


MSAA

Winter/Spring 2012

# The **MOTIVATOR**

Bringing Information to People with Multiple Sclerosis



*The Benefits of*  
**Physical and  
Social Activity**

Published by the Multiple Sclerosis Association of America

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QR-code enabled smartphone users may scan this image to view this issue of *The Motivator* on their mobile device.



The Multiple Sclerosis Association of America's mission is to enrich the quality of life for everyone affected by multiple sclerosis.

MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

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*Douglas G. Franklin*

**S**pring is in full bloom and summer is just around the corner! Here at MSAA, our signature fundraising event, Swim for MS, is gearing up for Summer 2012 with a new program, the Swim for MS Pool Party. With a goal of collectively raising \$100,000 in 100 days from swimmers across the country, the Swim for MS Pool Party allows you the freedom to customize your own special swim event. Just select a date, register, and host your “party” between Memorial Day weekend and Labor Day weekend. You can be as creative as you like. From simply swimming laps in your community pool, to organizing your own backyard “cannonball” or “Marco Polo marathon” fundraiser, the Swim for MS Pool Party has something to offer everyone! To register to host your “party,” or for more information about the Swim for MS Pool Party, please visit [www.msaapoolparty.org](http://www.msaapoolparty.org) or email [msaapoolparty@msassociation.org](mailto:msaapoolparty@msassociation.org). Dive into action to make a difference for everyone affected by MS!

One of the cornerstones of MSAA’s mission is bringing the best resources to the MS community. I am pleased to announce that MSAA has launched *My MS Resource Locator*, a unique database of information specifically geared to the MS community. Accessible at [resources.msassociation.org](http://resources.msassociation.org), *My MS Resource Locator* contains listings of national, state, and where appropriate, local resources to help connect you to the information and services you need. More information on this exciting initiative can be found in the “Program Notes” section of this edition of *The Motivator*.

In other programming news, our mobile phone application *My MS Manager*<sup>™</sup> was honored by the **Web Health Awards | MOBILE** with a Merit Award in the category of Mobile Application (for) Chronic Disease Management. To receive such an award for our first-ever mobile phone initiative is a great accomplishment! With this news, I am excited to announce that *My MS Manager* will soon be available to the Android market. Please check [www.msassociation.org](http://www.msassociation.org) for its official release. ♦

*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. He currently serves on the National Board of the Key Philanthropic Organizations Committee of the American Society of Association Executives; on the Executive Committee of Health First – America’s Charities Board in Washington, DC; and as President of the Multiple Sclerosis Coalition.*

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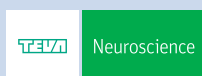
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# THE BENEFITS OF PHYSICAL AND SOCIAL ACTIVITY

The importance of filling your life with the activities and people you value

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**R**emaining active and engaged in life can be challenging with any chronic condition, including multiple sclerosis (MS). Despite the challenges, living a rewarding life – one that is filled with the activities and people you value – doesn't need to be out of reach. In this article, we'll discuss the benefits of physical and social activity for people living with MS, and provide some strategies for engaging (or re-engaging) in those areas.

## PART I: PHYSICAL ACTIVITY

People with MS may face major challenges when trying to resume physical activities that they enjoyed before their symptoms began. According to the article, “Physical activity and its measurement and determinants in multiple sclerosis” [RW Rotl, *Minerva Med.* 2008 Apr;99(2):157-65], “Overall, there is fairly strong and consistent evidence that individuals with MS are largely inactive compared with non-diseased populations... and the emerging research has highlighted the role of symptoms in explaining inactivity in this population.”

Although remaining active may be more difficult when experiencing symptoms, increasing one’s physical activity has the potential for significant health benefits among individuals with MS. Currently, no clear recommendations are available on the amount of physical activity that is appropriate for people with MS. Guidelines for adults without a chronic condition are 150 minutes of moderate-intensity aerobic activity (such as walking) per week, plus muscle-strengthening activities at least twice per week. The best advice is to talk to your doctor or physical therapist about the amount and type of regular physical activity that is right for you.

You may find many benefits to remaining physically active, both for your body and for your mind. Studies of individuals with MS indicate that exercise results in improved strength, reduced pain, less stress, improved mood, and greater endurance. Regular

exercise can also help prevent other diseases that can impact your life and your health. We know that exercise provides many benefits to your heart and vascular system. It can increase the efficiency of the heart, and decrease the risk of heart disease. Regular physical activity can lower blood pressure and decrease harmful (LDL) cholesterol, while increasing good (HDL) cholesterol. Exercise can also help regulate blood sugar levels and prevent diabetes. In addition, physical activity can help to maintain muscle strength, maintain bone density and reduce the risk of fracture, and regulate breathing.

Another important benefit of exercise for individuals with MS is that it can help you to maintain your current level of physical function, or perhaps even regain some of the function and strength you may have lost. For example, you might be able to strengthen your leg muscles, or improve your level of cardiovascular fitness, enabling you to remain independent and perform activities of daily living that are important to you. These may include basic, everyday activities such as bathing and dressing, taking care of things around the house, and running errands.

Remaining physically active can also improve some of the symptoms of MS. We know from research that people with MS who exercise can decrease pain and increase blood flow to the lower extremities. Exercise can also decrease hospitalizations resulting from some of the effects of MS. Exercise has been shown to improve energy levels and reduce general fatigue – an important issue for many

## FEELING YOUR BEST

individuals living with MS. Regular exercise may also help you to maintain your mental sharpness.

We also know that exercise can have a powerful impact on mood. People who are more active are less likely to experience low mood or depression. By the same token, research has shown that increasing your level of physical activity can be an effective way to improve mood. Inactivity might even contribute to the higher rates of depression we see in individuals with MS. One study

found that aerobic exercise was an effective treatment for major depression and was as effective as sertraline (the generic version of Zoloft®, an antidepressant) for treating major depression in older adults. Interestingly, people treated with exercise were significantly less likely to relapse back into a depressive episode as compared to those who only took the sertraline.

Even if you're not struggling with depression, exercise can still have a positive impact on mood and on the overall quality of your life. Physical activity is one of the most effective tools that we know of to relieve stress. Exercise can also help you to feel more in control of your MS symptoms. It can increase your self-confidence and contribute

to a healthier body image. And, depending on what kind of activities you do, exercise can provide great opportunities for social interactions. For example, you could walk regularly with a friend or neighbor, or perhaps find an exercise class designed specifically for people with MS. In many communities, there are MS aquatics programs and adapted yoga programs that are often appropriate for individuals with mobility issues.

Kathy Zackowski, PhD, OTR, MSCS is an



occupational therapist and assistant professor in the Department of Physical Medicine and Rehabilitation, Kennedy Krieger Institute, at Johns Hopkins University School of Medicine in Baltimore,

Maryland. Dr. Zackowski explains, “Individuals with MS can also take regular exercise classes and look for beginner classes. If you feel uncomfortable doing this, talk with the instructor so he or she knows to help you modify exercises or stretches that may be too difficult.”

Any exercise program needs to be appropriate for your capabilities and limitations, and may need to be adjusted as changes occur in your MS symptoms. A physical therapist experienced with the unique and varied symptoms of MS can be

helpful in designing a well-balanced exercise program, along with adjusting it in the future as needed. If you are thinking of starting a new exercise program, you should also consult with your physician to be sure the exercises will be safe for you.

Dr. Zackowski adds, “An occupational therapist can help you to make choices about how to fit in time for exercise and where in your home you can best do your exercises. He or she can also provide tips on how to conserve your energy with your daily tasks, so you have energy left for exercise.”

## ■ TYPES OF PHYSICAL ACTIVITY

Three main categories of physical activity will be reviewed in this article:

- **Stretching and flexibility**
- **Aerobic activity**
- **Strength training**

In general, a warm-up is recommended before engaging in any of these three types of activity. A warm-up just means getting your body moving for five to ten minutes. For example, you can do some light walking or wheeling, swing or punch your arms, roll your shoulders, or lightly tap your toes from side to side. Any slow and controlled movements that start to get your heart rate up will work as a warm-up.

Stretching and flexibility exercises can be done gently at the start of a workout (after you warm up), more deeply at the end of an aerobic or strength-training workout, or alone. Yoga is one example of an extended

stretching or flexibility type of workout. The gentle movements of tai chi may also be a good way to stretch. Although studies about the benefits of stretching are mixed, stretching can help you to improve your flexibility, provided your doctor approves. Better flexibility may improve your performance in physical activities (making basic activities of daily living easier) and decrease your risk of injuries by helping your joints to move through their full range of motion. Stretching also increases blood flow to your muscles.

*Here are some tips to consider when stretching:*

**Don't use stretching as a warm-up exercise.** You may hurt yourself if you stretch cold muscles. Either warm up before you stretch, or stretch after you exercise when your muscles are already warm.

**Focus on major muscle groups.** When you're stretching, focus on your calves, thighs, hips, lower back, neck, and shoulders. You may wish to focus on muscles and joints that are especially stiff from your work or play. Make sure that you stretch both sides of your body; if you stretch your left hamstring, be sure to stretch your right hamstring, too.

**Don't bounce.** Bouncing as you stretch can cause small tears in the muscle, making you less flexible and more prone to pain. Hold each stretch for about 30 seconds, remembering to relax and breathe as you wait for the 30 seconds to go by. Repeat each stretch three or four times.



**If a movement hurts, you've pushed too far.** Expect to feel tension while you're stretching, but not pain. If you feel pain, back off a bit until the pain goes away.

**Keep up with your stretching.** You can achieve the best benefits by stretching at least two to three times per week.

Aerobic exercise is any activity that increases your heart rate. This can include activities such as moderate to fast walking or wheeling, running, dancing, swimming, water aerobics, bicycling or arm cycling — the possibilities are almost endless! When you are doing aerobic exercise, monitoring your heart rate and level of exertion is very important. The three levels of intensity, or “hardness,” of exercise are light, moderate, and vigorous. In general, aiming for at least moderate-intensity exercise offers the best health benefits (again, with your doctor's approval). With moderate-level activity, you will feel as though you are working somewhat hard, but you will also feel that you can keep going for awhile. Your heart may be beating harder and faster than normal, but not extremely fast. Also, your skin may be warmer than normal and could be sweaty as well.

**Strength training** is simply moving weights or using resistance, with the goal of building muscle and bone strength. The three

basic factors in strength training are repetitions (“reps,” or the number of times you perform the move), sets (a certain number of repetitions performed in a row), and weight (the amount you are lifting, usually stated in pounds).

**Here are some tips for any strength-training regimen:**

**Start with lighter weights** until you are comfortable with the moves and your body

positioning. Whether you're sitting or standing, don't strain other parts of your body to complete the move.

