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ASSOCIATION OF AMERICA

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Summer/Fall 2015

THE Motivator

Published by the Multiple Sclerosis Association of America

Wellness in MS

THE IMPACT OF
NUTRITION, EXERCISE,
AND OTHER STRATEGIES

A Special Message from
MSAA's President and CEO

Aquatic Exercise
Video Now Available



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



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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A portion of this magazine has been printed on recycled paper using soy-based ink.

Now and Then

By Douglas G. Franklin

MSAA President and CEO

This title seems particularly timely as I am writing what is probably my last column as President & CEO of MSAA. I am retiring at the end of this year, and with MSAA's move to our new headquarters at 375 Kings Highway North in Cherry Hill, New Jersey, I was transferring old files when I came across the Spring 1999 edition of *The Motivator*... where I wrote my first column. That article talked about a new beginning for MSAA and my desire to lead the organization into the 21st century, finding more effective

ways to help people with MS live fuller lives. As I begin to close my chapter here, fulfilling 41 years of nonprofit management work, I can look back on my charity career as well as my tenure at MSAA as something that was nothing short of a blessing to serve.

MSAA has improved so many lives during my 16-year tenure and we have enjoyed the dedication and professionalism of so many hard-working employees and volunteers. It has truly been a team effort in every sense and I am so very proud and so very fortunate to have had the privilege of leading this dynamic group of professionals.

In 1999 I spoke about applying social marketing principles, which has the potential of changing the way people think, feel, and act. Helping private-sector companies realize that social investment is essential and strategically in their best interests was imperative to the growth of our programs and services. In 1999 when I arrived, MSAA had no corporate partners. Today we receive support from more



As Doug Franklin prepares for retirement, he reflects on his 16 years of service to MSAA by referring to an archived issue of The Motivator. This particular edition was published in the spring of 1999, introducing our new president and CEO to the MS community.

Doug Franklin stands happily by the window in his office at MSAA's new headquarters. One of his primary initiatives before leaving MSAA was to orchestrate the sale of the former building – which was no longer a fit for MSAA's needs – along with the purchase of a new, more appropriate home office, where efficiency and cost savings could be maximized.



than two dozen and we do so in a way that is transparent and mutually rewarding. We could not do all the things we do to help people with MS without the support of our partners. We're all here to help people with MS and that is the benchmark we focus on in every partnership.

When I began work for MSAA, there was a strong need for collaboration between the various MS organizations. Working together we formed the Multiple Sclerosis Coalition, creating collaborative partnerships that aspire to coordinate better service delivery and eliminate gaps in service. Speaking with a collective voice on public policy matters that affect our MS constituency has been critical to gain support for important access to care issues. It was my privilege to lead the MS Coalition as its President for nine years. My thanks to all of the other seven member organizations that make up the MS Coalition for their invaluable support and sincerity in always putting the person with MS first.

Honesty and integrity are the social mortar that holds a foundation together. MSAA has built one very solid organization that is praised across the country for its compassion and its kind, caring approach to embrace people with MS and walk their journey with them each and every day.

“IMPROVING LIVES TODAY” is more than just our tagline. It is a clarion call to action that everyone at MSAA lives each day, knowing that together we can make good things happen. We all know that it is truly in giving that we receive!

I have been fortunate to have had so many opportunities to work with many great people at this incredible association. The privilege, the pleasure, and the honor to serve as leader of this great organization have been all mine. ■

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

WELLNESS in MS



**The Importance of Nutrition,
Exercise, and Other
Vital Strategies**



UNLOCKING THE MYSTERY OF NUTRITION *Learning about Good Food Choices*

“What are we having for dinner?” is probably one of the most common questions that is asked each and every evening across America. So many choices are available! Whether dining at fast-food restaurants or gourmet eateries, ordering take-out, having a pizza delivered, or cooking at home – deciding on an option can be overwhelming... much less deciding on a healthy one!

So how do we know what choices are healthy? Throughout the media, you'll find countless diets and eating guidelines that we are encouraged to follow. Here is just a short list of the many diets that have been

Written by Amy McKay, M Ed, CSCS, CES

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Edited by Susan Courtney

developed for specific groups of people... these include the Zone Diet, the Atkins Diet, the Swank Diet, the Wahls Protocol, Weight Watchers®, the Caveman Diet, gluten-free diets, vegetarian, and vegan diets. Please see pages 14 through 16 for summaries of many popular diets.



ABOUT THE AUTHOR

Amy McKay is an Assistant Professor at Tarleton State University in Stephenville, Texas. She is a certified Strength and Conditioning Specialist for the National Strength and Conditioning Association, a certified Corrective Exercise Specialist with the National Association of Sports Medicine, a certified Sports Nutritionist and Specialist in Exercise Therapies with the International Sports Science Association, a certified Personal Trainer with the Aerobics and Fitness Association of America, and a Youth Nutrition Specialist with the International Youth Conditioning Association. She is an avid marathoner and tri-athlete. Amy believes that modifying exercise is necessary for everyone and strives to “find a way” for all to be involved. Her personal motto is to make every day “the best day ever!”

Please note that the information provided in this article is for educational purposes only and should not be considered as specific medical advice. Individuals should consult their physician before making any changes to their diet and nutrition, exercise and activities, or other lifestyle routines.

