over time, a deeper trust in the partnership and a sense of teamwork can result."

Dr. Weigel notes the importance of respite, stressing that the care partner needs to set time aside for him or herself. "This is the time to recoup – a care partner might need a few hours each week to participate in a favorite activity alone or with friends. This fulfills the care partner so he or she can continue to be a care partner."

Even a care partner who is at home most of the time should find ways to have some alone time. Phil relaxes by going into the bedroom and reading or talking on the phone to old friends or to his grown children. He uses his computer to pursue his writing hobby and to listen to music. He also enjoys spending time with their cats, who are a great source of comfort and companionship.

When More Help is Needed

Care partners sometimes need help with their responsibilities. Ms. Krawchuk notes that care partners should tell friends and extended family about the need for assistance. "Care partners often don't like to ask for help because they see it as an admission of failure. They overestimate their ability to continue operating at a certain level of providing care if they don't spread out responsibility. They think they should do it all, but asking for help is a fundamental skill of being a good care partner."

Ms. Krawchuk also notes the importance of being clear about what is needed. "Don't expect people to read minds. Ask openly before counting them out. They might not know that help is needed or wanted. Ask the right thing of the right person and be realistic. Don't ask your unemotional brother to lend a shoulder to cry on. Instead, ask him to help in some other way, such as changing the oil in the car."

When disability goes on for a long time, people might need to look for new sources of support. This might include hiring someone to clean and do laundry, or bringing home takeout meals instead of always cooking. She advises turning to organizations such as MSAA to find out what types of help are available.

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Finding Extra Help

Sometimes, one care partner isn't enough. When a care partner needs a break, or has to work, extra helpers might be needed. Many licensed and bonded home-health agencies do offer companion care or personal assistance care. Senior centers or local area agencies on aging and disability services are also good resources.

Sometimes, an individual with MS needs the help of a certified paraprofessional – which is a person who is trained as an aide in a specialized field such as healthcare. Care partners would be wise to check with the individual's health insurance company (including private insurance, Medicare, and Medicaid) to see if their plan covers any nursing care, certified nurses' aide care, or home-health care. Local home-health agencies that conduct background checks are a good resource to locate care for many individuals.

Some people with MS don't need medical care, but rather assistance with household duties they can no longer perform. Home-health agencies can still provide aides to drive, cook, clean, and shop. Some families find personal assistants through placing ads in their local newspapers or online at sites such as Care Guide at **www.careguide.com**.

Other families find assistance through neighborhood contacts. This might mean asking trusted neighbors or at your place of worship for referrals. Many licensed home-health agencies offer companion or personal-assistance care. Local agencies for aging/disability services are also good resources, as well as Eldercare Locator at **www.eldercare.gov**. Carefully screening and interviewing applicants before selecting one is important, as is choosing an applicant with written references and a background of providing care.

Sometimes, simple companionship is needed, rather than the services of a home-health aide. Local high school guidance counselors or college career centers can often find students who may be available for this type of work. High schools will sometimes count this as a student's work-study co-op. Even senior citizens might like to do companion work, so placing a call to the local senior center is another good idea.

FOR GENERAL ASSISTANCE

Information for care partners can be obtained from these resources:

Caregiver Action Network
www.caregiveraction.org | (202) 772-5050

Caregiver Magazine
www.caregiver.com

Eldercare Locator
www.eldercare.gov | (800) 677-1116

Family Caregiver Alliance
www.caregiver.org | (800) 445-8106

National Caregivers' Library
www.caregiverslibrary.org | (804) 327-1111

National Center for Assisted Living
www.ncal.org | (202) 842-4444

Part 3: DAY-TO-DAY LIVING

Living at Home

Assistive-care facilities are meant to provide a higher level of care than some individuals with disabilities can receive at home. However, Dr. Weigel says that some of the assistive-care facilities she has seen may not be appropriate for younger people. "In such instances, the level of activity and social interaction isn't the same as it is for elderly people. This can cause depression and social isolation." For this reason, she recommends taking the steps needed to allow a loved one to live at home longer. These steps include ensuring that the appropriate level of care may be given and that the home-living situation is as safe as possible. Assistive devices, and for some, a service dog, may also be very helpful. In addition, individuals may consult their local Centers for Independent Living for more information.

Assistive Devices are Available to Help

At some point, some people with MS may benefit from using assistive devices. These can range from mobility devices, such as canes, walkers, wheelchairs, and scooters… to communication devices, which include items such as voice-activated word-processing software, ergonomic computer keyboards, and adaptive trackballs. Even everyday devices – such as reminder ringtones on cell phones – can be used as assistive technology to prompt people to perform such functions as to take their medication at the same time each day.

Learning about what items are available to help with one's exact needs is vital. Physical and occupational therapists can be of much assistance in directing people to specific devices that can enable someone to perform activities that they might otherwise be unable to do. These can include items that not only assist with computers, communications, and a wide range of safety and mobility devices, as mentioned, but also a full array of aids for daily living, plans and products for adapting the home for greater accessibility, and more.

A great deal of information is available on the internet. Each state has an office of assistive technology, which may be able to provide a grant or loan assistance to obtain needed equipment, and possibly allow someone to try out an assistive device in advance.

Another resource is AbleData at **www.abledata.com**. Sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR), part of the United States Department of Education, AbleData maintains an extensive database of objective information on more than 36,000 assistive products. For each product, they provide a detailed description of the product's functions and features, price information (when available), and contact information for the product's manufacturer and/or distributors. Information is also given on customized products and do-it-yourself designs.

Searching through the products on this website gives browsers information on items from virtually every category that could require assistive technology and equipment. For example, individuals can easily locate information on vision and hearing devices, computers, daily living, housekeeping, recreation, environmental adaptations (home, office, and outdoor), transportation, walking, wheeled mobility, and more. If you have questions or need assistance, you may call the AbleData offices at **(800) 227-0216** to speak with an information specialist who can assist you with a database search.

MSAA also provides information on walking and mobility. This may be found at **mymsaa.org/about-ms/symptoms/mobility**. The information includes a three-part article titled "Mobility Independence and Safety," which includes a full section on wheeled mobility.

Adjusting to Assistive Devices that Help with Mobility, Safety, and Comfort

Dr. Weigel says it can be hard for some people with MS to give up walking unassisted and transition to using assistive devices. This transition can change one's perception of oneself to someone who is dependent. It can also be a reminder that MS is progressing, so it can bring up feelings of sadness. However, assistive devices increase independence because they enhance safety and conserve energy.

Dr. Weigel explains, "A man with MS who used a cane fought me when I told him he should use a power chair. When he went to Disney World with his family, he used a scooter. He came back and said it changed his life, because he could keep up with his grandkids, daughter, and wife. Nobody was afraid of him falling and he didn't get fatigued."

Since some individuals with MS may be resistant to using an assistive device, Ms. Krawchuk emphasizes, "Make it clear to the person with MS that an assistive device won't take away from who they are as a person. It will potentially add, since assistive devices allow a person to be more social instead of staying in the house all of the time."

Service Dogs

Some individuals with MS use service dogs, who are more than just pets. A service dog is trained to perform duties that specifically address the disability of the dog's owner. Since each person experiences his or her own specific disabilities and has different needs for assistance, each dog is custom-trained for the person it will help. For instance, a dog might be taught to pick up dropped items, open and close doors, and turn on and off lights for an individual using a wheelchair. A service dog might even pull a wheelchair.

Canine Companions for Independence (CCI) in Santa Rosa, California states that a service dog can also push buttons for elevators or automatic doors, and even assist with business transactions by transferring money, receipts, and packages. CCI has regional training centers across the country. Applicants who meet all CCI requirements attend a two-week team-training course before going home with their dog.

Ms. Krawchuk states that a service animal adds a level of comfort for both the person with MS and their care partner. "The care partner feels better when leaving the person with MS at home with a service animal. Doing so helps relieve feelings of guilt and also helps alleviate fear. It provides company and a feeling of security for the person with MS. The service animal becomes part of the family."

FINDING A SERVICE DOG

The following organizations train and provide service dogs to individuals with disabilities. Please note that interested individuals need to conduct their own research to assure that an organization is right for them. According to Pet Partners, a nonprofit research foundation, "Researching the field and examining your options are the best way to ensure that your choices for the service animal's appearance, disposition, and working style are compatible with your lifestyle and needs."