**Find a weight that you can lift between 10-15 times without getting too tired.**

If you can perform more than 15 reps easily, the weight is probably too light for you. If you have trouble getting to 10 reps before tiring, try a lighter weight.

**In general, two to three sets** of any given strength-training exercise is suggested, with a short rest in between.

**Don't work the same muscle groups every day.** You can either alternate muscle groups (upper body one day, lower body the next) or take rest days in between strength-training workouts to give your muscles time to recover.


Elastic exercise bands, available from physical therapists or at sporting goods stores, are a nice alternative to hand weights.





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Talk to your doctor about AMPYRA to learn if it is right for you. Do not take it if you've ever had a seizure or if you have certain types of kidney problems as this may increase your risk of seizure. Tell your doctor if you have kidney problems.

AMPYRA may cause serious side effects including kidney or bladder infections. The most common side effects are urinary tract infection, trouble sleeping (insomnia), dizziness, headache, nausea, weakness, back pain and problems with balance. Tell your doctor if you have any of these side effects that bother you or do not go away.

This is not the full safety information. For more information, please refer to the Medication Guide on the next page. This important safety information is not meant to replace discussions with your doctor.

For more information call toll-free 1-888-881-1918

*You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.*

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Read this Medication Guide before you start taking AMPYRA.

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

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

AMPYRA can cause seizures.

- Your chance of having a seizure is higher if you take too much AMPYRA or if you have kidney problems.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See “How do I take AMPYRA?”

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

### What is AMPYRA?

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

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

### Who should not take AMPYRA?

#### Do not take AMPYRA if you:

- have ever had a seizure
- have certain types of kidney problems

### What should I tell my doctor before taking AMPYRA?

#### Before you take AMPYRA, tell your doctor if you:

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

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

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

### How should I take AMPYRA?

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

### What are the possible side effects of AMPYRA?

#### AMPYRA may cause serious side effects, including:

- Kidney or bladder infections
- See “What is the most important information I should know about AMPYRA?”

#### The most common side effects of AMPYRA include:

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

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

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

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

### How should I store AMPYRA?

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

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

### General Information about the safe and effective use of AMPYRA

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

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

For more information, go to [www.AMPYRA.com](http://www.AMPYRA.com) or call 1-800-367-5109.

### What are the ingredients in AMPYRA?

**Active ingredient:** dalfampridine (previously called fampridine)

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

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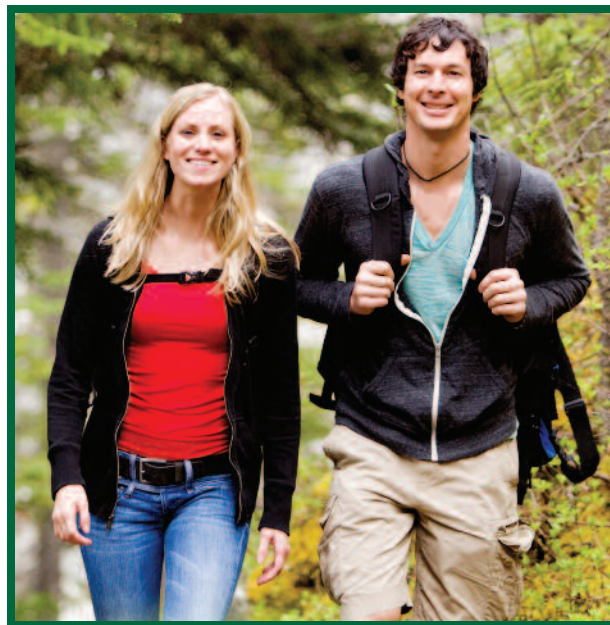
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They are inexpensive and easy to store, and come in several different resistance levels (different colors correspond to the degrees of difficulty).

## ■ SAFETY

Safety is a priority for any exercise program. Individuals with MS may need to pay particular attention to body-heat issues. If you are particularly sensitive to heat, you may consider using cooling methods while you exercise, such as a damp cloth, fan, spray bottle, or cooling vest. Heat-sensitive individuals should exercise during the cooler times of the day. People with MS also need to pay close attention to fatigue. If physical activity is making your fatigue worse overall, you may need to slow things down a bit. You will be more likely to stick to an exercise program if you implement it gradually, over a longer time period.



## ■ TAKING ACTION

So, how do you get started on an exercise program? You can find many ways to do this, but research shows that some strategies are better than others:

**Start gradually.** Make a plan for increasing your activity slowly.

**Find activities you enjoy and can do easily.**

Do you love to hike? Maybe swimming is your thing? If so, see if you can participate in these activities. Or, you can try something new! Take a class in something that is of interest and new to you such as Zumba, belly dancing, tai chi, or yoga. For many, just doing more of what you are already doing, such as walking, is a great place to start. You can increase the time and intensity gradually, maybe by 5 percent, and go from there.

**Find a way to work exercise into your daily or weekly routine,** so you won't have to think about it as much. Consider the time of day that you are the most energetic, and plan to exercise at that time.

**Goal setting is important,** and you can write down or tell someone what you intend to do. The most effective goals

are not simply to say, "I'm going to exercise." Be specific – ideal goals will include what you will do, when, where, how long, and so forth.

**Self-monitoring is also important,** and this can be as simple or as detailed as you would like. Check off the days you meet your goals, such as exercising at least 10 minutes or walking a certain distance. You may want to keep a log of your exercises, weight used, repetitions, and so forth.

**Feedback can be very helpful** to your progress. Look at the self-monitoring data you are keeping. How far are you walking

now versus two weeks ago? How many repetitions now versus when you started? Notice your progress. When you can't meet your goal, identify the barriers and see if you can find ways to safely overcome them. Keep in mind that with MS, you may have certain limitations that you didn't have before, and you need to avoid any type of overexertion – so goals that are too difficult will need to be adjusted to best fit your abilities.

**Positive consequences can provide motivation for**



you to continue to work toward your long-term exercise goals. As you reach new accomplishments, reward yourself! Don't be stingy. If you are moving in a positive direction, even though you might have only completed 50 percent of what you hoped, this merits recognition. Plan the reward ahead of time. Think of healthy ways to treat yourself that are easy to do and fit your budget. Ideas might include: renting a new movie to watch with family or friends, treating yourself to a healthy dessert (such as a

## RESEARCH ON THE BENEFITS OF EXERCISE

According to the article, “Effect of Exercise Training on Depressive Symptoms Among Patients With a Chronic Illness” [MP Herring, et al., *Arch Intern Med.* 2012; 172(2):101-111], lack of exercise and depression are commonly observed in individuals with chronic illness. In this meta-analysis, 90 articles involving studies of more than 10,500 inactive patients were systematically reviewed. Researchers concluded that for individuals with a chronic illness, exercise reduces the symptoms of depression. They also found that individuals who have mild-to-moderate depression and experience improved function from exercise, have the largest reduction in their depressive symptoms.

Another large review of research literature was conducted to determine the relationship between physical activity and cognitive function. Results were reported in the article, “Physical activity for the prevention of cognitive decline” [MD Denking, et al., *Z Gerontol Geriat.* 2012; 45:11-16]. Among the “practical conclusions” of this study, researchers found that “Physical activity is beneficial for older adults in primary, secondary, and tertiary prevention of dementia and it is never too late to start.” Researchers also found that moderate-intensity exercise, including brisk walking, for at least 30 minutes per day and five days per week, provided the best results.

fruit smoothie), buying something new to wear while working out, putting fresh-cut flowers in a vase to enjoy and remind you of your success, or simply allowing yourself some extra time to rest and appreciate what you have accomplished.

**Reminders are a quick and easy way to keep exercise on your mind** – and we can all use these types of cues and prompts.

Whether is it a low-tech sticky note on the bathroom mirror, a digital reminder on your smart phone, or a friend who calls you at the time you are due to be out the door — any reminder that works for you can help you to get going and stay on track. Another idea is to consider exercising at the same time each day (you can still vary your activities so some

days you only stretch and other days you are doing cardio or strengthening). By planning to exercise at the same time each day, this becomes easier to remember.

**Exercise with a friend.** Having someone to work out with is a great help to sticking with an exercise program. Walk with a neighbor, find a workout partner, or join a class at your local gym or YMCA/YWCA. This gives you the benefit of both physical and social activity at the same time! (The benefits of social activity appear in Part II of this article.)

**▣ RESOURCES TO HELP YOU**

If you need help getting started on an exercise program, many resources are available to help you! First, talk to your

**BE COOL**

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doctor to make sure exercise will be safe for you. A physical therapist who has experience in working with people with MS may have some great ideas. A local occupational therapist may know of community resources. Look into online resources such as the National Council for Physical Activity and Disability (at [www.ncpad.org](http://www.ncpad.org)) and MS-specific agencies and support groups. Your local YMCA/YWCA or community center may also have good and inexpensive options for increasing your physical (and social!) activity. MSAA has recently launched its new database, *My MS Resource Locator* (at [resources.msassociation.org](http://resources.msassociation.org)), which provides many contacts for a variety of services.

### ■ WHEN EXERCISE BECOMES A CHALLENGE

Kathleen Costello, MS, ANP-BC, MSCN, is a research associate/nurse practitioner at The Johns Hopkins MS Center (part of Johns Hopkins University) in Baltimore, Maryland. She notes, “Many times patients have fatigue levels or mobility issues that cause them to feel that they cannot exercise at all. It is tough to think that exercise can be incorporated in a day when one has barely enough energy to do what is absolutely necessary. In these situations, an evaluation with rehabilitation specialists can be most helpful to design an exercise program with goals that are realistic and attainable. Even when mobility is significantly compromised, exercise is still possible – and can still be quite beneficial.”

MSAA Senior Director of Services Cindy

Richman explains, “When patients experience more weakness or loss of strength, they really need to be evaluated by a physical therapist. The longer someone waits, the more difficult exercise and other activities may become for that individual. Sometimes spasticity is an issue that gets in the way, yet in most instances, spasticity can be managed. Often patients just wait too long or don’t realize their options – and this can be avoided. No one should miss out on the many valuable benefits of exercise and physical activity simply because he or she wasn’t aware of the opportunities available.

“I also want to emphasize that people who have more burden of disease may continue to exercise as well, provided they have their doctor’s approval. Physical and occupational therapists are able to recommend exercises designed specifically for individuals who need to perform activities from a sitting or even a reclining position. Finding a physical or occupational therapist with experience in MS is important, and consulting your neurologist or MS center for a recommendation is a good way to find the right professional. If this is not possible, individuals should ask questions to evaluate the therapist and ensure that he or she has enough experience with MS.”

Readers are also reminded that MSAA’s Multiple Sclerosis Information (MSi) online video and webinar library has two on-demand videos available to view on the topic of exercise. Both may be accessed by going to MSAA’s website at [www.msassociation.org](http://www.msassociation.org) and going to the MSi section.