And then we have the SAD Diet. The SAD Diet, aka Standard American Diet, has swept across the nation and may soon be the most popular nutrition program in the land. The SAD diet primarily consists of highly processed foods, fast-food, and food with little to no nutritional value. The SAD Diet lacks the ability to keep anyone healthy, especially if you have MS. All of these diets have left us wondering how we, as Americans, have taken the simple act of fueling our bodies and locked it in a box that would even intrigue Pandora!

On the following pages are the six essential keys to good nutrition, a sample list of healthy foods, and tips for healthy eating. Two mobile-phone apps to assist with recording and learning about foods

are also noted. Readers may find this information to be very helpful in designing an ideal diet plan for their own needs, under the supervision of their own doctor.

THE BASICS OF NUTRITION:

Six Essential Keys for Unlocking the Mystery

In an effort to learn more about nutrition, let's start with the basics. Six key groups are used to categorize the food we eat. Everything we eat consists of: (1) fats, (2) carbohydrates, (3) proteins, (4) vitamins, (5) minerals, and (6) water. I also teach my clients that unprocessed foods, whole foods, and REAL foods (foods that **R**elease **E**ssential **A**ntioxidants for **L**ongevity) are a better choice when it comes to healthy eating.

Key # 1: Two Sub-Types of Fats (or Lipids)

Saturated fats are typically solid at room temperature and include margarine, shortening, lard, and butter. I recommend avoiding margarine and shortening, and lard is not a good choice for anyone given the high fat content. However, if you enjoy using butter, I recommend that you do so in moderation.

Unsaturated fats are liquid at room temperature. These are often good REAL choices and include olive oil and peanut oil. Although the following oils are unsaturated, I encourage my clients to avoid these due to their unhealthy high omega-6 ratio: canola oil, corn oil, cottonseed oil, grapeseed oil, rapeseed oil, rice bran oil, safflower oil, sesame oil, soybean oil, and sunflower oil.

Key # 2: Two Sub-Types of Carbohydrates

Complex carbohydrates are great sources of long-lasting energy. All fruits and vegetables fall under the complex carbohydrate umbrella. I frequently remind my clients that complex carbohydrates are a great source of fiber. A diet high in fiber has been shown to reduce the risk of colon cancer and will also aid in a “regular” elimination schedule! If approved by your doctor, I encourage you to consume five servings of fruit and veggies daily. Whole-grain breads, whole-grain pastas, and brown rice round out this sub-type.

Simple carbohydrates create a quick blood-sugar rush when you eat them. Overconsumption of simple carbohydrates (sugars) has been shown to increase the risk of being diagnosed with type 2 diabetes. I advocate for limiting the consumption of

sugary drinks, juices, candy, cake, and all refined white flour. I’d like to offer the same suggestion in regards to eating less artificial sweeteners as well.

Key # 3: Two Sub-Types of Proteins

Complete proteins contain each of nine essential amino acids that we need to build healthy muscle tissue. All foods of animal origin are considered complete proteins. Most Americans get plenty of protein. For my clients who eat meat, I steer their grocery cart to leaner cuts of meat and low-fat dairy products. Aim for a minimum daily consumption of 55 grams of protein. The more active you are, the more protein you will need.

Incomplete proteins are also great sources of protein, even though they are missing a few amino acids. Nuts, seeds, and legumes are healthy options that complete this REAL food choice. Let’s keep eating them! By carefully combining incomplete proteins, my vegetarian clients are able to stay strong, vibrant, and healthy. If you are considering a vegan lifestyle, which means no animal products whatsoever, I recommend that you educate yourself and consult your doctor on the proper way to combine incomplete proteins to ensure your good health.

Key # 4: Two Sub-Types of Vitamins

Water-soluble vitamins simply dissolve within the body and are excreted when the body has absorbed what it needs to maintain good health. In my family, we make a conscious effort to eat healthy, but there are still pieces missing from our nutrition puzzle,



so I believe in taking a daily multiple vitamin. Readers should check with their doctor to see if vitamins are appropriate for them and the medications they are taking. Water-soluble vitamins include the nine different B vitamins and Vitamin C.

Fat-soluble vitamins include Vitamins A, D, E, and K. I ensure that my clients eat healthy amounts of REAL fat in their daily diet so that these fat-soluble vitamins can work within the body. The healthy amount of REAL fat is about 2 tablespoons of foods such as olive oil, coconut oil, or nut butters spread out through your day. In our house, we enjoy adding a tablespoon of almond butter to our morning smoothies. Another easy way to get healthy fats in your diets is toss fresh vegetables in olive oil before roasting or grilling.

With regard to Vitamin D, a deficiency in this vitamin is common among individuals with MS. For that reason, Ben Greenberg, MD, of the University of Texas Southwestern Medical Center says, “More than 75 percent of our patients have suboptimal Vitamin D levels. Given changes in diet and the environment over time, we are not consuming or activating as much Vitamin D3 as we used to, hence I recommend supplementation for all of my patients [with Vitamin D deficiency] to achieve more optimal levels.”

Key # 5: Minerals

Minerals are often the lost key to unlock great nutrition. Common minerals such as calcium, potassium, and magnesium are used for good bone and teeth health, energy production, nerve and muscle function, and immune-system health. If approved by one’s doctor, I recommend that all my clients take a mineral supplement. Similar to vitamins, readers should check with their doctor to see if minerals are recommended and safe with the other medications they may be taking.