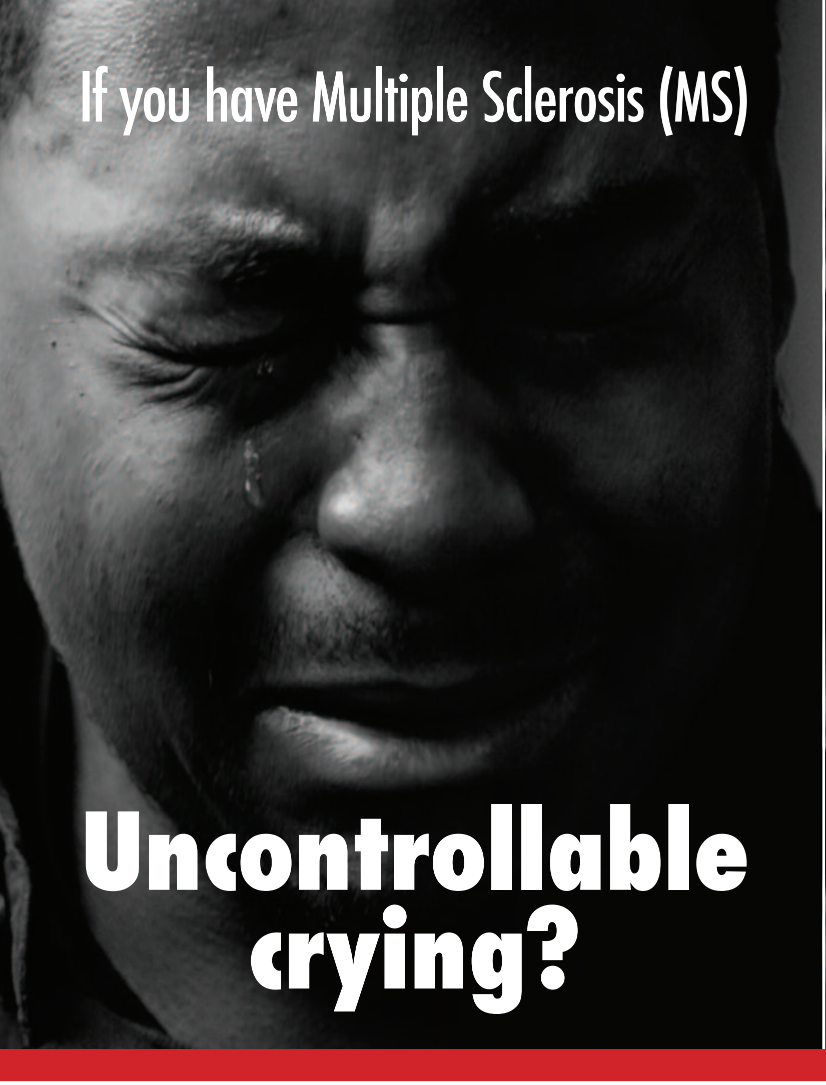
ORGANIZATION	WEBSITE	PHONE
Canine Companions for Independence	www.cci.org	(800) 572-BARK (2275)
Paws with a Cause	www.pawswithacause.org	(800) 253-7297
Pet Partners	www.petpartners.org	(425) 679-5500
Service Dogs for America	www.servicedogsforamerica.org	(701) 685-2242
Service Dogs for Independence	www.servicedogsforindependence.com	(520) 909-0531

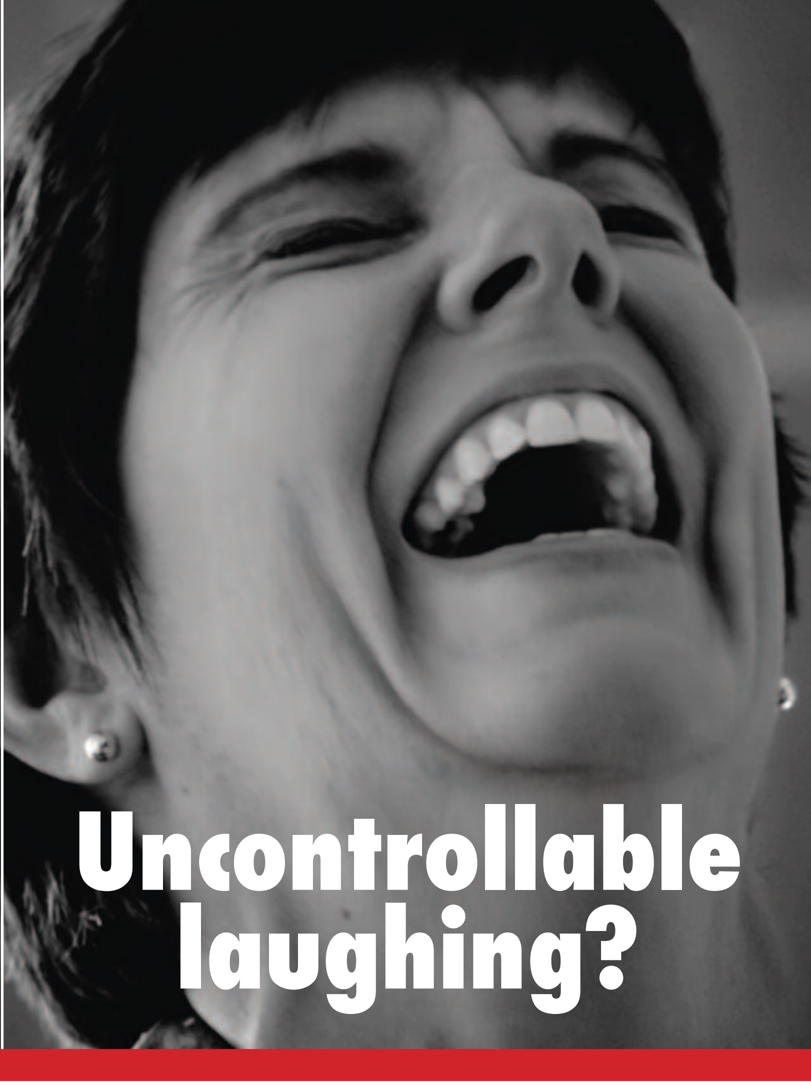
Safety

Creating a safe living environment for a care recipient is crucial. Therefore, after carefully evaluating the surroundings in the home, care partners should take the necessary steps to prevent any dangers that could result from accidents, fire, and other hazards.

Since fire prevention is of utmost importance, smoke detectors should be installed on each level of the house and checked regularly to assure they are working properly. Frayed electrical cords should be replaced, and electrical outlets must never be overloaded. Electrical cords should not be hidden under rugs, where they can wear down over time and cause the rug to catch fire. Care providers need to plan emergency escape routes, especially when mobility is affected. This route should be practiced with the individual with MS.

Falls and other accidents can occur as a result of some of the changes experienced with MS, and this presents extra challenges. Care partners should take preventive measures to help minimize the risk of injury for their loved one. For instance, simple changes can be made to reduce the risk of falls. Electrical cords and cables should never be placed where someone can trip over them. Wiping up spills immediately can prevent slipping. Shoes and





It could be **P**seudo**B**ulbar**A**ffect: **PBA**

PBA is a neurologic condition that triggers outbursts of crying or laughing in people with brain injuries or neurologic conditions such as Multiple Sclerosis.

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'**PBA** FACTS' is a FREE kit that explains the science of **PBA**, how it differs from depression and includes a self assessment to share with your doctor.

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*The PRISM Study was a nationwide study of patients 18+ with Alzheimer's disease, amyotrophic lateral sclerosis (ALS), Parkinson's disease, stroke, traumatic brain injury (TBI) or multiple sclerosis (MS) (1215 patients out of total study). Assessed PBA symptoms were measured by the Center for Neurologic Study-Lability Scale (CNS-LS) scores. A CNS-LS score ≥13 may suggest PBA symptoms and merits further diagnostic assessment. Patients or caregivers completed the assessment.

other objects should be put away, rather than left lying on the floor. Grab bars can be installed wherever necessary, not just in the bathroom. Also lowering the water temperature can help avoid burns. Plastic cups and containers can replace glassware to prevent cuts from broken glass. Shoes and slippers should have non-skid soles and should be replaced when they start to fray or lose support.

Using stairs can be difficult and even dangerous for some people with MS. One option is to have a stair lift installed. Some individuals may need to avoid stairs altogether, which involves moving their bedroom into an existing room on the first

☑ SAFETY CHECKLIST

- ☐ Keep exits, passageways, stairs, and floors clear of obstructions or tripping hazards.
- ☐ Place non-skid mats in tubs and showers.
- ☐ Install at least one grab bar in each tub and shower.
- ☐ If possible, hire an electrician to move light switches and temperature controls to wheelchair height.
- ☐ Keep lamps next to the bed to avoid having to leave the bed to turn off the light.
- ☐ Install night lights.
- ☐ Keep stairways well-lit and be sure switches are at the top and bottom of the stairs.
- ☐ Install sturdy handrails on both sides of stairs. Be sure they run the length of the stairs.
- ☐ Keep all cords out of the flow of traffic.
- ☐ Don't overload electrical outlets.
- ☐ Be sure smoke detectors are on each floor of the house and working properly.
- ☐ Install a carbon monoxide detector if your smoke detector doesn't include one.
- ☐ Ensure that throw rugs are slip-resistant.
- ☐ Post emergency numbers on or near the telephone.
- ☐ Create at least one emergency-exit plan in case of fire.
- ☐ If cognitive issues are present, additional safety precautions need to be taken, such as:
  - Keeping medications and toxic or dangerous items in locked cabinets.
  - Throwing away food prior to spoiling to avoid ingesting unsafe food.
  - Removing stove knobs so that the burners are not accidentally turned on.
  - Making sure electrical outlets are covered.