MSAA's Lending Library also has references available on the topic of exercise and MS. You may view a listing of MSAA's book and DVD collection available for free loan by going to MSAA's website and selecting "programs" and then "Lending Library" (presently in the left-side navigation).

## PART II: SOCIAL SUPPORT

Our social relationships have a powerful influence on our health and well-being. Social relationships are what tie us to the other people around us: our significant other, friends, family, co-workers, neighbors, and community or religious groups. The study of social relationships typically uses the following terms and definitions:

**Social Support:** this looks at what you can gain from social relationships. Social support is considered one of the most important benefits of social relationships.

**Social Network:** this is the web of social relationships that surround a person. Yes, this was a term, long before Facebook came into existence!

**Social Integration:** this refers to the extent of social relationships, including how many or how few one may have.



Social support can take many forms. Here are some of the most important ones.

**Emotional Support:** providing empathy, love, trust, caring, respect, and listening.

**Instrumental or Material Support:** tangible or concrete aid and services that directly assist a person in need. For instance, a person could provide instrumental support by driving someone to a doctor's appointment or helping someone to obtain an assistive device, such as a cane. Providing household goods or financial assistance is another example of this type of support.

**Informational Support:** providing advice, suggestions, and information that a person can use to address problems. An example of this would include a daughter looking for information on depression and MS on the internet, and then passing it along to her mother who has MS.

**Appraisal support:** providing information that is useful for self-evaluation purposes – in other words, constructive feedback, affirmation, and social comparison. This would include having someone you can trust to "tell it like it is," such as when you're blowing something out of proportion or acting unreasonably.

You can't tell by looking at someone whether they have "enough" social support.



Therapists have no objective test, like a blood test, that measures what levels of social support someone has. In order for researchers to gather information on social support, we use standardized questionnaires that are usually completed by the person being studied (this is called self-report), or sometimes questionnaires will also be filled out by the person's significant other or care partner. One of the questionnaires our group at the University of Washington uses is called the Multidimensional Scale for Perceived Social Support (MSPSS). Here are some examples of the types of statements that are used on the MSPSS where someone would rate on a scale how much they agree or disagree:

*There is a special person who is around when I am in need.*

*I get the emotional help and support I need from my family.*

*I can count on my friends when things go wrong.*

*I have a special person who is a real source of comfort to me.*

Scores on a questionnaire like the MSPSS can help us to determine whether an individual has strong social support, or whether he or she may need help expanding his or her social-support resources. To follow is a brief summary of some of the research findings on social support in people with MS.

First, for individuals with MS, social support may increase their ability to cope and adjust to their changing health issues. Just

knowing that you have a community from which you can get help can be empowering. Second, several health benefits were associated with higher levels of perceived social support. These benefits include:

- Lower levels of stress
- Better pain outcomes
- Protective factor against depression
- Better overall quality of life

### ■ WHY DOES SOCIAL SUPPORT MATTER?

Research has identified many good reasons to care about social support, but one of the most important might be the direct impact that social support can have on your health. Several theories have been developed to explain how social support contributes to health in general. One theory is that when you meet the basic human needs for companionship, intimacy, a sense of belonging, and reassurance of one's worth as a person, supportive relationships may enhance wellbeing and health, even if the person is dealing with a lot of stress. Sometimes this is referred to as "buffering," which uses the theory that the more social support we have around us, the more we're able to deal with stressful situations or events in our life (such as the diagnosis or management of a long-term illness). Social support may be particularly important for people living with a chronic condition like MS.

MS can also be stressful for spouses or partners. Significant others of individuals with MS often describe relationship changes that go



## VOLUNTEERS WANTED FOR PHONE STUDIES

The University of Washington is seeking volunteers for two studies. Both are conducted **over the phone** and are open to anyone living in the United States.

### INMOTION STUDY / EXERCISE AND DEPRESSION

**PI: Charles Bombardier, PhD**

This study is for people with SCI (spinal cord injury) or MS who are 45 years of age or older who are feeling down. This study compares two approaches to helping people become more physically active. This study is six months long and compensates up to \$120. The research team can be reached at **(866) 928-2114** or **agerrtc@uw.edu**. You may also visit **<http://agerrtc.washington.edu>**.

### TAKE CHARGE STUDY / SELF MANAGEMENT

**PI: Dawn Ehde, PhD**

This study looks at treatment for pain, fatigue, and depressed mood related to MS. Treatments teach you different ways of managing these problems in hopes of reducing them and their impact on your life. This study is 13 months long and compensates up to \$120. The research team can be reached at **(888) 634-6778** or **msrrtc@uw.edu**. You may also visit **<http://msrrtc.washington.edu>**.

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hand-in-hand with an MS diagnosis. Some significant others (or care partners) report feeling helpless and wishing they could do more, but are often not sure what they can do. Some significant others may be very good at one type of social support, such as instrumental support (tangible aid and services that directly assist a person in need), but aren't sure how to provide a deeper emotional support. Couples counseling may be an option during this time to ensure your relationship stays strong, that communication stays open, and to give both people the best tools to support one another. Support groups for spouses and care partners of people living with MS are also available and some may find these to be very helpful.

Dr. Zackowski notes, "Some occupational therapists are trained to provide strategies for enhancing your, and your partner's, social support network. Community rehabilitation centers are a good place to look for these types of supportive tools."

### ■ MAINTAINING SOCIAL SUPPORT DURING CRITICAL PERIODS

MS can be characterized as a series of transitions. During these critical periods, the demands and stressors associated with MS increase. At times, critical periods are directly associated with MS, such as when a person is initially diagnosed. At other times, these periods reflect changes in social roles. For example, the need to retire prematurely. During these critical periods, social support is vital.

**Initial Diagnosis.** When first diagnosed, individuals with MS often tell us about a

copying or adjustment period that takes place and is stressful. People living with MS (as well as their significant other) often describe feelings of anger around the time of their initial diagnosis. Feeling this way could have a negative impact on your relationship with your significant other, family, and friends. Working through and understanding these feelings – while eventually moving past them – are important. Of course, individuals still need to recognize that MS will continue to present certain challenges even after the anger is gone. Consulting a psychologist is one way to get some extra help during a time like this.

Other people report that participation in MS support groups can be very helpful during the diagnosis period. This allows people to connect with others who have similar struggles and experiences, as well as being able to learn more about MS from people who have lived with the disease longer. However, other people have reported that some MS support groups were not as helpful — if they didn't have people who were similar to them. For instance, a man with MS may benefit more from talking with other men; a mother with MS who has young children may prefer talking with other moms. Be sure to ask about the support groups you are considering and see if you can locate one that will best fit your needs.

Ms. Richman cautions, "Newly diagnosed individuals need to be careful about getting involved in a group too quickly. When individuals with MS do not have a good social-support system, seeking some transitional counseling first can be very

helpful as they go through an initial period of adjustment. Once they gain back some control, they may consider a group, but only if the group mirrors themselves. Participation in a group where attendees may be older and have much more burden of disease can make the situation worse for a newly diagnosed or younger patient. Failing to succeed in a group, along with the pressure that participation may bring, could be viewed as another failure – and I never want anyone to think that he or she cannot relate to and interact comfortably with his or her peers.”

**When symptoms are invisible.** Early in the course of the disease, when many symptoms of MS are “invisible,” some people discuss resistance to telling people (family, friends, etc.) about their diagnosis of MS. Unfortunately, this tactic can backfire and isolate the person even further. Keeping MS a secret could cut off a whole network of support, limit the types of support available to you, and may unevenly burden your significant other as they become your only confidant.

People with MS also report high levels of stress during a relapse, when their MS worsens, or during other periods of change (such as financial or healthcare-related), due



to their MS. They face a wide range of secondary conditions including pain, fatigue, depression, trouble sleeping, and trouble thinking or memory problems. A person living with MS may not be dealing with just one secondary condition, but is often juggling several, if not all of these problems. These secondary conditions may not only increase stress, but could also impact a person’s social relationships. For instance, a person who is feeling depressed may not be interested in

“hanging out” with other people; or a person struggling with fatigue may not have the energy to participate in the activities that he or she used to do with friends.

**When needs increase.** As time goes by after a diagnosis of MS, people in the social

network of a person living with MS may take on a new role: that of a care partner. Care partners accept the responsibility of taking care of someone who is aging, has a disability, or has a chronic condition. This is sometimes called “caregiving.” Responsibilities of care partners could include managing medications, helping with doctors’ appointments (scheduling, asking doctors questions, etc.), helping to dress or bathe the person, transportation, as well as taking care of household chores, meals, and bills.

In surveys we have conducted at the MSRRTC (MS Rehabilitation Research & Training Center), people have reported using their social networks far more often than paid care assistants to meet their caring needs — further evidence of how important a strong social network can be in the lives of individuals with MS. Research indicates that men and women approach the role of a care partner differently. Women are more likely to use their entire social network for support, whereas men with MS tend to rely primarily on their significant other. Men are less likely to ask for outside help and are reluctant to express their feelings about the situation.

The transition to a care partner relationship may be slow or fast, depending on what type of MS you have. People living with MS and their significant others have reported higher levels of stress during transitions that

are more unexpected or that happen quickly. Being prepared and planning for the future may ease the stress during these transitions. Also, having a social network of people who are willing and able to help out as needed may reduce the stress and take the burden off of the primary care partner. The MSRRTC has published a book, *The MS Workbook: Living Fully with Multiple Sclerosis*, which has a valuable chapter on care partner relationships. Some communities have caregiving classes that instruct people on how to be a good care partner. Check with your local Red Cross, senior services office, or local MS center to see if these classes are available in your area.

### ■ TAKING ACTION

Several options are available if you feel that your social support resources need strengthening. Here are some ideas:

## ***Physical Activities for Individuals with MS***

**By Maryann B. Hunsberger**

People with MS know how tricky it can be to get enough physical exercise. Yet, opportunities exist. Wellness centers at local hospitals, the local Y, colleges, high school adult evening classes, and senior centers are all good places to call to find mild exercise programs that can be tolerated by individuals with MS.

National organizations sometimes have local classes geared toward people with disabilities. Some programs to choose from are:

The Arthritis Foundation has classes suitable

for many people with MS. Their website, **arthritis.org**, has a “programs” section with various adapted exercise programs, including:

***Walk with Ease:*** An exercise program designed to reduce pain and improve overall health for people who can stand for 10 minutes without increased pain.

***Tai Chi:*** A program aimed at reducing pain and improving mental and physical wellbeing. The program uses gentle routines that are suitable for every fitness level.