Key # 6: Water

Water is the “master key” to open up each of the above nutrients. If you are chronically dehydrated, you may be feeling weak, fatigued, drowsy, or impatient. You could also be experiencing anxiety, depression, headaches, and constipation. Dr. Greenberg explains, “We routinely live life dehydrated. This puts stresses on our body that add up over time.”

Editor’s note: While avoiding dehydration is important, too much water can create unnecessary problems for people with MS-associated bladder dysfunction. Individuals should check with their doctor to see how much water is appropriate for them.

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

Important Safety Information

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

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

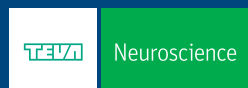
Reference: 1. COPAXONE® (glatiramer acetate injection) prescribing information. Rev. 1/2014. Teva Neuroscience, Inc.

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



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3-times-a-week COPAXONE[®] 40 mg offers:

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- Injection-free weekends*

*Injections must be at least 48 hours apart.



Treatment on your terms

COPAXONE[®]
(glatiramer acetate injection)

Important Safety Information (cont'd)

Call your doctor right away if you develop hives, skin rash with irritation, dizziness, sweating, chest pain, trouble breathing, or severe pain at the injection site. If any of the above occurs, do not give yourself any more injections until your doctor tells you to begin again.

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

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

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

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

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

Patient Information

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

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

What is COPAXONE?

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

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

Who should not use COPAXONE?

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

What should I tell my doctor before using COPAXONE?

Before you use COPAXONE, tell your doctor if you:

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

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

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

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

How should I use COPAXONE?

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

What are the possible side effects of COPAXONE?

COPAXONE may cause serious side effects, including:

- **Post-Injection Reactions.** Serious side effects may happen right after you inject COPAXONE at any time during your course of treatment. Call your doctor right away if you have any of these post-injection reaction symptoms including:

- redness to your cheeks or other parts of the body (flushing)
- chest pain
- fast heart beat
- anxiety
- breathing problems or tightness in your throat
- swelling, rash, hives, or itching

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

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

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

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

The most common side effects of COPAXONE include:

- skin problems at your injection site including:

- redness
- pain
- swelling
- itching
- lumps

- rash
- shortness of breath
- flushing (vasodilation)

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

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

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

How should I store COPAXONE?

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

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

General information about the safe and effective use of COPAXONE.

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

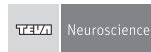
This Patient Information Leaflet summarizes the most important information about COPAXONE. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about COPAXONE that is written for health professionals.

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

What are the ingredients in COPAXONE?

Active ingredient: glatiramer acetate

Inactive ingredients: mannitol



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Distributed by: TEVA Pharmaceuticals USA, Inc., North Wales, PA 19454

Product of Israel

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

COP-41059

Unlocking the Box

Now that you know the basic keys to nutrition, let's unlock the box and begin to put a nutrition plan in action! If you are already following a diet plan under the advice of your doctor, and it is working for you – then stick with it! I applaud you for knowing what works best for *your* body.

If you are still trying to develop an eating strategy for optimal health, begin to pay attention to how you feel after you eat certain foods. Some foods may leave you feeling sluggish, moody, or tired. Other options will leave you feeling satiated and happy for hours! This is our goal: to help you build a meal plan that keeps you at your best.

HEALTHY CHOICES Healthy eating can be delicious and nutritious! If approved by your doctor, try to add the following foods to your grocery list.

AVOCADOS



Filled with heart-healthy monounsaturated fats; helps to lower LDL (bad) cholesterol

NUTS AND SEEDS



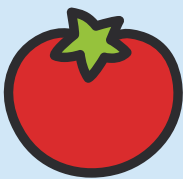
Can help lower cholesterol, boost brain power, and battle against stress and heart disease

OATS



This humble grain can lower cholesterol and is loaded with fiber to help you feel full longer

TOMATOES



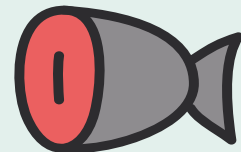
Loaded with lycopene, which protects against heart disease and prostate cancer

BEANS



Nutritional dynamos that are low in fat and filled with protein, fiber, and folic acid

FISH



Rich in omega-3 fatty acids, fish can boost mood, fight depression, and pack a protein punch

BERRIES



Fresh or frozen berries are packed with antioxidants, Vitamin C, and potassium

GREEK YOGURT & COTTAGE CHEESE



Loaded with calcium and protein; plain yogurt contains healthy probiotics ("good" bacteria) to assist with digestion

EGGS



A nutritious, versatile, economical, and great way to pack in some protein

I also recommend using MSAA's My MS Manager mobile phone application. This valuable app is available for your mobile device at no charge to help you log your notes about diet, nutrition, and how you are feeling after eating certain things.

Another app that I encourage each of my clients to use is MyFitness Pal. In my opinion, it is your new best pal for determining calorie content and nutritional content of everything, and it's easy to use! Both apps are free and may be downloaded from Apple or Android app stores.

Remember that no two people are exactly alike, and therefore, no two nutritional plans are exactly alike either. Unlock and open up an eating plan that puts you in the best possible health so that you can manage your MS powerfully. Unlocking the nutrition box should be FUN and delicious!

Each time I go to the grocery store, I try a new item from the produce department. New thoughts and behaviors surrounding food can be hard to create. Check out a book about nutrition, watch a healthy cooking show on TV to learn new ideas, or attend a healthy cooking class. Also, find an accountability partner. Having a buddy or a group of friends to encourage each other to eat REAL food helps to keep healthy eating habits in place.