Parts of this checklist were adapted from the Home Safety Checklist written by the United States Consumer Product Safety Commission.

floor of their house or possibly adding a room onto the first floor. Other options include moving to a ranch-style house or a first-floor apartment or condo.

For people who can't afford to make big changes, care partners should be sure that stairways have sturdy railings on both sides that reach from top to bottom. At the top of stairways, small-diameter grab bars (about five inches long) should be available for people with MS to grab. These are also useful directly inside exterior doors.

Dr. Weigel emphasizes that making a house accessible can help the individual with MS to stay in his or her home as long as possible. "This can be costly, but it has such benefits. Most people want to stay in their homes. But, depending on the level of disability, they are at a greater risk for falls and complications if there isn't the right level of care at home. So, doing everything to make a home accessible is best."

In addition, maintaining a medication list, a first-aid kit, and a list of doctors as well as emergency numbers is important in a crisis. A working knowledge of cardiopulmonary resuscitation (CPR) can save a care recipient's life when an emergency strikes. The American Red Cross offers CPR classes in many areas. Go to **www.redcross.org** to find a local class.

Knowing When to Stop Certain Activities

Care partners should always show respect to the individual being cared for and expect the same from others. Still, at some point, certain activities may have to be limited or discontinued. How does a care partner recognize when the time has come, and how should he or she handle this? Dr. Weigel says, "Approach it before a problem happens, such as a burn, dropping dinner, falling, a car accident, or getting lost while driving. If a person has more trouble with balance, then you could assume that he or she would have more problems bathing. If having trouble with arm coordination, he or she will have cooking problems."

Dr. Weigel talks about the benefits of approaching the situation with concern rather than blame. "Instead of saying, 'You can't do this anymore,' say, 'I worry about you bathing when home alone because I love you and don't want an accident to happen.' Assure the person that asking for additional help won't put an undue burden on the care partner. People often don't ask for help because they feel like a burden."

If an individual has cognitive or visual problems, "then they can't drive," says Dr. Weigel. "Honesty is the best policy. Say, 'I've noticed your right foot drop is getting worse. Are you still comfortable driving? I'd be happy to drive,' or 'Maybe we should look into hand controls.' Things like driving can be touchy and sometimes you need to enlist the help of a healthcare provider to discuss this with your loved one with MS."

Finances

People with MS and their care partners often experience financial difficulties. Medical expenses combined with loss of income can wreak havoc on a family's finances.

Phil says he and Shelley haven't gone out to dinner in three years. "Money is an issue and we need a new car. We have bills to pay off. We owe tens of thousands of dollars for ER visits and ambulance rides. She has fallen several times and we have had to call 911."

Shelley began receiving SSI (Supplemental Security Income) and Medicaid benefits eight years before marrying her husband. When she married, she lost all her benefits. As a woman who had spent years raising children at home, she hadn't earned enough money to qualify for SSDI (Social Security Disability Insurance) and Medicare. "Society advocates American values with getting married, and then you are penalized. It makes no sense," says Phil. "It caused an incredible amount of anxiety. We had to pay for all her doctor visits in full. We went through nearly all of our savings."

Phil searched for assistive programs, which he describes as being "like a full-time job." Shelley's various MS medications cost up to $3,000 a month, so Phil located a patient assistance program that she qualified for. Shelley now gets her medication free of charge. Eighteen months ago, Phil found a physician outreach program for his wife that pays for primary care and referrals to specialists, but not for diagnostic tests. "We have so many unpaid bills. We can't go to MS clinics in the area because of having no insurance. All the stress makes the MS worse."

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TOOLS FOR MEDICAL EXPENSES

- A **Flexible Spending Account (FSA)** allows employees to pay for out-of-pocket health and dependent care costs on a pre-tax basis. This lowers payroll-related taxes.
- A **Health Savings Account (HSA)** lets participants save money specifically for health costs while receiving a tax break. Unused HSA funds can roll over to the next year.
- Through the Affordable Care Act, individuals with financial issues or pre-existing conditions may now purchase **health insurance** through the Marketplace. This act also enhances Medicare and Medicaid coverage. Please see MSAA's new online **My Health Insurance Guide**, at **mymsaa.org/healthinsurance**, for more information.
- For **prescription assistance**, please visit **Needymeds**, found at **www.needymeds.org** or by calling **(800) 503-6897**, and the **Partnership for Prescription Assistance** at **www.pparx.org**.
- **Short-term disability insurance** pays a percentage of your salary when temporarily disabled. According to **Insure.com**, a typical policy provides a weekly portion of one's salary, usually 50 to 66 percent for 13 to 26 weeks. Most policies have a maximum benefit amount per month.
- **Long-term disability insurance** picks up where short-term disability stops. This pays a percentage of one's salary until age 65.

MSAA's website also lists prescription assistance programs for several types of medications used for MS, including disease-modifying therapies as well as medications used for relapses and symptom management. For more information, please visit: **mymsaa.org/about-ms/sources.**

Only GILENYA® combines proven efficacy to cut MS relapses in half vs a leading injectable in a once-daily* pill.

GILENYA reduced the frequency of relapses by 52% in a 1-year study vs Avonex®, and by 54% in a 2-year study vs placebo.

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.

Once-daily GILENYA™ (fingolimod) capsules 0.5 mg

SPEAK UP TODAY!

Ask your doctor if GILENYA is right for you, and join the thousands of people already speaking out against their relapsing MS.

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(CONTINUED FROM PREVIOUS PAGE)

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, or vomiting.
- 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.
- Narrowing or blockage of the blood vessels in your brain may lead to an interrupted blood supply or bleeding into your brain. 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 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, 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 while taking GILENYA and for at least 2 months after stopping GILENYA treatment.

The most common side effects with GILENYA were headache, flu, diarrhea, back pain, abnormal liver tests, and cough.

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.

GILENYA™
(fingolimod) capsules 0.5 mg

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

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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
   - tiredness
   - body aches
   - chills
   - nausea
   - vomiting
3. **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 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, 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 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 that may lead to a stroke or bleeding.** This problem usually gets better when you stop taking GILENYA. Call your doctor right away if you have any of the following symptoms of a stroke or bleeding in your brain, including:
  - ○ 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
- flu
- diarrhea
- back pain
- abnormal liver tests
- cough

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 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.

Manufactured by: Novartis Pharma Stein AG
Stein, Switzerland

Distributed by: Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936

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Dr. Franco says, "MS can threaten financial, emotional, and time resources. If this occurs, heightened stress as well as vulnerability result, leaving both the person with MS and the care partner feeling overwhelmed, frightened, and drained, especially if other needs go unmet."

Families facing such challenges should seek help, both financially and emotionally. In addition to local and government assistance, the Department of Housing and Urban Development (HUD), at **HUD.gov**, provides counseling on housing and credit issues. Readers may also contact an MSAA Client Services Specialist at **(800) 532-7667**.

Independence and Dignity

Providing care for a person with MS, while allowing the individual to retain his or her independence and dignity, can be a juggling act for care partners. For instance, a care partner may wonder how to assist his or her loved one with dressing, bathing, and bathroom time while allowing for autonomy and privacy. One way to work this out is to involve the person with MS in decision-making about their capabilities.

Dr. Weigel states that discussing goals is a good way to help provide balance and include the person with MS in making decisions. "Sit down and go through a day's activities and figure out what the person with MS can accomplish on his or her own, even if certain things take longer. Then figure out which activities the person would like to at least try before asking for help. Safety has to be considered first, of course."

Phil realizes that his wife fears losing her self-sufficiency, so he does everything with this in mind. "I don't want her to lose herself, so I try to balance helping her and letting her do what she can do. Those two things sometimes clash. Also, I find that validating my wife is important to maintaining her dignity. Saying positive things about her and the things she can do helps to boost dignity."