***Aquatic Program:*** This warm-water\* non-weight-bearing exercise program is designed to reduce pain and improve overall health and is suitable for every fitness level. (\*Please note

### Private counseling with a psychologist.

Sometimes it's difficult to determine where to draw the line in a social relationship. Perhaps your current network is not qualified to help you with the particular problem you're dealing with. Counseling and problem-solving with a psychologist or therapist may help you to determine what assistance you need and who might provide the best support. A good counselor can also help you with coping and stress management. The good news is that more and more health insurance plans are now covering coun-



seling (at least partially). If you are experiencing difficulties with pain, fatigue, depression, sleep, or memory, ask your doctor for a referral to a rehabilitation psychologist. Check with your health insurance to find out what they will cover.

### Couples counseling with a psychologist.

Intimate relationships change in the face of a chronic condition and some couples may benefit from talking to a licensed psychologist or counselor. Some therapists may specialize in couples counseling, so be sure to ask if that is their specialty.

*that warm water is usually contraindicated in MS and is recommended to be below 85° F; water temperature should be discussed prior to starting an aquatic program.)*

**Exercise Program:** *A low-impact program that helps reduce pain and decrease stiffness. The gentle range-of-motion exercises are suitable for every fitness level.*

Individuals seeking a Certified Inclusive Fitness Trainer can search the American College of Sports Medicine's Pro Finder link at **certification.acsm.org**. These trainers lead people with disabilities in safe, adapted exercise.

Individuals with MS who can't keep up with their old treadmill routine might like underwater

treadmills. Because these treadmills are on a pool floor, at least half of the body is submerged in water, removing weight from joints and allowing for a pain-free cardiovascular workout. Call local physical therapy organizations and rehabilitation hospitals to find these treadmills.

Hippotherapy uses horseback riding to increase trunk strength, balance, and endurance. Participants often enjoy spending time with the horses, while the experience of sitting up high and feeling the horse walk effortlessly across the ground can also have a freeing effect on the rider. Visit **americanhippotherapyassociation.org** for more information. ■

**Support groups for individuals with MS.** Some people find that talking with other people who have similar experiences and understand what it's like to live with MS is particularly helpful. Support groups are offered through a variety of organizations and could be in-person, over-the-phone, or online. Some groups are led by a peer (someone else with MS), whereas others are led by a professional facilitator.

**Support groups for care partners (or significant others) of people with MS.** These types of groups give your significant other a

chance to connect with other people who are going through similar experiences that they are.



**Caregiving Training Classes.** The American Red Cross offers information and local classes on caregiving. To learn more, visit [www.redcross.org](http://www.redcross.org) and type “family caregiving” in the search window. This will bring you to a

list of options, which includes a detailed publication (titled *Family Caregiving*) that may be downloaded and viewed or purchased. Local caregiving classes are

## ***Social Activities for Meeting New People***

**By Maryann B. Hunsberger**

How can someone with MS get out and meet new people? In many cases, they can accomplish this in the same way that people without MS meet people – by participating in activities that focus on things they enjoy. It's easier to find things to talk about with people who share the same interests. People who enjoy reading can discuss their favorite books at a book club. Gardening enthusiasts can get new tips and make new friends at a gardening club. Additionally, book stores may offer

occasional book signings, while large garden/home improvement centers often hold various instructional classes.

Taking – or teaching – adult evening classes at local high schools and community centers can be a great way to find like-minded people. Whether teaching techniques of painting or learning more about playing Bridge, these classes provide an outlet for encountering others who enjoy the same hobbies. Community colleges also have many classes available, from noncredit floral arranging classes to for-credit international language classes. Can you really meet new people in your local college's French class? Mais oui! (Roughly translated... “Of course!”)

provided by the Red Cross as well. Nine one-hour classes are offered on topics such as legal and financial issues, home safety, personal care, and healthy eating. Another good resource for caregiving classes is the National Family Caregivers Association (NFCA). You may learn more by visiting their website at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org). The NFCA offers educational workshops to instruct family caregivers on how to communicate more effectively with healthcare professionals. They recommend that anyone interested visit their website to see if a workshop is scheduled in his or her community.

**Get Involved.** Some people prefer to find support that is unrelated to MS, such as becoming more involved with a local civic organization (local parks, local government, community center, humane society, etc.).

Volunteering is another way to find friends. Rather than stewing about the abused animals you care about – donate your time at an animal shelter, feeding and showing love to neglected animals. You'll meet people who love animals in the process. If you're concerned about homeless people, take time to serve meals at the nearest homeless shelter. Reading to individuals who are visually impaired is another important and rewarding volunteer opportunity. You'll meet other volunteers while providing help, no matter which cause you choose.

And if thinking about volunteering... you can combine your desire to volunteer with your need for exercise and social activity, all while

Check out what volunteer opportunities are available in your area.

**Group Exercise.** This can be as simple as meeting your family or friends for a Saturday walk in the park (if able, walking in general is a great form of exercise for everyone), or if you're more ambitious, joining a running group (these are often associated with running stores). Group exercise, such as Zumba, yoga classes, or spin classes (using stationary bikes at the gym) can bring a sense of camaraderie as you accomplish a challenge together as a group. Some people report that exercising with a group also adds a sense of accountability to continue week to week (in contrast to individual exercise, where it's sometimes too easy to give yourself a day off!). Depending on the magnitude of your symptoms, your local gym or specialized gyms

*(continued on page 28)*

raising money to help individuals with MS! MSAA's Swim for MS program allows participants to have an individual or group swim event – anywhere and anytime – to help raise funds for the programs at MSAA. Please visit [msassociation.org/swimforms](http://msassociation.org/swimforms) for more information.

People with MS who use wheelchairs sometimes find it hard to meet others when so much of the world is inaccessible. Some individuals who meet others during social activities at accessible houses of worship find that newer worship buildings are generally more wheelchair-friendly. The community living section at Wheelchairnet

*(continued on page 28)*





GILENYA for relapsing forms of multiple

POSSIBLE

## GILENYA. Proven to significantly reduce the

**GILENYA reduced the number of relapses by 52% in a 1-year study versus IM interferon beta-1a. In fact, 83% of people taking GILENYA remained relapse-free versus 70% taking IM interferon beta-1a.**

**GILENYA was also proven effective in a separate 2-year study versus 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

GILENYA may cause serious side effects such as:

- Slow heart rate, especially about 6 hours after your first dose. If your heart rate slows down, you might feel dizzy or tired, or be aware of a slow or irregular heartbeat. Your doctor will watch you for the first 6 hours after your first dose for any serious side effects. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor if at any time you have dizziness, tiredness, or a slow or irregular heartbeat. If you stop taking GILENYA for 2 weeks or more, you will need to repeat this observation.
- 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. 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, can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. 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.
- 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

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sclerosis (MS). Discover your

# BILITIES

number of relapses in the first once-daily\* pill.

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. Call 1-877-598-7237 for more information.

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; a heart rate less than 55 beats a minute; heart problems; a history of fainting; a fever or infection, or if you are unable to fight infections; eye problems; diabetes; breathing or liver problems; or high blood pressure. Also tell your doctor if you have chicken pox or have received the vaccine for chicken pox. Your doctor may do a test for the chicken pox virus, and you may need to get the vaccine for chicken pox and wait 1 month before starting GILENYA.

Tell your doctor about all the medicines you take,

including medicines for heart problems or high blood pressure; medicines that could increase your chance of infections, such as medicines to treat cancer or control your immune system; or ketoconazole (an antifungal) by mouth. If taken with GILENYA, serious side effects may occur. You should not get certain vaccines while taking GILENYA, and for at least 2 months after stopping.

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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Freedom from injections is finally an option. Ask your doctor if GILENYA is right for you.**



*\*GILENYA can result in a slow heart rate when first taken. Your first dose will be given in a doctor's office or clinic, where you will be watched for 6 hours. If you stop taking GILENYA for 2 weeks or more, you will need to repeat this observation.*

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

**MEDICATION GUIDE**  
**GILENYA™ (je-LEN-yah)**  
**(fingolimod)**  
**capsules**

Read this Medication Guide before you start using GILENYA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your 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 the first dose. Your heart rate will usually slow down the most about 6 hours after you take your first dose of GILENYA. You might feel dizzy or tired or be aware of a slow or irregular heartbeat if your heart rate slows down. Usually, if you experience these types of symptoms due to the slowing down of your heart rate, they will occur during the first 6 hours after the first dose. Your doctor will watch you for the first 6 hours after you take the first dose to see if you have any serious side effects. Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA.

Call your doctor if at any time you have:

- dizziness
- tiredness
- a slow or irregular heartbeat

**2. Infections.** GILENYA can increase your 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 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. Macular edema 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 age 18.

**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 heart rate less than 55 beats a minute
- heart problems
- a history of fainting (syncope)
- a fever or infection, or you are unable to fight infections. 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
- 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, you can call the GILENYA Pregnancy Registry at 1-877-598-7237.

- 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,** including prescription and non-prescription medicines, vitamins, and herbal supplements.

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:

- Medicines for heart problems or high blood pressure
- 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.

- Medicines that could raise your chance of getting infections, such as medicines to treat cancer or to control your immune system.
- ketoconazole (an antifungal drug) by mouth

Ask your doctor or pharmacist for a list of these medicines if you are not sure.

#### How should I take GILENYA?

- Your first dose of GILENYA will be given in a doctor's office or clinic, where you will be observed for 6 hours after your first dose of GILENYA.
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- If you start GILENYA again after stopping for 2 weeks or more, you will start taking GILENYA again in your doctor's office or clinic.

#### 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:

- **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 1-800-332-1088.

#### 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](http://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 trademark of Novartis AG.

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*(continued from page 23)*

may be interested in providing a personal trainer who may have some experience with the effects of MS.

Ms. Richman notes, “When starting out with a new counselor or therapist, you need to make sure that he or she is right for you. You should ask what this professional knows about chronic illness; ask about his or her credentials, as well as his or her connection to MS. Once you have met with the counselor or therapist, ask yourself if you felt comfortable talking with the individual and why. Having a good fit with your therapist will greatly assist in getting the most benefit from your sessions.

“With regard to group exercise, if an

individual with MS cannot do the same things as his or her spouse, friend, family member or child, he or she has options to exercise in a parallel way. For example, if a friend or family member is running on the treadmill, someone with MS could be alongside him or her on a stationary bike – allowing them to exercise together. Another idea is to swim together, where the natural buoyancy of water enables a patient to enjoy greater mobility. Driving a scooter as another person walks alongside is another example of how to stay active together. These types of parallel activities may encourage people to look for creative ways to make exercise work, while spending more social time with others.”

### ***Social Activities for Meeting New People***

*(continued from page 23)*

**(wheelchairnet.org)** has links regarding accessible worship.

Some people meet friends at exercise classes for people with disabilities. The Arthritis Foundation (**arthritis.org**) stresses that their adapted exercise classes are held in an environment that encourages social interaction.