On the previous page are healthy choices and shown below are tips for a better diet. On pages 14 through 16 are overviews of several popular diets. Please note that while no single diet has been proven to slow the course of MS, healthy eating in general may be beneficial for individuals with MS – both in terms of better overall health as well as a reduction in the risk of other medical conditions.

EATING WITH YOUR HEAD: 10 Tips for Healthier Eating

1. Eat a source of **fat, protein, and complex carbohydrates** at each meal.
2. Eat your meals on **smaller plates** and learn the importance of **portion control**. A serving size of protein is the size of your palm, and the stomach is about the size of a quart-size Ziploc-type bag.
3. Read the label. Most **processed foods are packed with un-REAL ingredients**.
4. Drink adequate amounts of **water**.
5. Ideally, choose to eat **only whole grains**.
6. Take your grocery shopping trips **when you are alert and full** instead of tired and hungry.
7. Eat foods that are **in season**, when foods are at their **peak nutritional value**. Find out what's in season at bit.ly/seasonalproduceguide.
8. If you are in a situation where you want to eat a decadent treat or dessert, try using the **Three-Bite Strategy**. Savor each of those three bites and then push it away!
9. Try to **eat the fruit instead of drinking the juice**. Orange juice creates a sugar rush, while a whole orange provides three grams of fiber!
10. **Slow down your entire meal-time routine**. Put your fork back down on your plate between bites. Take a sip of water between bites. Let your body tell you when it is satisfied.

Popular Diets

Several well-known diets are available for individuals with certain goals in mind, such as losing weight, improving health, or reducing the risk of developing other conditions, such as diabetes and heart disease. To follow are highlights of some of the major diets used in the United States to help with these different dieting goals. This list was compiled by Dr. Lacey Bromley, a physical therapist who specializes in neurological and vestibular rehabilitation. She is certified as a multiple sclerosis specialist and is currently completing her PhD course work in Rehabilitation Sciences, with an emphasis on how nutrients impact

immune-modulated diseases. For a list of references used, please contact MSAA at **(800) 532-7667**.

Doctors agree that eating a healthy diet to promote general wellness and prevent certain other medical conditions, could potentially have a positive impact on MS and its symptoms. Neurologist Dr. Allen Bowling specializes in MS. He has authored several books on this topic, including *Optimal Health with MS*. To follow are those diets that Dr. Bowling finds to be beneficial for overall health; additional diets are listed on page 16. Please note that MSAA does not endorse or recommend any particular diet.

■ TLC DIET

BASIC CONCEPTS

Therapeutic Lifestyle Changes, also known as the **TLC Diet**, is a dietary pattern recommended by the National Cholesterol Education Program, part of the National Institutes of Health, to control high cholesterol. This pattern focuses on reducing saturated fats and cholesterol, while also focusing on weight control and physical activity. Physical activity must be maintained regularly along with the diet, with at least 30 minutes of exercise each day.

RESTRICTIONS/SPECIAL CONSIDERATIONS

No food restrictions are included; however, general guidelines include:

- Intake of saturated fat needs to be below 7 percent of the total calorie intake.
- Daily cholesterol needs to be below 200 milligrams.
- Sodium intake is limited to 2,400 mgs per day.
- A total of 25 to 35 percent of daily total calories should come from fat intake.

■ WEIGHT WATCHERS DIET

BASIC CONCEPTS

Weight Watchers *PointsPlus*® program, launched in November 2010, assigns every food a point value, based on its protein, carbohydrate, fat, and fiber.

RESTRICTIONS/SPECIAL CONSIDERATIONS

This program has no food restrictions, although nutrient-dense foods are given lower points so you can eat more and stay full longer.

DASH

BASIC CONCEPTS

The **DASH** diet (**D**ietary **A**pproaches to **S**top **H**ypertension) is a dietary pattern promoted by the National Heart, Lung, and Blood Institute (part of the National Institutes of Health). It was originally designed to lower blood pressure and is not a weight-loss plan. The DASH diet is a healthy way of eating, designed to be flexible for the American lifestyle. Some consider it the Americanized version of the Mediterranean diet. It is rich in fruits,

vegetables, and low-fat or nonfat dairy. It also includes: whole grains; lean meats, fish, and poultry; plus nuts and beans. It is high in fiber and low to moderate in fat.

RESTRICTIONS/SPECIAL CONSIDERATIONS

This diet does not restrict specific foods; however, it discourages refined and processed foods.

MEDITERRANEAN DIET

BASIC CONCEPTS

The Mediterranean diet is inspired by the traditional dietary patterns of Greece, Southern Italy, and Spain. It was found that although these countries consume greater amounts of fat, they have lower rates of cardiovascular disease.

RESTRICTIONS/SPECIAL CONSIDERATIONS

No specific restrictions are included; however, this diet is based on:

- High intake of olive oil, legumes, whole grains, unrefined foods, fruits, and vegetables.
- Moderate intake of fish, dairy products (mostly cheese and yogurt), and wine.
- Low intake of non-fish meat and meat products.