Diana's daughter Jennifer assists her mother with those things she truly cannot do on her own – such as driving and transferring in and out of her power chair – while ensuring that her mother does the rest. When she takes her mother out after physical therapy, her mother chooses where to eat, orders her meal, and feeds herself. After eating, Diana decides where she wants to go. "If we visit the mall, she decides which stores to stop in, and she makes her own purchases. This way, she retains as much independence as possible."

Diana's children regularly acknowledge the things Diana does for her family. Jennifer frequently thanks her mother for being the family's spiritual leader who prays for them, advises them, and teaches them about faith. Her sister Christina consistently acknowledges the emotional and verbal support their mother gives to family members and how she cheers on her grandchildren for their accomplishments.

Enjoying Life Together

Having fun as an individual, a couple, or a family can take some resourcefulness when MS is involved. Often, a reduction in outside activities is necessary to accommodate a person's health. Sometimes, old activities can be adapted, but other times, finding or creating new activities is necessary.

Dr. Franco emphasizes focusing on activities the individual can do, including volunteer work. "The important thing is to do something you like that keeps you connected to others in a meaningful way."

She also notes the value of associating with others online. "The internet offers a new array of connection for many. Facebook, MS blogs, support groups, and forums are all easily available."

Dr. Weigel urges individuals with MS and their care partners to socialize, regardless of logistical challenges. "Spending time with friends and family and being part of a spiritual community are ways to help prevent social isolation."

Ms. Krawchuk states that creativity is key to wellbeing and having fun together. "I realize how challenging all of this is. But, the more creative you are, the more you can succeed in finding hope and joy. Look for things in common beyond the illness that you like and can do together. It could be movie nights, game nights, wheelchair dance parties, binge-watching your favorite show, or cooking, to name just a few examples."

Diana's daughter Jennifer found a new way to have fun with her mother. "It dawned on me that she can't dance anymore. She loves dancing and is the one who taught me to dance. So, I picked her up from her wheelchair and danced with her. She loved it! When we get home from shopping now, I put on music and we dance together. I lift her from her chair and hold her up, and we dance."

Diana Hill with her husband, Joe

Diana's family ensures that she is able to be at most major family events, no matter what they must do to accomplish that. Sometimes, the event comes to Diana. The family annual New Year's Eve party used to be held at various family members' homes. The party is now always held at Diana's house, with everyone pitching in to ready Diana and her home, and to provide whatever is needed for the party. "It takes time to do these things, but we do it for her quality of life and so that we and our kids get to spend quality time with her," says her daughter Christina.

Despite the financial and socialization challenges the Sissers face, Phil states, "Shelley is as devoted to me as I am to her, regardless of anything that comes our way. MS has allowed us to express our love in new and different ways. That is the sustaining force for me."

Ms. Krawchuk notes, "Actively seeking out big and small moments of joy, hope, and laughter is so important. These moments may look different than they used to, but they are still there." ◆

by Dr. Jack Burks
Chief Medical Officer for MSAA

Does Age Affect Long-Term Therapy?

Dr. Jack Burks

(Note: The questions below were sent in by two different clients.)

Q: **(a) I was diagnosed with MS in 2003. I was on Avonex for three years, then Copaxone for seven years. I had no relapses and only mild further deterioration overall. My neurologist, an MS specialist, recently took me off my disease-modifying therapy because I turned 60 years of age. Can you comment on the relationship of age to the effectiveness of a long-term therapy?**

(b) Is it true that after someone has been living with MS for 20 or 30 years, the need for one of the available disease-modifying drug therapies diminishes? After three or more decades of MS, does the course of the disease typically slow down or even stop in a significant number of cases, if any?

A: You have both asked a very controversial question. Does MS naturally "burn out" at a certain age and does the need for treatment go away? The subject is debated often and very little scientific data are available. In my many years of MS experience, I have found much variability exists between patients.

Before the discovery of DMTs, I thought many patients had slowing of their disease course after age 60 or 65. They clearly had fewer relapses, and the disease progression slowed. However, many still had disease progression and some continued to have relapses.

This leads to another very controversial question. If you stop having relapses, should you stop your disease-modifying therapy? The majority of neurologists with whom I discuss this issue say that they do not stop treatment. They believe that the reason the relapses have stopped, and the disability is less than expected, is because these drugs are working. Therefore, stopping the effective drug will expose a patient to a possible worsening of his or her disease.

In regard to the first question (a), your neurologist has a different viewpoint. I respect your neurologist's position, but I am resistant to stopping a treatment that may be responsible for a good outcome, especially if the patient is tolerating the drug well. Stopping the drug may increase MS damage, and we may have more trouble getting this new disease activity under control. More research is needed before I would feel "safe" in withdrawing treatment. Is it worth taking the gamble?

I believe that this decision, like other MS-treatment choices, should be a "shared decision" between the doctor and the patient. There is no "one size fits all" with MS treatments. Most disease-modifying therapies are only in the body for a few days. If you do stop your Copaxone, I would suggest close monitoring for a possible increase in your MS disease activity, including an MRI evaluation. Should it occur, the MRI may detect early disease re-activation.

Q: In an earlier issue of *The Motivator*, I read that a woman was having trouble confirming if she has MS. I have been experiencing the same problem for the past two years. I am still getting tested, and even though the MRI showed that I have lesions, the doctors have told me that this is due to my diabetes. Do people with diabetes have brain lesions similar to people with MS?

A: Sometimes it is difficult to distinguish between MS and diabetes with brain lesions as shown on an MRI. However, many details can help to differentiate the two conditions. Some patients with diabetes may have MRI brain lesions due to small areas of ischemia (decreased blood flow), which may be confused with MS damage and vice versa. Often the neuro-radiologist can differentiate MS lesions from those with diabetes, when considering details such as lesion size, location, and with MS, their enhancement with gadolinium dye.

MRI damage seen in the spinal cord is most likely MS. Do you have lesions in your spinal cord? Spinal fluid analysis can often help to separate the two diseases, as can the responses in an eye test called "visual evoked potentials." Additionally, MS usually causes relapses or attacks that affect various parts of the body. Diabetes lesions are often but not always "silent," with no obvious flare-ups (relapses). MS symptoms usually begin before age 40, while lesions with diabetes often develop later.

In summary, while there is not one specific test for MS, findings from your medical/neurological history, physical examination, MRI of the brain and spinal cord, spinal fluid analysis, visual evoked response test, and other tests can usually allow an MS expert to sort out the diseases. I also want to note that some MS patients also have diabetes, so these individuals would need to be treated for both illnesses. An opinion from a neurologist/MS expert is best in this type of situation.

To Submit Questions…

Please submit your questions to:

MSAA
Questions for Ask the Doctor
c/o Dr. Jack Burks
706 Haddonfield Road
Cherry Hill, New Jersey 08002

Readers may also send in questions via email to **askdr@mymsaa.org.** Please be sure to write "Ask the Doctor" in the subject line.

Q: I am a 77-year-old mother of five. Two of my sons have died (one as a newborn) and another at age 27 (autopsy showed multiple blood clots). My surviving son is 57, disabled with heart problems, and has many symptoms of MS, but has not been diagnosed. My two daughters, ages 58 and 51, both have advanced MS – one with relapsing-remitting MS and the other with progressive MS.

My older children have a different father than my younger children. My first husband

died in a car accident, and my second husband (also deceased) had Parkinson's disease, as did his father. While I have no signs of MS, my maternal grandmother had a condition that may have been MS and left her bedridden for many years. Has the medical community come to any conclusions as to whether or not MS is hereditary?

A: This is an important question and thank you for bringing it our readers' attention. Yes, a connection does exist between genetic factors, environmental factors, and infectious factors relating to the risk of getting MS.

Specifically, about 400 genes, mostly related to the regulation of the immune system, have been identified as being associated with MS susceptibility. This is a small number of genes compared to the entire gene pool.

What is the overall risk in the United States? Generally, the risk of MS in our country is about one in 1,000 people. If a close, blood relative has MS, the risk increases to 1 to 2 percent. If a non-identical twin has MS, the risk is 2 to 5 percent. For identical twins, if one has MS, the other twin has about a 30-percent risk for developing MS.

Caucasians have a higher risk than non-Caucasians. Women have a higher risk than men. Other risk factors may be related to a virus or viruses. Epstein-Barr virus is a leading candidate for association with MS risk. Smokers have a higher risk than non-smokers. And people with low vitamin D have a higher risk than people with normal Vitamin D.

In summary, many risk factors have been associated with MS. While genetics is among these factors, so far, no single "MS gene" has been found. Nonetheless, other risk factors can be lessened by not smoking and treating a Vitamin D deficiency with prescribed supplements. Research continues into the risk factors for MS. ◆

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 clinical professor of neurology at the Florida International University in Miami and has authored textbooks, chapters, and articles on MS.


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When it comes to relapsing-remitting multiple sclerosis (RRMS)...