Centers for Independent Living in every state provide support groups for people with disabilities where friendships can form. Find your local center at **ilru.org**. These centers also provide information and referral to other disability-related organizations with opportunities for socialization.

Travel agencies specializing in wheelchair-accessible vacations can allow wheelchair

users to see the world while making friends, both on cruises and on land tours.

According to Accessible Journeys (**disabilitytravel.com**), some important accommodations to seek from accessible travel agencies are meet-and-greet services at airports and train stations, accessible van rentals, and fully accessible hotels. The book, *101 Accessible Vacations: Travel Ideas for Wheelers and Slow Walkers* by Candy B. Harrington, can be an ideal starting point for those seeking accessible vacations.

Many people with disabilities choose to meet other disabled individuals through online groups and message boards. These can provide socialization to people who have difficulty getting out of the house. ■

**IN CLOSING**

Dr. Zackowski concludes, “The most important thing to get across is that people with all disability levels can benefit from increased activity, but it needs to be done thoughtfully. In my experience, patients are very careful about which physician they choose for their medical needs (i.e., a physician with training in MS), but they are not as careful about whom they pick for their physical and occupational therapists (i.e., do the therapists have experience with MS and do they trust their judgment?).

After getting a physician’s agreement that exercise is safe, each person should see a physical therapist to provide specific recommendations. It might be nice to talk a bit about the physical therapist’s qualifications for doing this type of work (i.e., are they trained in the neurology of MS?). I also think that occupational therapy should be included in one’s exercise plans. Occupational therapists play a major role in providing



energy-conservation training, teaching activity modifications, and providing resources for equipment to allow for increased activity within one’s home environment... just to name a few of the ways in which they can help.”

MSAA Chief Medical Officer Dr. Jack Burks adds,

“This article integrates

theoretical, scientific, and practical components to support the value of physical and social wellbeing, as people with MS learn to cope with and adapt to their MS. The lessons to be learned and implemented are important for everyone in the MS community, both with or without MS.

“The principles presented are informative, providing ‘words to live by’ as we all strive to increase our quality of life. Everyone has his or her own ‘style’ as to what works best. There is no ‘one size fits all’ in how we approach physical and social activities. However, many points in this article are applicable to all of us.” ■

**ABOUT THE AUTHORS**

Samantha Artherholt, PhD is a research counselor and Aimee Verrall, MPH is a researcher at the University of Washington in Seattle, Washington. They work across two center grants called Rehabilitation Research & Training Centers (RRTCs). One RRTC focuses on multiple sclerosis and the other looks at aging with a physical disability. The RRTCs conduct a variety of research including surveys and randomized controlled trials.

## Why Don't Approved Drugs Work for Progressive MS?



*Dr. Jack Burks*

**Q:** Since my diagnosis almost six years ago, it seems as if research is truly making progress with medications to treat MS relapses. The really great thing is that MS patients now

have an oral medication available to them, in addition to the medications given through injections or infusions.

Most of the new medications are for those with relapsing-remitting MS (RRMS). Is there any effective drug for those of us with progressive MS? And, if the medications for RRMS can reduce relapses, why wouldn't these same medications work to slow the progression of MS for individuals who do not have relapses?

### 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@msassociation.org](mailto:askdr@msassociation.org). Please be sure to write "Ask the Doctor" in the subject line.

**A:** Thanks for your excellent thoughts and good questions. No medication is approved by the FDA (Food and Drug Administration) for MS-disease progression, unless relapses are also present. The postulated mechanism of action of current MS treatments is a reduction of inflammation in the brain and spinal cord. Inflammation is thought to cause relapses.

The cause of progressive symptoms is not as well understood. We think a degenerative (versus an inflammatory) process is partially responsible for MS progression. While the eventual understanding will likely be much more complicated, this theory says that anti-inflammatory drugs work against inflammatory cells but do not work well on degeneration, the cause of progression.

Our hope is to find medications that will help both inflammation and degeneration. The good news is that research into treatments for progression (and even remyelination) is in progress. Therefore, the future for those with progressive MS is looking brighter.

**Q:** I was diagnosed with MS in 2007 and have done really well. After trying two other injectable disease-modifying therapies, I am now taking Betaseron. I had to have a catheter once to help me urinate. The urologist put me on Flomax and that straightened everything out. I am off Flomax at this time and doing well.

My question is: can MS cause problems in the vaginal area? I have problems sometimes with my vaginal area becoming inflamed, swollen, and very irritated. I have had these problems for years. I have also had diarrhea for years. During my last episode I went to my gynecologist and he really did not know what was going on. What kind of doctor should I see for this problem?

**A:** I am pleased that you are doing well with your MS. Vaginal symptoms are not uncommon in MS. Dryness with poor lubrication, irritation, pain with intercourse, and intense muscle spasms with (or without) intercourse may be related to MS.

However, something else may be going on and I would suggest that you seek another opinion from a second gynecologist. Your urologist may also have some helpful suggestions. I would also have your thyroid checked since a low thyroid can contribute to this problem. Vaginal infection is another possibility. Some MS patients with vaginal muscle spasms are helped with anti-epilepsy drugs or drugs used to treat painful sensations in other parts of the body. Neurontin® (gabapentin), Lyrica® (pregabalin), and Cymbalta® (duloxetine HCl) are examples.

Diarrhea is also seen in MS patients, but it is not as common as constipation. I recommend that you discuss this issue with your neurologist or a gastrointestinal specialist. The specific treatment will depend on the exact cause of your diarrhea.

**Q:** I am a 45-year-old female and was diagnosed with MS a little more than two years ago, but had symptoms for more than a year before that. This year I have steadily gotten worse, and have gone from a cane to a walker, then a wheelchair and now a power chair. It has recently started to affect my hands quite badly.

My question is about my legs that are always cold, and it feels as though they are sitting in a bucket of ice. I have other family members and friends who also have MS, but no one else has this issue. My legs have been like this for about a year and a half. Is there anything that can be done about my legs feeling cold? It isn't too bad in the summer, but in the winter I am freezing all of the time. I know that too much heat is not good for people with MS, but the hotter the better for my legs, although it still doesn't warm them up completely. Any suggestions would be most helpful!

**A:** Your first paragraph is very disturbing. The rapidness of your declining neurological condition is extremely unusual. In one year, going from a cane to a power chair leads me to suggest that you consider a second opinion about your MS and its treatment.

“Cold legs” can be a symptom of MS, although other causes are also possible. Your doctor may send you to a specialist for consultation. Treating this symptom is a challenge. A specialty MS center near you might be your best source of information.

*(continued on page 34)*



## Phase III Results Announced for Oral Laquinimod

On March 15, 2012, Teva Pharmaceutical Industries Ltd. and Active Biotech announced that the results of the ALLEGRO Phase III study of oral laquinimod were published in the March 15, 2012 edition of the *New England Journal of Medicine*. The article, titled “Placebo-Controlled Trial of Oral Laquinimod for Multiple Sclerosis,” (G Comi, et al.; *N Engl J Med*. 2012;366:1000-9), details this randomized, double-blind Phase III study conducted at 139 sites in 24 countries. Of the 1,106 participants with relapsing-remitting MS (RRMS), half received oral laquinimod (0.6 mg once daily), and the other half received a placebo, over a period of two years.

The study showed that oral laquinimod slowed the progression of disability (as

measured by Expanded Disability Status Scale [EDSS]) by 36 percent, and reduced the annual relapse rate by 23 percent for individuals with RRMS. Additionally, oral laquinimod reduced the number of new or enlarging lesions (as shown on magnetic resonance imaging [MRI]), and also reduced the progression of brain atrophy (brain-tissue loss) by 33 percent. The most common adverse events were headaches, nasopharyngitis (inflammation of the nasal passages and upper part of the throat), and back pain. Elevated liver enzymes occurred more often in the treatment group, although these were transient, without symptoms, and reversible. No deaths were reported in the treated group.

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## Application Submitted for BG-12; FDA Approves Avonex® Pen™ and Initial Dosing Regimen

On February 28, 2012, Biogen Idec announced that they have submitted an application to the United States Food and Drug Administration (FDA) for approval of BG-12 (dimethyl fumarate), an experimental oral drug for the treatment of relapsing-remitting multiple sclerosis (RRMS). In clinical trials, including the Phase III DEFINE study (with 1,200 patients) and the Phase III CONFIRM study (with 1,232 patients), BG-12 reduced MS-disease activity significantly, while showing favorable safety and tolerability data. These placebo-controlled

trials were conducted globally, studying the effects of 240 mg of BG-12 given (orally) either twice or three times per day over the course of two years.

Also on February 28, 2012 Biogen Idec announced that the United States Food and Drug Administration (FDA) had approved both a new device (the Avonex Pen) as well as a new initial-dosing regimen for Avonex (interferon beta-1a). These two approvals are aimed at assisting patients who are either taking Avonex presently, or who are just starting Avonex.

*Many of these news items also appear on MSAA's website ([www.msassociation.org](http://www.msassociation.org)) under "Recent News." Some of the online versions of these news items may include some additional information. For more information on any of the approved or experimental treatments for MS, please refer to the "MS Research Update" appearing in the Summer/Fall 2011 issue of *The Motivator*. You may view, download, and print this article from our website by going to "Publications" and then selecting "The Motivator" in the left navigation. Readers may also contact MSAA's Helpline at (800) 532-7667 for more information.*

### **The Avonex Pen**

The Avonex Pen is the first intramuscular autoinjector approved for an MS medication. The other self-injected treatments for MS are given via subcutaneous injections, which do not require as deep of an injection. Since Avonex is injected intramuscularly, patients may find this type of self-injection to be more difficult, and they may experience increased pain and anxiety as well. The Avonex Pen is designed to be easier to use (than the present Avonex Prefilled Syringe alone) and is designed to reduce both pain and anxiety.

The Avonex Pen incorporates the current Avonex Prefilled Syringe, along with a thinner and shorter needle. Other features of the Avonex Pen include an automated insertion of the needle and delivery of the medication, as well as a design that helps to stabilize the device while performing an injection.

### **Initial Dosing Regimen**

The FDA has also approved a schedule for starting low and gradually increasing the dose of Avonex at the start of therapy. The

reason for this change in the initial dosing of Avonex, which introduces the drug gradually (known as titration), is to help reduce the incidence and severity of flu-like symptoms. These can often occur when starting an interferon therapy.