VEGETARIAN DIET

BASIC CONCEPTS

The vegetarian diet has multiple versions:

1. Vegan or “total vegetarian” – This form of a vegetarian diet uses no animal products, including dairy. If done correctly, a vegan diet can reduce heart disease and other chronic disease linked to unhealthy eating. However, this type of strict diet can also cause certain nutritional deficiencies.
2. Lactovegetarian – This type of diet follows a Vegan diet, but adds dairy and eggs.
3. Semi-Vegetarian – The most common version of this is the “Pescetarian Diet,” which adds fish to the lactovegetarian diet.

RESTRICTIONS/SPECIAL CONSIDERATIONS

- Vegan diets are the most restrictive and foods eliminate ALL animal products, including eggs and dairy.
- Individuals using a vegetarian diet should consider that this eating pattern tends to be low in protein, iron, omega 3 fatty acids, Vitamin D, calcium, zinc, and Vitamin B-12. When done correctly with supplementation as needed, these diets can be heart-friendly and nutritious.

Other Diets

ATKINS DIET: This four-phase diet limits carbohydrates and leads to ketosis, a natural process that promotes weight loss and improved control of blood-sugar levels.

SWANK DIET: Roy L. Swank proposed his diet in 1948 for the treatment of MS. He observed that people with MS did better with less saturated fat (although never scientifically proven). Omega-3 fatty acids (oily fish, flaxseed, cod liver oil) and multi-vitamins/mineral supplements are recommended.

WAHLS DIET: Dr. Terry Wahls, who has MS, designed this diet to “feed” her mitochondria (cell structures that break down nutrients to create energy). Three levels help people transition to healthier eating. These start with reducing sugars and the removal of gluten, eggs, dairy, refined oils, and processed foods; then greater consumption of meats, seaweed, fermented foods, nuts, seeds, and raw foods; and finally increased amounts of non-starchy vegetables and fruit, daily coconut oil, while removing grains, legumes, soy, and white potatoes.

ZONE DIET: This diet strives to balance protein, carbohydrates, and fats to control three important hormones (insulin, glucagon, and eicosanoids). Based on your size, gender, and goals, you are given a meal plan that consists of “blocks” and a list of foods and proportions to fit those blocks.

Many other diets exist, including: the **PALEO DIET** (aka caveman diet), based on the belief that our bodies haven’t evolved and we need to eat as our caveman ancestors did; **GAPS** (Gut And Psychology Syndrome Diet),

which avoids certain carbohydrates with the rationale that these are difficult for the body to digest; **FODMAPS** (Fermentable Oligo-saccharides, Di-saccharides, Mono-saccharides, And Polyols), based on research showing that certain short-chain carbohydrates are poorly absorbed in the small intestine; and **gluten-free** diets.

According to Dr. Bowling, “There is an exciting new wave of understanding about diet and MS. Specifically, there is growing evidence that MS may be adversely affected by many of the dietary factors that we already know have negative effects on common medical conditions such as heart disease, obesity, and diabetes. These unhealthy dietary factors, which unfortunately are standard components of the average American diet, include relatively low intake of dietary fiber and polyunsaturated fats and relatively high intake of saturated fat, salt, and calories.

“I think that many people get excessively caught up in trying to figure out which exact diet is *best* for MS. To clarify this situation, I hope that we will have high-quality research studies of diet and MS over the next five to ten years. If these studies are done, my prediction is that there probably is not one exact diet that is best for MS, but that a positive effect may be derived by following a wide range of diets that are based on basic principles of healthy eating.

“What is ‘healthy eating’? To answer that question, I often quote the well-known nutrition writer Michael Pollan: ‘Eat food. Not too much. Mostly plants.’”

THE BENEFITS OF EXERCISE

Important Pieces to the Puzzle

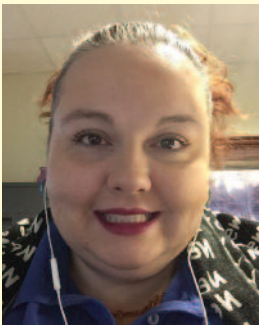


We all know that exercise is good for our overall health. However, Newton's first Law of Motion states that every object will remain at rest or in uniform motion in straight lines unless compelled to change its state by the action of external forces. The human body was designed to move, so you will need to exert some force to get your body moving! That being said, here are a few specific ways that exercise (and I am aware that some of you don't like the word "exercise"!), or "planned movement," shall we say, can improve your quality of life.

Dr. Greenberg explains, "A healthy diet and exercise program is essential to health. Our bodies and physiology developed over hundreds of thousands of years to be

incredible machines. They function despite tremendous abuse, but over time, this abuse takes a toll. A healthy diet along with exercise helps to control weight, improve cardiovascular health, and probably contributes to the health of the nervous system."

The best exercise is the one that you will do on a consistent basis and that you will enjoy. Our lives are often too busy to make time for exercise. A fun way to recognize the countless benefits of movement is to learn how the puzzle pieces fit together, so you can see the big picture. We'll first talk about how activity affects mood (on page 21), and then go on to give you five puzzle pieces (pages 22 and 23) – each with an area of health that may benefit from exercise!



Putting it All Together

Kim Caffey was diagnosed with MS in 2007. She has been able to improve her health by attending some of MSAA's educational events, featuring fitness and nutrition expert Amy McKay – who is also the author of this article. By employing her strategies for better nutrition and exercise, Kim has lost 30 pounds and is now enjoying a better quality of life!