I DON'T MS AROUND.

My RRMS treatment has a proven track record of reducing the number of relapses. And I know that it's working for me.

I also know I've got support because BETAPLUS® has got my back: Hey, I can talk to an MS-certified BETA Nurse at any time, 24/7!

I get support tools I can really use... and how great is a $0 copay?* Believe me, I can really use that, too!

BETASERON® (interferon beta-1b) is a prescription medicine used to reduce the number of relapses in people with relapsing forms of multiple sclerosis (MS). This includes people who have had their first symptoms of multiple sclerosis and have an MRI consistent with multiple sclerosis. BETASERON will not cure MS but may decrease the number of flare-ups of the disease.

My medicine is BETASERON.
Because when it comes to RRMS,
I DON'T MS AROUND.

IMPORTANT SAFETY INFORMATION

Do not take BETASERON (interferon beta-1b) if you are allergic to interferon beta-1b, to another interferon beta, to human albumin, or mannitol.

Please see additional Important Safety Information and brief summary of Medication Guide on following pages.

BETASERON®
(interferon beta-1b)
0.3 mg for SC injection

Model used for illustrative purposes only.

DON'T MS AROUND. Talk to your doctor and see if BETASERON is right for you.
Visit **ExploreBETASERON.com** today

IMPORTANT SAFETY INFORMATION (continued)

BETASERON can cause serious side effects, including:

Liver Problems Including Liver Failure. Symptoms of liver problems may include yellowing of your eyes, itchy skin, feeling very tired, flu-like symptoms, nausea or vomiting, bruising easily or bleeding problems. Your healthcare provider will do blood tests to check for these problems while you take BETASERON.

Serious Allergic Reactions. Serious allergic reactions can happen quickly and may happen after your first dose of BETASERON or after you have taken BETASERON many times. Symptoms may include difficulty breathing or swallowing, swelling of the mouth or tongue, rash, itching, or skin bumps.

Depression or Suicidal Thoughts. Call your healthcare provider right away if you have any of the following symptoms, especially if they are new, worse or worry you: thoughts about suicide or dying, new or worse depression (sinking feeling or sadness), new or worse anxiety (feeling uneasy, nervous or fearful for no reason), trouble sleeping (insomnia), acting aggressive, being angry, or violent, acting on dangerous impulses, hallucinations, other unusual changes in behavior or mood.

Other possible serious side effects with BETASERON include:

Heart Problems. BETASERON may worsen heart problems including congestive heart failure. Symptoms of heart problems may include swollen ankles, shortness of breath, decreased ability to exercise, fast heartbeat, tightness in chest, increased need to urinate at night, not being able to lay flat in bed.

Injection Site Problems. Serious skin reactions can happen in some people including areas of severe damage to skin and the tissue below the skin (necrosis). These reactions can happen anywhere you inject BETASERON. Symptoms of injection site problems may include swelling, redness, or pain at the injection site, fluid drainage from the injection site, breaks in your skin or blue-black skin discoloration. Change your injection site each time you inject BETASERON as it will lessen the chance of you having a serious skin reaction. Avoid injecting BETASERON into an area of the skin that is sore, reddened, infected or has other problems.

Flu-like Symptoms. BETASERON can cause flu-like symptoms including fever, chills, tiredness, sweating, muscle aches when you first start to use it. These symptoms may decrease over time. Taking medicines for fever and pain relief on the days you are using BETASERON may help decrease these symptoms.

Seizures. Some people have had seizures while taking BETASERON, including people who have never had seizures before. It is not known if the seizures were related to MS, to BETASERON, or to a combination of both. If you have a seizure after taking BETASERON call your healthcare provider right away.

Blood Problems. You may have a drop in the levels of infection-fighting white blood cells, red blood cells, or cells that help you form blood clots. If drops in levels are severe, they can lessen your ability to fight infections, make you feel tired or sluggish or cause you to bruise or bleed easily.

Risk to Pregnancy:

BETASERON can harm your unborn baby. BETASERON may cause you to lose your baby (miscarry). If you become pregnant while taking BETASERON call your healthcare provider right away. You and your healthcare provider should decide if you should continue to take BETASERON.

Most Common Side Effects:

The most common side effects of BETASERON include low white blood cell count, increases in your liver enzymes, headache, increase in your muscle tension, pain, rash, problems sleeping, stomach pain, weakness. These are not all the possible side effects of BETASERON.

Tell your healthcare provider if you have any side effect that bothers you or that does not go away. Tell your healthcare provider about all the medicines you take and your medical conditions.

Please see brief summary of 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.

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*Some restrictions apply. Please visit **www.BETASERON.com/affordability** or call **1-800-788-1467** for more information. Patients who are enrolled in any type of government insurance or reimbursement programs are not eligible. As a condition precedent of the copayment support provided under this program, eg, copay refunds, participating patients and pharmacies are obligated to inform insurance companies and third-party payors of any benefits they receive and the value of this program, as required by contract or otherwise. Void where prohibited by law, taxed, or restricted. Patients enrolled in Bayer's Patient Assistance Program are not eligible.

Bayer HealthCare

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BETASERON®
(interferon beta-1b)
For injection
0.3 mg per vial
For subcutaneous injection

Brief Summary of Medication Guide BETASERON (bay-ta-seer-on)
interferon beta-1b
(in-ter-feer-on beta-one-be)

Read this Brief Summary of the Medication Guide. For more information read the full Medication Guide and talk with your healthcare provider about your medical condition or your treatment.

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

BETASERON can cause serious side effects, including:

- **liver problems including liver failure.** Symptoms of liver problems may include:
  yellowing of your eyes, itchy skin, feeling very tired, flu-like symptoms, nausea or vomiting, bruising easily or bleeding problems.

Your healthcare provider will do blood tests to check for these problems while you take BETASERON.

- **serious allergic reactions.** Serious allergic reactions can happen quickly and may happen after your first dose of BETASERON or after you have taken BETASERON many times. Symptoms may include:
  - difficulty breathing or swallowing
  - swelling of the mouth or tongue
  - rash, itching, or skin bumps
- **depression or suicidal thoughts.** Call your healthcare provider right away if you have any of the following symptoms, especially if they are new, worse, or worry you:
  - thoughts about suicide or dying
  - new or worse depression
  - new or worse anxiety
  - trouble sleeping (insomnia)
  - acting aggressive, being angry, or violent
  - acting on dangerous impulses
  - hallucinations
  - other unusual changes in behavior or mood

What is BETASERON?

BETASERON is a prescription medicine used to reduce the number of relapses in people with relapsing forms of multiple sclerosis (MS). This includes people who have had their first symptoms of multiple sclerosis and have an MRI consistent with multiple sclerosis. BETASERON is similar to certain interferon proteins that are produced in the body. It will not cure your MS but may decrease the number of flare-ups of the disease.

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

Who should not take BETASERON?

Do not take BETASERON if you are allergic to interferon beta-1b, to another interferon beta, to human albumin, or mannitol. See the end of this leaflet for a complete list of ingredients in BETASERON.

What should I tell my healthcare provider before taking BETASERON?

Before you take BETASERON, tell your healthcare provider if you:

- have or have had depression (sinking feeling or sadness), anxiety (feeling uneasy, nervous, or fearful for no reason) or trouble sleeping
- have or have had liver problems
- have or have had blood problems such as bleeding or bruising easily, low red blood cells (anemia) or low white blood cells
- have or have had seizures
- have or have had heart problems
- are pregnant or plan to become pregnant. BETASERON can harm your unborn baby. BETASERON may cause you to lose your baby (miscarry). If you become pregnant while taking BETASERON call your healthcare provider right away. You and your healthcare provider should decide if you should continue to take BETASERON.
- are breastfeeding or plan to breastfeed. It is not known if BETASERON passes into your breast milk. You and your healthcare provider should decide if you will take BETASERON or breastfeed. You should not do both.

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

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

What are the possible side effects of BETASERON?

BETASERON may cause serious side effects. Call your healthcare provider right away if you have any of the serious side effects of BETASERON including:

- **See "What is the most important information I should know about BETASERON?"**
- **heart problems**. BETASERON may worsen heart problems including congestive heart failure. Symptoms of heart problems may include:
  swollen ankles, shortness of breath, decreased ability to exercise, fast heartbeat, tightness in chest, increased need to urinate at night, not being able to lay flat in bed.
- **injection site problems**. Serious skin reactions can happen in some people including areas of severe damage to skin and the tissue below the skin (necrosis). These reactions can happen anywhere you inject BETASERON. Symptoms of injection site problems may include:
  - swelling, redness, or pain at the injection site
  - fluid drainage from the injection site
  - breaks in your skin or blue-black skin discoloration

  It is important for you to change your injection site each time you inject BETASERON. This will lessen the chance of you having a serious skin reaction at the site where you inject BETASERON. Avoid injecting BETASERON into an area of skin that is sore, reddened, infected or has other problems.
- **flu-like symptoms.** BETASERON can cause flu-like symptoms including:
  fever, chills, tiredness, sweating, muscle aches when you first start to use it.
  These symptoms may decrease over time. Taking medicines for fever and pain relief on the days you are using BETASERON may help decrease these symptoms.
- **seizures**. Some people have had seizures while taking BETASERON, including people who have never had seizures before. It is not known if the seizures were related to their MS, to BETASERON, or to a combination of both. If you have a seizure after taking BETASERON call your healthcare provider right away.