The new dosing regimen is provided on the Avonex label to physicians and patients, and may be facilitated using the Avostartgrip kit. This kit includes a set of three devices that work with the Avonex Prefilled Syringes, each filled with the titrated doses of Avonex. Specifically, 7.5 mcg is given in the first week, 15 mcg is given for week two, and 22.5 mcg is administered for week three. The full dose (of 30 mcg) starts in week four. PLEASE NOTE: This titration schedule should only be used by individuals who are just starting Avonex.

### **For More Information**

For more information, please see Biogen Idec's press releases on these topics at [www.biogenidec.com](http://www.biogenidec.com). For general information about Avonex, please visit [www.avonex.com](http://www.avonex.com).

## Antibody Test Identifies New Risk Factor for PML

On January 20, 2012, the United States Food and Drug Administration (FDA) announced that three factors are now identified with increasing the risk of progressive multifocal leukoencephalopathy (PML) for individuals with multiple sclerosis (MS) being treated with Tysabri® (natalizumab). PML is a potentially fatal brain infection with the JC virus (JCV), in people with weakened immune systems. The FDA has approved a labeling change, which adds the results of a newly approved test for the presence of anti-JCV antibodies, to the two previously listed risk factors. The following three PML risk factors now appear on Tysabri's labeling:

- The presence of anti-JCV antibodies, which identifies a previous exposure to the JC virus
- Longer duration of Tysabri treatment, especially after two years
- Prior treatment with an immunosuppressant medication, such as mitoxantrone (Novantrone®), azathioprine (Imuran®), methotrexate, cyclophosphamide (Cytosan®), or mycophenolate

Each of these three factors increases the PML risk and the combination of all three increases the risk to as high as 11 in 1,000 (or slightly more than one percent). The new validated JCV antibody detection test (Stratify JCV Antibody ELISA test) was cleared by the FDA on January 20, 2012 and is now commercially available from Quest Diagnostics. A positive test indicates a previous JCV exposure, but does not indicate the development of PML.

JCV typically remains dormant in those exposed to the virus, but may become active when the immune system is weakened. An individual needs to be anti-JCV antibody positive in order to be at risk of developing PML, although a person who is negative could be exposed to the virus at any time. Whether or not a person has received any prior treatment for their MS, about 55 percent of individuals with MS are anti-JCV positive.

For more information on this label change, please see Biogen Idec's press release at [www.biogenidec.com](http://www.biogenidec.com) and the FDA announcement at [www.fda.gov/Drugs/DrugSafety/ucm288186.htm](http://www.fda.gov/Drugs/DrugSafety/ucm288186.htm).

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## Ask the Doctor

*(continued from page 31)*

Neurontin® (gabapentin), and other medication, as well as biofeedback, self-hypnosis, guided imagery, massages, warm (not hot) towels, vitamin B-12 shots, and niacin are suggestions that have not been proven in clinical studies, but may be of help

to you. In extreme cases, an autonomic nerve block may be considered. ♦

*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.*

## FDA Safety Announcement for Gilenya

On December 20, 2011, the FDA posted a Safety Announcement on its website, noting the death of an individual with MS on the day following a first dose of Gilenya (in November, 2011). The article states: “At this time, FDA cannot conclude whether the drug resulted in the patient's death. FDA is continuing to evaluate the case and will communicate any new information that results from this investigation.” It also advises: “Patients with MS should not stop taking Gilenya without talking to their healthcare professional.”

To view the FDA announcement, please go to [www.fda.gov/Drugs/DrugSafety/ucm284240.htm](http://www.fda.gov/Drugs/DrugSafety/ucm284240.htm). Anyone with questions may also contact Novartis at (888) NOW-NOVA (888-669-6682) or call MSAAs Helpline at (800) 532-7667.

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## European Agency Recommends Increased Monitoring with First Dose of Gilenya

On January 20, 2012, the European Medicines Agency (EMA) announced that it has started a review of Gilenya (fingolimod) in response to reports of potential heart issues associated with the first dose of this drug. The EMA is responsible for the scientific evaluation of medicines developed for use in Europe, similar to the Food and Drug Administration (FDA) in the United States. According to a press release issued by the EMA, “The review was started following reports of heart problems in patients taking Gilenya, as well as the death of one patient in the United States less than 24 hours after the first dose. The exact cause of this patient’s

death is still unexplained.”

The EMA is advising doctors in the European Union to “intensify cardiovascular monitoring” following the initial dose of Gilenya. Readers should note that (1) this advisory does not apply to doctors in the United States and (2) no changes will be made to Gilenya’s labeling at this time.

To view EMA’s press release, visit [www.ema.europa.eu](http://www.ema.europa.eu), select “News and Events,” followed by “News and Press Release Archive,” and then type “Gilenya” in the keyword search and enter. Scroll below the search box to select, “European Medicines Agency starts review of Gilenya (fingolimod).”

## MSAA Launches *My MS Resource Locator*

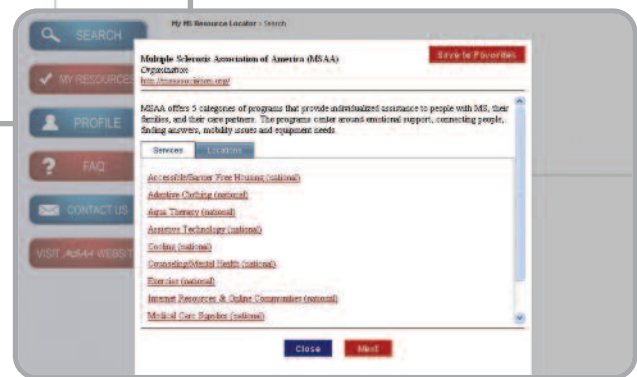
As an organization with more than 40 years of service to the multiple sclerosis community, MSAA fully understands the complexity of MS and how each person's experience is truly unique and ever changing. Whether you are recently diagnosed or living with MS for many years, new and challenging issues can arise at any time. Unfortunately, locating accurate, well-researched information and resources with a specific focus on multiple sclerosis can also be just as challenging.

Recognizing these factors and the need to assist our MS constituents, MSAA is extremely proud to announce the creation of a new national program titled, *My MS Resource Locator*. Designed as a tool to help find the answers you need, *My MS Resource Locator* is an MS-specific database offering targeted information and unique support services, including detailed guides. The carefully checked database contains listings of national, state, and where appropriate, local resources to help connect you to the information and services you need.

Supported by a grant from Novartis Pharmaceuticals Corporation, the development of *My MS Resource Locator* originated as an internal database used by the MSAA Client Services department. With



*My MS Resource Locator is an MS-specific database offering targeted information to help direct users to information and services.*



the long-term goal of making this database available to the MS community through our website, MSAA has worked extensively to prepare and expand the program for public access. Through the continued support of Novartis, MSAA has been able to incorporate many new upgrades, add new listings, refine the searchable categories, and develop much-needed companion guides to help focus visitors on understanding and selecting the most appropriate resource to meet their needs.

*My MS Resource Locator* is accessed at [resources.msassociation.org](http://resources.msassociation.org). Its categories include: Education/Employment, Financial Assistance, Health and Wellness, Housing, Insurance, Legal, Medical, Resources for Managing Chronic Illness, Therapy and Rehabilitation Services, and Products/Equipment for Managing Disability.

The guides for these topics offer comprehensive definitions of key terms, useful descriptions of products or services, and helpful tips or suggested questions to ask when contacting the resource.

“We are very excited to see this project progress through its many stages, revisions, and upgrades, and now be able to share it directly with the MS community through our website,” states MSAA Chief Operating Officer Robert Rapp. “While internet search engines can be useful for many purposes, locating reliable, accurate resources specific to MS can often lead to a frustrating and disappointing experience for the online user. The categories and information included in *My MS Resource Locator* direct users toward MS-focused content and includes the benefits of detailed explanations and helpful advice. Also, as another effort to assist our clients, MSAA’s trained Helpline consultants continue to be available to provide additional support and answer any questions through our toll-free phone line and email.”

As mentioned, a key component in the creation of *My MS Resource Locator* is the inclusion of guides for all topics. For example, visitors who explore the Health and Wellness section can find helpful information on exercise and MS. This includes suggested questions to ask their doctor prior to starting a program, strategies for safe and effective workouts, and descriptions about many common activities such as aquatics, yoga, and hippotherapy.

The development of *My MS Resource Locator* as a tool to help our clients find

targeted resources and learn about strategies regarding the successful management of MS is part of a new philosophy supported by MSAA called *Shared Management*. This is a concept whereby both the patient and healthcare provider have a shared responsibility for working together and striving to achieve the best health outcomes. To support this effort, MSAA is continuing to develop a series of tools to help our clients become proactive and work toward better health. As you may know, we have recently developed our S.E.A.R.C.H.<sup>™</sup> program, which helps identify key questions to ask your doctor when “searching” for a disease-modifying therapy. Also, the development of MSAA’s mobile phone application, *My MS Manager*<sup>™</sup>, has generated more than 6,000 free downloads, allowing patients to input and store their medical information, track symptoms, and create specialized reports to share with their doctor.

As we launch this very new and exciting program initiative, we invite everyone to log onto [resources.msassociation.org](http://resources.msassociation.org), access *My MS Resource Locator*, and provide us with your comments and feedback. Please also feel free to call and speak to our Helpline staff at (800) 532-7667 to learn about this and other MSAA programs. ♦

COMING SOON...

Look for MSAA’s  
**Newly Redesigned Website**  
This Fall!

## HAVE CAMERA, WILL TRAVEL

*MS has become a steady force in the fast-paced life and career of music photographer Anna Webber*

MS gives structure to Anna Webber's life. At age 25, the recently named MSAA Ambassador has built a reputation and career as a top portrait photographer in the music industry.

Her work is diverse. Recent shoots include the ranking master of minimalist classical music, Philip Glass, and the contemporary alternative rock star Beck ... together! This was quite a combination of musical styles!

Anna has taken several portraits of country music legend Willie Nelson. She is hosting a party, during which she will do portraits of participating bands, all at Nelson's home in Austin. This party is a part of this year's South by Southwest Festival, one of music's biggest events. In February, she worked for L'Oréal and TRESemmé at Fashion Week in New York. In January, she was at the Sundance Film Festival in Utah, where she added music icons Paul Simon and Quincy Jones to her portfolio.

Anna maintains bases in New York City, Austin (where her brothers live), and Los Angeles (her hometown). Her life is busy. She can be anywhere at any time, including as a representative for MSAA!

Anna's active life and ever increasing exposure via magazine spreads, album covers, etc. looked to be in jeopardy when



she was diagnosed with MS in 2009. One of her brothers was diagnosed two years earlier.

Rather than keeping Anna from working and moving forward in her career, MS gave her life shape and focus. She says it grounded her. It provided her a schedule of sorts by which to pace her life and to make sure she paid attention to herself and her health amid the bustle.