While attending these MSAA educational events, Kim notes that she has learned about portion control, the importance of drinking water, and the value of exercise. According to Kim, "Making small changes to my bad eating habits helped a lot. I started exercising on the elliptical machine three times a week. There were some days that were hard but I pushed through them. If I was having a bad day, I would exercise sitting in a chair. My motto is 'baby steps.' One small change makes a world of difference! I feel better in general, which makes my MS more manageable. My goal is to live a long life."

For adults
with MS-related
walking
difficulties



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

Actor portrayal

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

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

IMPORTANT SAFETY INFORMATION

Do not take AMPYRA if you

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

Take AMPYRA exactly as prescribed by your doctor.

Before taking AMPYRA, tell your doctor if you

- have kidney problems or any other medical conditions

- are taking compounded 4-aminopyridine
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby.
- are breast-feeding or plan to breast-feed. It is not

known if AMPYRA passes into your breast milk.

- You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.
- are taking any other medicines

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

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



ampyra®

(dalfampridine) 10 mg
EXTENDED RELEASE TABLETS

THAT'S WHEN I ASKED FOR THE WALKING PILL

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

*Limitations and restrictions apply.

IMPORTANT SAFETY INFORMATION continued...

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

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

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

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

Please see the Patient Medication Guide on the following page.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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

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

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

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

AMPYRA can cause seizures.

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

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

What is AMPYRA?

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

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

Who should not take AMPYRA?

Do not take AMPYRA if you:

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

What should I tell my doctor before taking AMPYRA?

Before you take AMPYRA, tell your doctor if you:

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

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

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

How should I take AMPYRA?

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

What are the possible side effects of AMPYRA?

AMPYRA may cause serious side effects, including:

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

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

The most common side effects of AMPYRA include:

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

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

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

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

How should I store AMPYRA?

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

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

General Information about the safe and effective use of AMPYRA

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

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

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

What are the ingredients in AMPYRA?

Active ingredient: dalfampridine (previously called fampridine)

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

Distributed by: Acorda Therapeutics, Inc.

Ardsley, NY 10502

Issued 01/2014

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

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How Does Activity Affect Mood?

The Conversation between Brain and Body

By Charles Overstreet, PhD

Professor of Psychology

Tarrant County College, Fort Worth, Texas

Mental Health Consultant

A common question is, “**Should I exercise if I have MS or will it make my symptoms worse?**” Studies have shown that **prescribed exercise**, which is exercise that a physician recommends, does not appear to increase the severity of MS symptoms. Actually, increasing your activity can decrease your loss of function and increase strength and agility. **Depression and anxiety** can actually make symptoms of MS worse. While this sounds bad, the good news is that you can do something to counter these effects. Increasing activity and exercise has been shown to have positive effects on mood, including the reduction in the symptoms of both depression and anxiety in people with MS.

Let’s look at some positive effects of exercise on mood:

Exercise and activity increases **resilience (hardiness)** by providing body feedback that is the opposite of feeling weak. This raises **confidence**, which in turn reduces anxiety.

An **increase in activity** changes brain chemistry and can **reduce symptoms of depression**. Depression reduces motivation. Motivation reduces depression. Be motivated to be active, both physically and socially. The social isolation that results from pain and loss of function can cause depression. Activity, including exercise and social connection, can reverse symptoms of depression.

Emotion affects posture, but posture also affects emotion. So, a positive change in **posture**, as well as facial expressions, can have a positive effect on mood. Paying attention to posture by sitting-up straight, standing straight, keeping eyes raised, and making eye contact, along with a positive facial expression, can all have a profound effect on mood.

And...your **thinking** changes when you plan, carry out, and complete an exercise regime by increasing **confidence**. This requires you to be more **proactive** and gives you a sense of control, reducing anxiety. The disease causes you to be **reactive** and promotes **pessimism**. Being **proactive** promotes **optimism**, which is a much healthier state of mind.

Talk about it. Make positive statements to others about your progress. This changes your thinking and promotes positive changes in facial expressions and posturing, which encourages positive emotions. Even your tone of voice is a feedback loop. You hear your own voice when you speak – its pitch, loudness, and the content of your speech. Make a hopeless statement and you’ll become frustrated or sad. Optimistic statements tend to lift your mood.

Repetition and time are necessary for your new activity level to become familiar, so stick with it. Anticipate positive results. Take notice when there are signs of improvement in your functioning, including your daily activities, and enjoy the success!



How the Benefits of Exercise **PIECE TOGETHER** for Overall Health

BLOOD PRESSURE

HOW THIS PIECE FITS: Exercise dilates blood vessels. It also helps you burn excess fat, which further reduces blood vessel constriction. On average, losing five to ten pounds of weight leads to a drop in systolic pressure of up to eight points. This is the same amount that some blood pressure medications can achieve.

WHAT TO TRY: Exercises that get your heart rate up are ideal. Depending on your level of ability, try swimming, attending a water aerobics class, walking, cycling, or participating in armchair exercises. If possible, you may want to gradually work your way up to participating in exercise for three-to-four times per week, and for some, as much as 45 minutes per session. You will want to achieve a time period that works best for you, depending on your doctor's recommendations... and enjoy a beneficial effect on blood pressure!

COGNITIVE PERFORMANCE

HOW THIS PIECE FITS: Exercise promotes the growth of blood vessels in the brain, which can combat mild cognitive impairments. Researchers at the University of North Carolina at Chapel Hill School of Medicine took images of the brain in 14 older adults and found that those who were aerobically active had a greater number of small blood vessels. Their vessels were also wider, allowing for better blood flow, and had less "tortuosity" or twisting, which can weaken blood flow.