The most common side effects of BETASERON include:

low white blood cell count, increases in your liver enzymes, headache, increases in your muscle tension, pain, rash, problems sleeping, stomach pain, weakness.

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

These are not all the possible side effects of BETASERON. For more information, ask your healthcare provider or pharmacist.

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

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

General information about the safe and effective use of BETASERON.

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

What are the ingredients in BETASERON?

Active ingredient: interferon beta-1b
Inactive ingredients: albumin (human), mannitol
Diluent contains sodium chloride solution.

Manufactured for:
Bayer HealthCare

Bayer HealthCare Pharmaceuticals Inc.
Whippany, NJ 07981

Manufactured in Germany

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6800602BS 521-154-0001-14

Plegridy™ Approved for Relapsing Forms of MS

On August 15, 2014, Biogen Idec announced that the United States Food and Drug Administration (FDA) had approved Plegridy™ (peginterferon beta-1a) for the long-term treatment of relapsing forms of multiple sclerosis (MS). Manufactured by Biogen Idec, this new medication is the 11th disease-modifying therapy (DMT) to be approved for MS since the early 1990s. Plegridy is given once every two weeks through a subcutaneous self-injection.

Medication Description and Dosing

Plegridy is a pegylated version of interferon beta-1a. Pegylation is a chemical modification of a molecule (in this case the interferon beta-1a molecule) that extends its half-life, which refers to how long a drug stays active in the body before it is metabolized or eliminated. Given the longer half-life, Plegridy does not need to be taken as often as the presently approved self-injected DMTs for MS, which range from once daily to once weekly. This is the first pegylated drug to be approved for the treatment of MS.

Interferons appear to reduce inflammation by modulating a favorable balance between cells that increase inflammation and cells that decrease inflammation. They also reduce the transport of damaging lymphocytes into the brain. Lymphocytes are immune-system cells produced to fight infection and disease.

This new medication has been studied in two groups – with injections given either every two weeks or every four weeks; the two-week dosing was submitted and selected for approval. Additionally, the 125-mcg dose is administered subcutaneously, which is easier and more comfortable than intra-muscular injections, using either the Plegridy Pen (a ready-to-use autoinjector) or a prefilled syringe.

Study Results and Side Effects

Plegridy was submitted to the FDA based on the results from the first year of the two-year ADVANCE study. This Phase III clinical trial is an international multi-center study, which is placebo-controlled and double-blinded (so neither the patients nor the treating professionals know who is getting the active treatment). During the first year of this two-year study, the 1,512 participants with relapsing-remitting MS (RRMS) were randomized to receive either the active drug or the placebo, given either once every two weeks or once every four weeks. After the first year of the study, those given a placebo were switched to the active drug.

According to MSAA's 2014 edition of its *MS Research Update* (written by Stephen Krieger, MD and reviewed by MSAA Chief Medical Officer Jack Burks, MD), "Plegridy dosed every two weeks significantly reduced MS disease activity versus placebo. Relapses [the annual relapse rates] were reduced by 36 percent, and new brain lesions by 67 percent, compared to placebo at one year. Disability outcomes were also positive in this one-year trial. In total, the proportion of disease activity-free patients over one year was significantly higher in the two treatment groups compared to placebo."

According to Biogen Idec's press release issued on August 15th, Plegridy reduced the risk of 12-week confirmed disability progression, as measured by the Expanded Disability Status Scale (EDSS), by 38 percent compared to placebo. In addition to reducing the new or newly enlarging T2-hyperintense lesions by 67 percent (as noted in the prior paragraph), Plegridy also reduced the number of new gadolinium-enhancing lesions by 86 percent compared to placebo.

According to Biogen Idec's press release, in addition to injection-site reaction and flu-like illness, more specific common adverse reactions included fever, headache, muscle pain, chills, injection-site pain, weakness, injection-site itching, and joint pain. The pharmaceutical company also notes that the two-year safety data from the ADVANCE study were consistent with safety results observed in year one.

For more information, please see MSAA's full online article at **http://mymsaa.org/news-msaa/1165-plegridy-approved** (or by going to MSAA's website at **mymsaa.org** and selecting this article under "News from MSAA"). Readers without internet access may call MSAA at **(800) 532-7667** to request a copy of the online article. ◆

Written by Susan Wells Courtney

Reviewed by Jack Burks, MD,
MSAA Chief Medical Officer

Highlights from the 2014 Joint ACTRIMS-ECTRIMS Meeting

Every three years, two international organizations come together to discuss the most recent research findings in the area of MS. The sixth joint conference of ACTRIMS (Americas Committee for Treatment and Research in Multiple Sclerosis) and ECTRIMS (European Committee for Treatment and Research in Multiple Sclerosis) took place in Boston in September. This summary focuses on topics of particular interest to the MS community. Only a fraction of the more than 1,700 scientific papers and almost 200 presentations will be addressed in this article.

Experimental Therapies

Lemtrada® (alemtuzumab, formerly Campath), is given intravenously each day for five days, and again one year later, daily for three days. Lemtrada has been submitted to the United States Food and Drug Administration (FDA) for approval; a decision is expected in late 2014. The majority of patients treated with Lemtrada (alemtuzumab) in the CARE-MS I study (a Phase III comparison of alemtuzumab and Rebif in treatment-naïve patients) were free of new brain lesions and MRI activity at year three. Although the majority of the patients did not receive treatment after the first two yearly courses of Lemtrada, most continued to experience a slowed yearly rate of brain volume loss over three years.

Laquinimod is an oral medication taken once daily under investigation for the treatment of RRMS. In the Phase III BRAVO trial, treatment with laquinimod resulted in a significant reduction in brain atrophy (a reduction in both grey matter and white matter in the brain) compared to placebo. Using pooled data from the ALLEGRO and BRAVO trials, researchers determined that laquinimod demonstrated significant benefits in relapse rate, disability, walking, and MRI outcomes in patients with RRMS with EDSS (Expanded Disability Status Score) scores more than 3, which is a level where the individual is able to walk but experiences difficulties in other areas.

Daclizumab (also known as Zenapax®) is given by intravenous infusion every four weeks and is also studied when given in subcutaneous injections. This medication is under investigation for the treatment of both RRMS and secondary-progressive MS (SPMS). Primary results were reported for the DECIDE study in which 1,841 RRMS patients were randomized to treatment with either Avonex (interferon beta-1a) 30 mcg every week or daclizumab HYP (high-yield

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process) 150 mg every four weeks, both delivered by subcutaneous injection (under the skin). Treatment with daclizumab resulted in a 45-percent reduction in annualized relapse rate (ARR), a 54-percent reduction in new and newly enlarging T2 lesions, and a 65-percent reduction in new gadolinium-enhancing lesions. Risks associated with daclizumab treatment were infections, rash dermatitis, and liver enzyme abnormalities.

Generic Disease-Modifying Therapies

A nine-month randomized, double-blind trial of 794 people with RRMS, called "GATE," demonstrated that generic glatiramer acetate was equivalent to Copaxone® and superior to placebo in both safety and efficacy. The concept of generic versions of MS disease-modifying therapies is relatively new to the MS community, as the original drugs were protected by law to have a certain period of exclusivity. As these time periods expire, other pharmaceutical companies may look to provide similar drugs. MSAA published an online article on this topic, titled "The Issues Surrounding Generic Versions of MS Drugs." This may be viewed by going to MSAA's website at **mymsaa.org** and selecting this article below "News from MSAA."

Other Topics

OCT: Optical coherence tomography (OCT), a non-invasive imaging test that uses light waves to take cross-section pictures of the retina, might help determine brain atrophy without the need for a brain MRI. Researchers found that certain changes in the retina accurately reflected grey matter atrophy in the whole brain, especially in those with progressive MS.

Parasitic Infections and MS: Parasite infection was found to be protective against MS disease activity in a group of 12 parasite-infected MS patients. Compared to those not infected, parasite-infected MS patients experienced a significantly lower number of relapses, a lower change in EDSS scores, and fewer brain lesions on MRI. Conversely, when treated with anti-parasitic drugs, the parasite-infected group experienced worsening of their disease.