"My injection is like a clock," Anna says. "Whatever else I'm doing, I have to pause to take my medication. In that regard, MS has become a steady force, a reality check."

"Except for my injection, my life has no regularity. Being aware of the need to take medication reminds me to exercise, watch what I eat, and be disciplined about health. Having MS gave me an attitude of wellness and proportion that might not have occurred to me if I wasn't living with a chronic disease."

"MSAA helps by providing My MS Manager™. I downloaded the app onto my iPhone, and it reminds me when to take my injection while listing other medications I take, my exercise routine, and other things that help me keep control of MS."

Like most creative people, Anna has always liked stories. Now she writes her own stories,

and also plays percussion instruments, in addition to her photography. She finds expression in words and music, but pictures always dominated her imagination, and they have come to dominate her life.

“My mother gave me a 35mm Minolta camera when I was a child,” Anna says. “I joined a photography club, and that was the beginning. No one had to push me to delve deeper and deeper into photography. I was enamored with what you could capture on film.

“My father and two brothers are musicians. I began taking pictures of their band. While attending Pepperdine University, I met Baron Wolman, the first chief photographer for *Rolling Stone*. Although I was majoring in business and creative writing, I was able to study with Baron, and he became a mentor.

“In my junior year, I went to Florence and studied with Jill Furmanovsky, a photojournalist whose work is collected by museums. She shot photos for Pink Floyd and many other legendary musicians. I learned a lot about portraits and other sides of photography, like developing 35mm film. I started taking pictures, getting published, getting commissions, and it all keeps going.”

As an MSAA ambassador, Anna will raise awareness about MS and talk about how the disease grounds her while she maintains an active life. She will make appearances on MSAA's behalf, speak about MSAA when she is interviewed on talk shows and for magazines, and serve specifically as the ambassador for MSAA's mobile phone app, *My MS Manager*. ♦

## THE PHILANTHROPY CIRCLE

*The following thoughtful corporations and foundations have contributed generously to MSAA to help enrich the quality of life for everyone affected by multiple sclerosis. Organizations providing gifts of \$10,000 or more are shown in this listing.*

### **GUARANTORS** (\$500,000 and up)

EMD Serono, Inc. and Pfizer Inc  
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Genentech, Inc.  
Questcor Pharmaceuticals, Inc.

### **INNOVATORS** (\$25,000 to \$49,999)

Genzyme Corporation  
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### **ADVOCATES** (\$10,000 to \$24,999)

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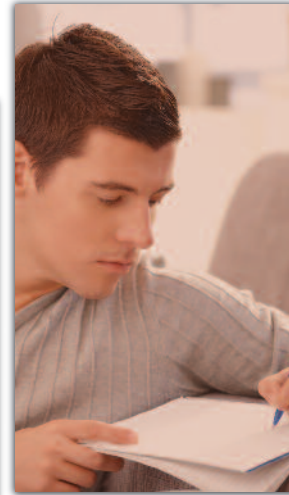


## Express Your Feelings

By Maryann B. Hunsberger

*Find therapeutic benefits, enjoyment, and even profit through writing!*

I started journaling before the term was even coined. In those days, I called it writing in a diary. My diary wasn't a floral fabric-covered hardback empty book that was purchased in a greeting card store. It was a marble composition book, a spiral notebook, a stenography pad, or any other type of bound paper that I could write on. My early diaries were written with the kind of pen we used at school back then: a fountain pen (the kind that contained an ink cartridge, not the kind that Ben Franklin dipped into an inkwell). That reveals two things about me: (1) I'm too old for high school, but younger than Betsy Ross; and (2) I've been writing for a really long time.



I wrote in my diary every day from the time I was 8 years old, whether I was happy or sad. As a child, I wrote when my grandmother died, when math stumped me, and when my favorite singer (Davy Jones) married someone other than me. As an adult, I wrote when I met my husband, when we bought a house, and when we had children. Journaling was more than a hobby. Opening that book and pouring out my deepest feelings became a habit that bolstered my spirit through even the roughest times. When

*Please note that MSAA receives many writing samples throughout the year. Unfortunately, we do not at this time have any specific outlet in which to publish writings, so we ask that you please do not send in writing samples. However, individuals who have published books that may be of specific benefit to the MS community may submit a book to be considered for donation to MSAA's Lending Library, a free book-loan service to individuals with MS. If the book is determined to be appropriate for MSAA's Lending Library, five or more copies are required to be donated to meet the needs of individuals requesting books. Some books may be selected for the Spread the Word column – please see page 48 for this issue's highlighted books.*

I became disabled, my diary was one of the first sources of comfort that I turned to.

For people with physical disabilities, including MS, it's tough to deal with such potential issues as losing mobility and skills, possibly giving up a career, and perhaps even losing friends or romantic partners. Sometimes, people with MS find it tough to talk about the way their symptoms affect their lives. A journal can be the sanctuary that

people with MS need – no matter what a person admits to his or her journal, the journal won't respond with pat answers or be judgmental. Journaling often helps people to clarify their jumbled thoughts, and in the process, allows them to understand their feelings. Often, writing about one's feelings can be enough to make one realize that everything isn't as bleak as it seems.

Matthew D. Lieberman, UCLA associate

## WRITER SPOTLIGHTS

Individuals with MS often try their hand at writing – and many, if not all, succeed! But as with any community of people, the styles and types of writing vary greatly. In this section, we are spotlighting three writers who each have MS, but have different styles of writings and different objectives. We hope that you will be inspired by their personal stories.

**Editor's note:** MSAA does not specifically endorse or recommend any of the following published works. The purpose of spotlighting these writers is to let readers know that members of the MS community can often excel with their writing, and that individuals may choose from any number of writing styles that best fit their interests.

### Carol Anita Ryan

One of Carol's last traveling adventures was to sail on a 36-foot boat across the Pacific. This is the basis for her memoir, *Right Now Is Perfect: A Romance, An Adventure, The Unexpected Thereafter*, published in 2010. It concludes with the unexpected diagnosis of primary-progressive multiple sclerosis, and the impact of progressing disability. The story is described as, "An imperfect romance on a crowded sailboat unfolds as the four-person crew sails among the beautiful, isolated islands of the South Pacific. French Polynesia, the Cook Islands, American Samoa, Samoa, Fiji and New Zealand are the landfalls you'll discover along the way."

Carol explains, "I was diagnosed in 1998 at age 50 with primary-progressive MS. It has affected my left side primarily and I can no longer stand nor use my left hand. One of the main advantages of writing and marketing a book has been to be a part of the writing community. With my mobility problems, it is hard not to become isolated. Attending book signings and writing groups is very stimulating. Talking about sailing allows me to forget for the moment my current situation."



professor of psychology and a founder of social cognitive neuroscience states, “This is ancient wisdom. Putting our feelings into words helps us heal better.” According to Medicine Web (at [www.medicineweb.com](http://www.medicineweb.com)), writing our thoughts and feelings to further psychological healing and personal growth is known as “therapeutic writing.” They list five benefits of such writing:

- Better coping with stress
- Reduced physical symptoms of certain diseases
- Fostering self-awareness
- Reducing anxiety
- Developing self-esteem

People often want to know how to get started with journaling. These ideas might be helpful:

**Write every day so it will become a habit.**

Start with ten minutes each day. If you're not

ready to write about your feelings, write about how your day went or how you hope the day will go. Write about your job, your significant other, your children, your landlord, your mother-in-law, your current symptoms, or whatever comes to mind. Can't move your left leg? Write about it. Feeling drained after being in the sun? Jot it down. Have a special prayer request? Record it in your journal. Eventually, you'll be able to write about the fear or anger your symptoms cause and which parts of your life you'd like to change.

**Don't worry about laughing or crying while you write**, since expressing emotions is therapeutic. Whether you're feeling silly, angry, or worrisome, it's okay to let those feelings show in your writing.

**Don't worry about how your words**

### Frank G. Poe Jr.

Frank retired after he was diagnosed with secondary-progressive MS. He later volunteered as a high school coach, and through his sports writing for the local newspaper, was able to make a difference for the students and prevent some of the sports programs from cancelation. Frank has written and published *Raven Wings and 13 More Twisted Tales* (2010) and *Star Child and 13 More Twisted Tales* (2012), short story collections written expressly for adults and not for children. In the abstract from his second book, Frank's writing is described as, “Rich with dark humor, his tales examine our relationships, society, religion, and even politics with alternative histories and flat-out science fiction.”

Frank states, “After a severe relapse in 1997, I battled back, regaining vision in one eye and walking with the help of a cane. I intend to bring attention to the disease and have pledged a portion of my book royalties to MS charities. I remain positive. Although I no longer coach, I share free information with students on poetry and creative writing, while encouraging them to become politically active.”



sound – journaling is meant to help express feelings, not to be graded by an English professor. If fear about inadequate grammar is holding you back, turn to online dictionaries and the grammar checkers in word-processing software.

Choose your favorite pen and write with flair! Journal writers can forget about the fountain pens I once used. If you prefer to write by hand, a wide assortment of pens and markers are available, including colored and/or scented gel pens and calligraphy markers.

### *Paper or plastic is your next choice!*

Today's journal keepers can choose from writing in plain composition books, decorative fabric-lined empty books, or on a computer screen. For people with MS who have difficulty with hand skills, it's often easier to type than to write by hand. Easier yet is using voice-to-text recognition software, such as "Dragon Naturally Speaking." Use whichever method is the easiest and most affordable for you!

If you like poetry, try your hand at writing some poems in your journal. You can find lots of tips on writing poetry at [www.creative-writing-now.com](http://www.creative-writing-now.com). It's up to you whether you want your poems to rhyme. Online rhyming dictionaries, such as the one at Rhyme Zone, [www.rhymezone.com](http://www.rhymezone.com), can be helpful. Merriam-Webster's Rhyming Dictionary can be purchased at [www.amazon.com](http://www.amazon.com) or at your local bookstore.

Try writing personal essays to focus on a particular circumstance that you want to

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expound on. Begin by making an outline with an opening statement that briefly summarizes your main ideas and your point of view. State three points of interest without explaining them. Write a closing statement by rephrasing your introduction. Then, go back and fill in each main point. Let your feelings flow as you write and don't think about grammar until you're finished.

Fatigue is a common symptom of MS, so you might not always have the energy to write all of the time. On those days, the most you might be able to write is, "I'm too tired to write." That's okay. Just write that sentence, but don't let your illness stop you

altogether.

Laura Hillenbrand, the author of *Seabiscuit* and *Unbroken*, has dealt with debilitating chronic fatigue syndrome since 1987. She typed *Seabiscuit* with her laptop perched on a stack of books when too dizzy to look down. When too weak from her illness to sit up, she typed lying in bed. Hillenbrand was homebound and largely bedridden for two years while writing *Unbroken* as she dealt with overwhelming exhaustion, weakness, muscle and joint pain, memory problems, and vertigo.