WHAT TO TRY: Learn any aerobic exercise that requires you to use your memory and coordination at the same time. Some may find dancing to be a fun way to exercise! You may feel like you have two left feet, or two left arms in the beginning, but it will become easier as your brain makes the connections with your muscles. By getting out of your comfort zone, you can enhance your overall fitness, and have fun at the same time. Remember that dancing with a cane, walker, or in a wheelchair is a great way to enjoy exercise as well!

ARTHRITIS

HOW THIS PIECE FITS: Just like your muscles, your bones need blood supply to stay strong and healthy. Any physical activity increases blood flow and can therefore help your bones and joints receive oxygen and nutrients. Oxygen and nutrients can also help repair and rebuild damaged tissues.

WHAT TO TRY: Activities such as yoga, cycling, swimming, and water aerobics all offer movement that is constant, while providing the benefit of little to no impact on stiff or sore joints. Steering away from high-impact exercises is recommended. Aquatic exercise has the added benefits of buoyancy, a cool temperature, and other factors that can make it an ideal exercise for many individuals with MS. For tips and resources, please check out MSAA's Swim for MS online Aquatic Center at aquatics.mymsaa.org.

GASTROINTESTINAL ISSUES

HOW THIS PIECE FITS: When your body is moving, your gastro-intestinal (GI) system is moving as well. Exercise is one of the best tools used to combat constipation problems. Exercise also helps to relieve stress, so it can relieve some of the triggers associated with irritable bowel syndrome.

WHAT TO TRY: Exercises that use the lower extremities help the bowels move regularly and more efficiently. Walking, running, and cycling are all great choices, depending on your level of ability. If you have limited movement in your lower body, consider using passive assisted range-of-motion exercises. A licensed physical therapist or a certified Corrective Exercise Specialist could teach you this form of individualized exercise.

NEUROPATHY

HOW THIS PIECE FITS: The secretion of inflammatory chemicals may trigger neuropathic pain. Regular exercise can reduce the secretion of these chemicals. Exercise also releases natural opioids in the brain that have a relaxing effect on the brain's pain receptors.

WHAT TO TRY: A recent study at Louisiana State University found tai chi to be a great form of exercise for people with neuropathy. The slow, intentional, repetitive, and continuous patterns in tai chi bring a multitude of benefits to the participants.

MAINTAIN YOUR FRAME

Better Posture for Better Living



Have you ever wondered what your closet would look like if there were not any hangers for your clothes? All of your clothes would end up on the floor in a messy and unorganized pile. Within our bodies, our skeletal system acts like hangers, providing support for our muscles, connective tissues, and internal organs. Our skeletal system provides a structural framework for our bodies.

We need to keep our spines aligned to be able to enjoy the benefits that great posture can bring to our lives. Bad posture can make your neck creak and your shoulders ache, but recent research shows that the negative effects go well beyond what you might expect.

So heads-up! Here are some interesting ways that posture can affect you – and ways you can get out of the slump.

A sad posture deepens depression

In a recent study from the San Francisco State University, students were told to either walk down a hall in a slouched position or to skip. The slouchers reported increased feelings of depression and lower energy than the skippers. In fact, even our language reflects this connection between proper posture and emotional affect – someone weak is called “spineless” and someone strong “has a backbone”!

This picture demonstrates the poor posture that many people who use canes or walkers have. The spine is flexed forward creating added stress on each muscle connected to the spine. In addition, the field of vision is DOWN, instead of up and in front of you. Look up and out at the world around you!



This photo shows proper posture with the support of an assistive device. Notice that the spine is in its proper alignment for functional and efficient movement throughout the day. It is also hard to hide the SMILE on his face because he feels better and is ready to face the day.



Photos: Kurt Mogonye

FOR RELAPSING FORMS OF MULTIPLE SCLEROSIS (MS)



**ONE PILL
ONCE A DAY***

**HALF THE
MS RELAPSES***

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

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

Join the more than **115,000** people who have been treated with GILENYA worldwide. This includes people in clinical trials and those prescribed GILENYA by their doctors—and every one of them is saying **"HEY MS, Take This!"**

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

IMPORTANT SAFETY INFORMATION You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or warning stroke, or certain types of heart failure.

Do not take GILENYA if you have an irregular or abnormal heartbeat (arrhythmia), including a heart finding called prolonged QT as seen on an ECG, or if you take medicines that change your heart rhythm.

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

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



*Talk to your doctor to see
if GILENYA is right for you.*

gilenya.com



IMPORTANT SAFETY INFORMATION

GILENYA® may cause serious side effects such as:

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

- Increases in blood pressure (BP). BP should be monitored during treatment.

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

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

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

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

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

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see additional Important Safety Information on previous page.



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

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

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

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

GILENYA may cause serious side effects, including:

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

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

After you take your first dose of GILENYA:

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

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

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

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

- fever
- chills
- tiredness
- nausea
- body aches
- vomiting

3. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as an MS attack (optic neuritis). You may not notice any

symptoms with macular edema. If macular edema happens, it usually starts in the first 3 to 4 months after you start taking GILENYA. Your doctor should test your vision before you start taking GILENYA and 3 to 4 months after you start taking GILENYA, or any time you notice vision changes during treatment with GILENYA. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye called uveitis.