Gut Microbial Environment: Studies have related gut dysbiosis (an imbalance in the micro-organisms in the gut resulting from too few good bacteria and/or too many harmful bacteria) with development or severity of many conditions including Crohn's disease, type I diabetes, obesity, and autism. The Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Hospital in New York City and University of California San Francisco MS Center are collaborating to study whether gut dysbiosis may have an impact on MS.

Iron Deposits: Neurodegeneration (injury to nerves) is associated with the accumulation of iron in the oligodendrocytes (cells that produce and repair myelin), and appears to contribute to disability in MS. Brain tissue from individuals who died from complications of MS showed that iron was primarily stored in the oligodendrocytes.

Remyelination: Signs of remyelination (myelin repair) may be present even in cases of profound axonal (nerve) damage. Examination of brain biopsy tissue from patients with early MS (obtained to exclude diseases such as infection or cancer) revealed that signs of remyelination are sometimes present, despite the fact that these lesions were mainly demyelinated (where myelin is no longer present).

Although remyelination occurs, it is often not sufficient to prevent irreversible damage and progressive disability. Researchers are beginning to understand the steps in the remyelination process. Oligodendrocyte progenitor cells (OPC) have been identified as one of the main cell types responsible for remyelination. These cells can now be identified through the use of certain markers, allowing the process to be studied in depth.

MS Treatment with Myelin Peptide Skin Patches: MS treatments that could more specifically inhibit the inflammatory activity of the immune system would potentially represent an improvement over current medications that have a more global effect. To that end, researchers tested a myelin peptide-infused skin patch in two different doses compared to a placebo, to determine whether it could help stop the inflammatory response that can result in damage to the brain.

The patches strongly suppressed the inflammatory response and also resulted in a positive clinical effect. Compared to the placebo group, patients in the treated group had positive responses with respect to the number of brain lesions, annual relapse rate (ARR), the number of individuals who were relapse free, disability, and EDSS scores. There were no serious adverse events. Redness and itching in the local area of the patch was observed in 20 percent of the patients in the treatment group.

Stem Cells: Results of a Phase I safety study of stem cell transplantation were reported. Twenty-four patients with RRMS or SPMS, who had EDSS scores of 3.0 to 6.5, received a single IV infusion of mesenchymal stem cells that were derived from their own bone marrow. No significant safety issues resulted and no serious or severe adverse events occurred; there were minimal infusion-related side effects.

The trial was not designed to test efficacy and there was no evidence of either disease activation or improvement with respect to brain lesions or any other measures tested. The safety study was successful, but before Phase II trials are considered, many questions need to be addressed. Issues of cell dose, route of administration, number of infusions, and whether to use cells from the patient or a disease-free donor, are all questions to be resolved. ◆

*To view this article in its entirety, please see this item under "News from MSAA" at **mymsaa.org**.*

Written by Margaret M. McCormick, RN, BSN, MSCN

Reviewed by Jack Burks, MD, MSAA's Chief Medical Officer

by Peter Damiri
Vice President of Programs and Services

Know Your Insurance Options

MSAA proudly announces the creation of a new addition to the **mymsaa.org** website, dedicated exclusively to helping the MS community better understand and utilize health insurance. Titled, My Health Insurance Guide, this comprehensive online resource center offers a wealth of easy-to-follow information about the Health Insurance Marketplace under the Affordable Care Act (ACA), Medicare, Medicare Advantage, and Medicaid.

This initiative is supported by unrestricted educational grants from: Biogen Idec; Genentech; Genzyme, a Sanofi company; and Novartis Pharmaceuticals Corporation. The new section of MSAA's website divides content into targeted areas covering private insurance and Medicare. With the goal of making complex information easier to understand, My Health Insurance Guide includes a useful glossary of common insurance terms, helpful questions to ask and points to consider when looking at plan coverage, steps for appealing a denial, and downloadable brochures on the ACA Marketplace and Medicare. It also provides two archived webinars, and a brand-new educational video titled, "What You Need to Know About the Affordable Care Act."

This on-demand video is made possible through support from Teva Neuroscience. The video features MS neurologist Dr. James Bowen and a nationally recognized health insurance expert addressing the specialized healthcare needs of the MS community. These two experts also provide insights into making informed policy selections in the 2015 Marketplace.

For individuals looking to learn more about Medicare, the website provides extensive information on Original Medicare (Parts A & B) with the option of purchasing a prescription plan (Part D), Medicare Advantage Plans (Part C), as well as supplemental Medigap policies. Guiding individuals throughout the site are easy-to-follow charts and numerous resources with direct links to **Medicare.gov** as well as other nonprofit organizations.

With open enrollment for the Health Insurance Marketplace and Medicare coming soon, MSAA encourages you to visit My Health Insurance Guide at **mymsaa.org/healthinsurance** or call **(800) 532-7667, ext. 154** and speak to one of our Client Services Specialists. The more you know, the better prepared you will be to obtain the best healthcare possible and help stay on top of this complex and ever-changing disease.

Finding Resources to Help on Your MS Journey

Whether you are newly diagnosed or have been living with MS for many years, MSAA understands that each person's journey with multiple sclerosis is unique and ever changing. Because of the complexity and uncertainty of the illness, it can also be challenging to find information that matches where you are in your journey with MS.

Recognizing the need to help the MS community find a clear, direct path to the information they need now, MSAA is currently working to develop a new section on our website titled, My MS Journey. Made possible through support from Teva Neuroscience, My MS Journey will organize MS-specific content and information into three distinct channels:

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

We anticipate launching My MS Journey by the end of 2014. Please check our website, **mymsaa.org**, in the coming months! ◆

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Thoughts about Giving

by Kimberly Goodrich
Senior Director of Development

Let Us Help You Help Others

In previous articles in *The Motivator* and posts on our blog, MS Conversations, I have talked about the current controversy over whether charity ratings are really helpful in giving a true picture of an organization's effectiveness in meeting their mission. Does a number or a star really help you know if a nonprofit is having an impact?

Earlier this summer, I attended a luncheon on this topic with Steve Nardizzi, CEO of Wounded Warrior Project (WWP). Nardizzi gave several examples where ratings from charity watchdogs were not helpful in determining if an organization is meeting its mission. In some cases, the ratings were even misleading. One example was the Central Asia Institute, formerly run by Greg Mortenson, co-author of *Three Cups of Tea*. During the time that Mortenson was ordered to pay back more than one million dollars in misused funds, his organization had a four-star rating. How does this help us decide where our dollars should go?

Eight years ago WWP had higher charity ratings than it does today. But at that time they had only 10 million dollars to spend on their programs for wounded veterans. To spend more, they needed to raise more, but feared that if they spent more money on fundraising it would affect their ratio of fundraising and administrative costs as compared to program expenses. This created a vicious cycle many nonprofits find themselves in – they want to do more to serve their mission, but are unable to invest in things that help businesses grow – such as staff training, recruitment, and new fundraising ideas that may take time to build.

Last year, MSAA provided diagnostic MRI assistance to 70 percent more people than the year before. Our mobile phone app was downloaded by an additional 7,000 people who now use it to track their symptoms and improve their daily lives. These are increases we are proud of and that make the decision to invest in additional fundraising streams worthwhile.

Today WWP continues to grow despite mediocre ratings and higher percentages spent on overhead. Why? Because its supporters see the incredible impact they are having on the lives of wounded veterans. By making a conscious effort to invest in fundraising, marketing, and staff, WWP now has lower ratings with the charity watchdogs, but they now have 176 million dollars to spend on their programs for wounded veterans. By ignoring the ratings and focusing their resources on their mission, more veterans are helped. And really, isn't that what it's all about?

At MSAA our mission is to improve the lives of those living with MS. Like WWP, the amount we spent on fundraising last year went up. Some think this is bad. However, MSAA's increase in fundraising helped our overall ratings to go up with some of the charity rating agencies.

This increase in fundraising led to a significant increase in revenue (16.5-percent growth last year). This increase in revenue in turn allowed us to help more people living with MS. We provided diagnostic MRI assistance to 70 percent more people than the year before. Our mobile phone app was downloaded by an additional 7,000 people who now use it to track their symptoms and improve their daily lives. These are increases we are proud of and that make the decision to invest in additional fundraising streams worthwhile. ◆

Submit Your Best Work for MSAA's 2015

Art Showcase

Flowers in Pot
Tammy Jennings
Monterey, CA

Autumn Still Life
David Desjardins
Union, ME

*This year, MSAA is launching the **Four Seasons Showcase**, in addition to our annual **MS Ability Art Showcase**.*

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

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

For more information, contact:
Angel Serrano, MSAA
706 Haddonfield Road
Cherry Hill, NJ 08002
Email: showcase@mymsaa.org
Phone: (800) 532-7667, ext. 117

Artwork will be featured on MSAA's website beginning March 2015 in recognition of MS Awareness Month. Each month we will highlight one artist and his or her work.