Knowing Hillenbrand's background makes it possible to see her own struggle in the stories she writes about other people who face obstacles. Not everyone with a disability will write bestselling novels, but everyone who wants to write can use writing

as a way to get through the hardest parts of having a disability.

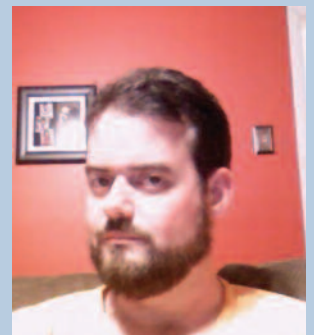
People who journal sometimes want to learn more about the craft. *The Elements of Style* by Strunk and White and *The Associated Press Stylebook* are great reference books to purchase. An online writing class, or one at the local college, can also help expand writing knowledge.

Some journal keepers might want others to see their writing. A search for "free blogs" brings up several sites where journal writers can share their thoughts with others through online blogs. (The term "blog" can be used as a noun or a verb, but in general, refers to a website typically containing brief blurbs with comments and personal opinions from one or more individuals.) Another way to showcase your blossoming writing skills is through

## Joshua Evitt

"I had been teaching high school English for about four years when I started having problems," Josh explains. "After a rather sudden loss of feeling, followed by Lhermitte's sign [a lightening-like sensation down the back when the neck is flexed], a clear diagnosis was made. I have used my abilities with written language to act as a vent when needed. While I cannot draw much (picture a kid who almost failed art class), I find an adequate outlet in the written word. I do not limit my writings to MS; I wrote all through college and I now compose poems for my wife and daughter. Given the symptoms of MS, I have had to take on rather less active diversions, and I find solace and some consolation in my writing."

Josh finds comfort in writing poetry about his MS. His ongoing work, *My Affair with MS*, is "a sonnet cycle of my dealings so far with MS that hopefully will finish with an end to the disease." He writes prose about his experiences with MS – including symptoms, treatments, concerns, and hope for the future.



penning letters to editors of local newspapers. When you feel strongly about a particular topic or an article in the newspaper, pen a letter to the editor. If you do this once a month, people will begin to recognize your name. Clip and save each of your published letters.

To develop more published pieces, volunteer to compose newsletters for your church, your child's Scout troop, or your classic-car club. Scan and send copies of your published letters and newsletters to your favorite online sites with ideas for articles you'd like to write. Sites such as [www.about.com](http://www.about.com) offer information about a vast variety of topics and allow aspiring writers to become recognized lay experts in the areas they choose to write about. Print and save any articles that you publish online. Soon, you will have a fulfilling hobby that helps you express yourself and that familiarizes online editors with your writing.

If you want to take your writing a step further to earn some income, send your published articles and letters to community newspapers, local magazines, and nearby businesses with a resume and a cover letter offering your writing services for a fee. Nearby businesses might use your talents to write content on their website. Local magazines could possibly use an article about any number of things – such as couponing, car repair, or the best fishing spots in your county. Community newspapers, for example, might want you to write a column on parenting with a disability. Another option is to purchase a copy of *Writer's Market* to find

publications that might publish your work.

Last but not least, for individuals who are truly inspired, options such as writing and publishing a how-to book, a memoir, a fictional novel, or even a screenplay, are all within the realm of possibilities! Of course, this requires a tremendous amount of work and dedication, but the end product can be greatly rewarding. For anyone without formal training, instructional books and computer software are available to assist you through the process. These may be found by going to your favorite book retailer or online bookstore. Adult-school classes at your local high school or community college are sometimes offered as well. A recent addition to MSAA's Lending Library is the book, *Writing Books for Fun, Fame & Fortune*, which may help you to get started. (Please see page 48 for more information.)

Remember, it's up to you as to how far you want to go. Most journal keepers don't seek an audience for their writings – they simply want a safe place to free their emotions – and doing so can often help individuals to feel better. Others may desire to put their written works out to the public, maybe as a blog entry or a letter to the editor. And for the most ambitious... magazine articles, novels, and even screenplays may be in your future! Whatever you choose to do will no doubt give you pleasure and promote personal growth. Writing is a therapeutic, fun, and sometimes profitable way to express yourself... so pick up your favorite pen and paper, or turn on the computer, and start writing! ♦

# Stories to Inspire

## A Card Game with Numbers Adds Up to Success

By Beth Lawler

My father, Kevin Lawler, was diagnosed with MS in 1976, at age 36. In the days of no MRI's (magnetic resonance imaging), it took a few years of symptoms before the diagnosis became clear.

By 1986, he was in a wheelchair and had to stop working as a commercial real estate broker. By 2000, it became necessary for him to go to a nursing home. He has now been there for 12 years and my mother, Anne, visits him there daily after her workday in New York City.

My dad is an incredible survivor. He keeps an amazingly upbeat attitude, every day, even though his body has completely failed him and he cannot do anything for himself. The simplest tasks that most people take for granted, like sipping a drink, are a challenge to him. In spite of this, he never feels sorry for himself and does not expect others to feel sorry for him either. He is always positive and happy – everyone at the nursing home is amazed by his attitude, his ability to laugh and joke with them, and his desire to entertain people.

One of the things that has kept him busy in the nursing home is a numbers' card game that he invented, called "Arithmecards." In



*Anne and Kevin Lawler, Beth's parents, who both possess an upbeat and inspirational attitude toward any challenges that come their way.*

this game, he lays out eight cards (each labeled with a number between one and nine), and uses the four mathematical functions (addition, subtraction, multiplication, and division) through seven of the cards, to "equal" the eighth card.

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***"He is always positive and happy – everyone at the nursing home is amazed by his attitude, his ability to laugh and joke with them, and his desire to entertain people."***

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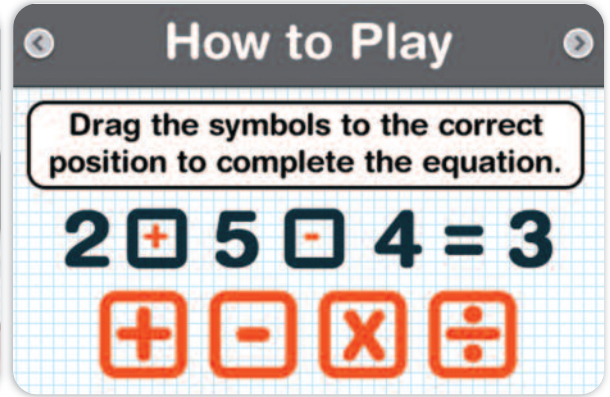
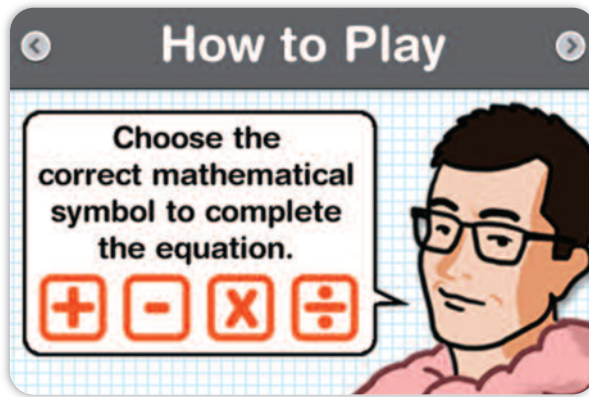
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My dad has since developed this game into an app, and renamed it "App-ithmetic." It is available now on iPhones, iPods, and iPads. Presently, the app is available for free download via the Apple iTunes store. He is so excited, as this game has been his lifeline

over the years, giving him something to focus on and giving him a goal – to make this game a success. We

are all hopeful that the game will become popular and perhaps even profitable for him, however, just having it available as an app is a huge achievement for my dad in itself.

My father is truly an inspiration to all who meet and work with him. He has risen above his daunting circumstances and is a role model to all who know him. ♦



*App-ithmetic – free at the Apple iTunes store – is an accessible and fun game consisting of arithmetical puzzles. With different levels of difficulty, it will challenge both beginners and experts alike, while helping to keep math skills sharp.*

2012 MSAA

# Art Showcase

The theme this year is “**Change**” – a reflection on positive changes in the life and experiences of the artist.

We received **83 works of art submitted by 39 artists living with MS** throughout the country.

We are delighted to be able to present to you this artwork and we hope that you, too are inspired.



Lois Flanigan,  
**Old Friend**  
2012 Art Showcase

Please enjoy the online gallery of the 2012 Art Showcase by visiting [msassociation.org/artshowcase2012](http://msassociation.org/artshowcase2012)



# Spread the Word

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

Written by Dawn A. Marcus, MD  
Published by Demos Health  
MSAA Book #10



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

## *Writing Books for Fun, Fame & Fortune*

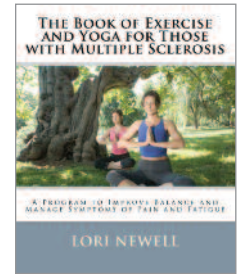
Written by Rik Feeney  
Published by Richardson  
Publishing  
MSAA Book #11



This book provides inspiration and instruction for writing your own nonfiction book – whether the topic is business expertise, personal experience, or anything you are passionate about that may be of interest to others. Well-written and sometimes humorous, this resource gives “sure-fire methods” to guide readers through the steps required to publish and market a book of their own.

## *The Book of Exercise and Yoga for Those with Multiple Sclerosis: A Program to Improve Balance and Manage Symptoms of Pain and Fatigue*

Written by Lori Newell, MA  
Published by CreateSpace  
MSAA Book #218



Author Lori Newell is a certified health and fitness specialist, as well as a certified yoga instructor, with more than 25 years of experience. In her book, Newell provides instruction on a wide variety of movement therapies, such as range-of-motion exercises, low to no-impact aerobics, strength training, and yoga. Many of these movement techniques are specifically geared to individuals with MS and accommodate a wide range of abilities.

## *MSAA Lending Library*

*To borrow books featured in this column or any other book in MSAA's Lending Library, please send us your name and address. We will send you an application and a list of books for the Lending Library. MSAA and its clients greatly appreciate any donations made to help build the Lending Library. If you would like to donate a book to the Lending Library, you need only send it to us at the address below. Please address all correspondence to:*

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**(Please reference book number)**

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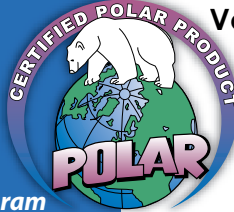
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**Please note:** MSAA is *not* distributing free mobile phones. A mobile phone application (or "app") through the iTunes store is available as a free download to individuals with MS or their care partners to use on their iPhone, iPad, or iPod touch.