Submissions will be accepted until December 18, 2014.

*For submission guidelines, please visit **support.mymsaa.org/artshowcase**.*

A Psychologist's Perspective of His Own MS

People in any career field may develop multiple sclerosis – it does not discriminate – and this includes doctors too. **Mack Stephenson, PhD** is a psychologist who began exhibiting the symptoms of MS while in the service, although he was not diagnosed until after leaving the Navy. As both a doctor and a teacher, he decided to learn about the disease and its treatments, and then write about his experiences and observations. To follow are some key passages from Dr. Stephenson's book. We're also proud to feature someone who served our country.

The Ability to Find Meaning in Our Lives: "It can at times be a struggle to find meaning in our experiences and in our lives. And yet our own personal search for meaning is incredibly important both for ourselves and for those close to us (especially our children, of whatever age, and our spouse). There are various places to get this kind of wisdom…

"Maybe your source of wisdom is your friends. Maybe it is your family. Maybe it is your church. Maybe it is your books… But whatever the source, you need to tap into it, to access it. You need help and support from outside of yourself. But I would certainly say (and think it is crucially important) that it would be much better for you to make sure that you are not socially isolated. That is just a recipe for sadness and misery, not to mention bitterness."

Know Your Limitations: "My wife has become a very good 'handyman.' You know that 'honey-do' list? Well, I'm doing hardly any of it anymore… She was always pretty handy, but lately she's been pressed into service quite a bit.

"I have a large cast-iron clock on my wall. It is probably three feet in diameter. One day, the battery needed to be replaced. When my wife came home, I was standing on a ladder trying to get the wall clock down from the wall. I think her exact words when she walked in were, 'What on earth are you doing?' She didn't say, 'You fool,' but I could hear it in her voice. And she meant it... I'm not stupid or anything. Disabled and walk funny, yes. Stupid, no… My neurologist called this, 'impulsiveness'…

"I've just got to say that a man's got to know his limitations…. A good example of this is that a little while ago I bought a new bike for my son. It was really nice. As I looked at it, I thought, 'I can ride that stupid thing. DUH!' I was wrong. Then I figured it was just a fluke that I fell the first time. Wrong again. I should have been wearing a helmet. As we walked in the door, I told him to make sure that he didn't tell his mother. She would certainly not like what I had done. That little bugger immediately went in and ratted me out. I think it was the first thing he did. You just can't trust kids these days… And to be honest, that is a hard thing (the limitations, not the trust). You may not even realize that something is a problem until you are well into it…"

Opening the World through Technology: "I used to be a university professor. I would lecture in front of a class... I loved it. But actually, I can do the same thing over a tablet computer and an Internet connection. I don't need to actually *drive* to the university and traipse across campus to get to a classroom. Heck, I can teach students from my living room!

"And speaking of technology, how about an electric wheelchair? …I never thought that I would value it so greatly… I can now go to the mall with my wife or children. I have independence, and don't need someone else to push me around. I think it is easy to miss the fact that independence is very important and meaningful… Another issue is my phone. I text my daughters a lot. I use texts a lot for my business. But I hardly ever type the text. I just dictate it. Can I tell you how much nicer that is for me?

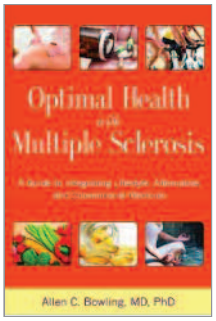
"Much of my personal wisdom and insight would simply not be available to other people were it not for technology. It would be lost along with my walking ability. So there is a *human* capital issue here. There is a lot I can give, but much of that is made possible only through technology... For me, technology is about opening my world."

Life Changes: "MS is a difficult disease. Actually, I don't think there is an easy one, and it is important for you to recognize that everyone has significant life challenges. But there are still things you can do to make life better. Do those things... Take care of yourself. Pay attention to your eating, sleeping, and exercise… Make sure you have good relationships with the important people in your life. You don't want to get caught up in the bickering or the pain of holding a grudge.

"Be easy on others. They are doing the best they know how… We need to understand that it can be very frustrating to be so dependent on others. Heaven knows that I get that. But that might be one of the challenges that you face. It may address one particular weakness you have. So learn from it. I believe that such learning is a major reason that we are even here on the earth… In receiving help, we may help others to actually do what is good. So we need to understand that asking for help may actually be of benefit to others. Don't exclude them from the opportunity to serve." ◆

Dr. Stephenson has a PhD and one year of post-doctoral study at Harvard Medical (Children's Hospital). He spent seven years in the United States Navy, running the special education diagnoses for 12 Department of Defense schools on a remote island overseas. He has been a teacher, has worked for the family courts, was President of his state's Psychological Association, and ran a very successful private practice. He has a wonderful wife and four great children. You're Going To Rio: A Psychologist's Journey In Multiple Sclerosis, by M.B. Stephenson, PhD, is available on Kindle and may be purchased by going to ***www.amazon.com.***

Optimal Health with Multiple Sclerosis



Written by Allen C. Bowling, MD, PhD
Published by Demos Health
MSAA Book #354

For many years, Dr. Allen Bowling has been a prolific writer of books on treating MS – many of which feature complementary and alternative medicine – as well as details on conventional medicine and symptom management. In his latest book, Dr. Bowling provides a seven-step guide to integrating lifestyle, alternative, and conventional medicine.

Every major symptom of MS is addressed, along with research and information on various types of harmful conditions (such as alcohol, smoking, and toxins) and countless forms of alternative therapies (this includes biofeedback, homeopathy, pets, and supplements, to name a few). This enormous resource is extremely reader-friendly and each section includes lists of books and articles for additional reading. In addition to borrowing this book from MSAA's free Lending Library, this book may also be purchased through **www.demoshealth.com/store**.

MS Madness!

Written by Yvonne deSousa
Published by SDP Publishing
MSAA Book #411

Subtitled "A 'Giggle More, Cry Less' Story of Multiple Sclerosis," *MS Madness!* is an enjoyable book for anyone looking to uncover the lighter side of MS. Authored by a woman with MS, the story is written in a conversational tone, connecting the reader with her many unique encounters and entertaining perspectives. Ms. deSousa takes readers on her journey through her daily events, including her relationships, school and work, doctor visits, and much more, all while sharing her comical thoughts on how she interprets the sometimes bizarre situations.

When the pharmacist refuses to give her a large prescription of Vitamin D at one time – making her return to the pharmacy every few days – she wonders if he thought she was going to try to sell it illegally to "unsuspecting folks who were already drinking their fair share [of Vitamin D] in their milk." Not only can members of the MS community relate to her physical, cognitive, and emotional ups and downs, but readers will find themselves laughing out loud throughout the book. In addition to borrowing this book from MSAA's free Lending Library, this book may be purchased through **www.amazon.com**.

*To borrow books featured in this column or any other book in **MSAA's Lending Library**, please visit **mymsaa.org/library** to view a list of books available and to complete a form. When ordering a book, please reference the book number listed. Readers may also call MSAA at **(800) 532-7667** for more information. MSAA and its clients greatly appreciate any donations made to help build the Lending Library. Please send your book donations to: **MSAA Lending Library, 706 Haddonfield Road, Cherry Hill, NJ 08002**.*

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706 Haddonfield Road
Cherry Hill, NJ 08002 USA

CHANGE SERVICE REQUESTED

Watch for MSAA's **Year-End Events!**

November and December are busy months for MSAA! Here are a few highlights:

November 13: Voting begins for our fun **Thanksgiving eCard competition**. Each year, MSAA posts a variety of colorful online greeting cards, and website visitors are invited to vote for their favorite ecard!

November 24: The **winning card is revealed,** but the full selection of free eCards will be available to email to friends and family!

November 27: Happy Thanksgiving!

December 1: Cyber Monday, where online shoppers find great savings… please be sure to go to Amazon Smile at **smile.amazon.com**, where MSAA will receive a portion of the profits when signed on as your favorite charity!

December 2: Giving Tuesday, when everyone is encouraged to give. MSAA's programs and services are funded solely through contributions, so **your donations are urgently needed to provide vital assistance to the MS community**.

December 31: Last day to give to MSAA in 2014 for **Improving Lives Today!**

Donations are gratefully accepted via:

- Online at **mymsaa.org**
- Phone at **(800) 532-7667, ext. 146**
- Mail to:
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