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

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

What is GILENYA?

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

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

Who should not take GILENYA?

Do not take GILENYA if you:

- have had a heart attack, unstable angina, stroke or warning stroke or certain types of heart failure in the last 6 months
- have certain types of irregular or abnormal heartbeat (arrhythmia), including patients in whom a heart finding called prolonged QT is seen on ECG before starting GILENYA
- are taking certain medicines that change your heart rhythm

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

What should I tell my doctor before taking GILENYA?

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

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

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

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

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

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

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

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

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

How should I take GILENYA?

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

What are possible side effects of GILENYA?

GILENYA can cause serious side effects.

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

Serious side effects include:

- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior reversible encephalopathy syndrome) has occurred rarely in patients taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated it may lead to a stroke. Call your doctor right away if you have any of the following symptoms:
 - sudden headache
 - confusion
 - seizures
 - loss of vision
 - weakness
- **breathing problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.
- **liver problems.** GILENYA may cause liver problems. Your doctor should do blood tests to check your liver before you start taking GILENYA. Call your doctor right away if you have any of the following symptoms of liver problems:
 - nausea
 - vomiting
 - stomach pain
 - loss of appetite
 - tiredness
 - your skin or the whites of your eyes turn yellow
 - dark urine

The most common side effects of GILENYA include:

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

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

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

How do I store GILENYA?

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

General information about GILENYA

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

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

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

What are the ingredients in GILENYA?

Active ingredient: fingolimod

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

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

GILENYA is a registered trademark of Novartis AG.

Manufactured by: Novartis Pharma Stein AG
Stein, Switzerland

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

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The remedy: Imagine a flashlight right in the middle of your chest at the sternum. Sitting or standing, your flashlight should always shine directly forward. Now, keeping your head centered over your shoulders, extend the top of your head toward the ceiling, keeping your head level and not lifting your chin. Next, lift the corners of your mouth toward the sky... and SMILE!

A poor posture backs you up!

When you sit in a crunched position, your viscera (intestines) are folded up like an accordion and that can slow everything down!

The remedy: Yoga and Pilates are great forms of exercise to strengthen your core and help get things moving. One pose that can rev up a sluggish gut is the Cobra: lie on your belly while resting your head on your lower arms. Raise your forehead and look upwards, allowing your weight to rest on your chest. Letting your head fall back a little, raise your belly further off the mat, as if someone is behind you, lifting your shoulders up and back.



A lazy posture while watching television may impact your health.

Some studies suggest that watching television for long periods of time while slouching on the couch, or spending too much time sitting still in front of the television, may increase your risk of certain health problems down the road, including diabetes and cardiovascular disease.



The remedy: Don't let the TV tune you out! When you choose to watch television, as we all do, try to sit as tall as you can. For able-bodied individuals, you may try using a ball for support. This could also be a great time to rest in a "90/90" position. During commercial breaks, again if able, stand up from your chair; then sit down in a smooth and controlled motion. If you are in a wheelchair, try doing a bit of spinal rotation (please see photo and caption on next page) or alternating extensions.

This photo demonstrates spinal rotation. Spinal rotation is a fantastic exercise to stimulate range of motion and flexibility in our spine. It is also very helpful at stimulating your internal organs to function more efficiently and effectively. Visualize your spine as a spiral stair case that extends to the sky as you rotate. If needed, a physical therapist can teach you how to perform spinal rotation on your own.

Photo: Kurt Mogonye



A frumpy posture makes you appear heavier!

Does this chair make me look fat? Well, yes, but only if you are slumped over in it! We've become a nation of professional sitters... when you are slouched over, your internal organs have nowhere to go but down and out, so you immediately appear less fit!

The remedy: The solution for this one is simple. Get up if you can and move as much as you can. When we stand or sit tall – and this applies to sitting in a standard chair or in a wheelchair – as opposed to sitting with poor posture, we burn 20-percent more calories! By doing so, we also strengthen our muscles, boost metabolism, and increase bone density.

A constricting posture cuts off circulation.

Our bodies are machines that move fluid and gases back and forth. Prolonged sitting, especially with your legs crossed, can cut off the flow, increase pressure in your abdominal wall, and even cause spider veins and tingling in your legs.

The remedy: To get blood flowing to your lower body, stand up and find your best posture,

then lift one leg up so your thigh is horizontal to the ground, keeping your knee bent so your calf and foot hang down. Keep your standing leg locked (but not hyper-extended) and hold for five strong breaths, pushing your breathing down to your diaphragm. Repeat on the opposite side. If you are in a wheelchair and are able, try extending the leg while sitting with a lengthened spine. Another important strategy is to try to break the habit of sitting with your legs crossed. This simple act allows oxygenated blood to flow freely.

A crumpled posture stresses you out!

A recent study from Harvard showed that people who adopted powerful postures (open shoulders and straight spines) experienced a 20-percent increase in testosterone levels (related to strength) and a 25-percent decrease in cortisol levels (related to stress). Conversely, people who slouched had a 10-percent decrease in testosterone and a 15-percent increase in cortisol. This hormonal imbalance can even affect how you feel, potentially reducing your self-confidence and your ability to deal with daily stressors. Sitting in a slouched posture can compound

the problem. Shallow chest-breathing strains the lungs – and your lungs must move faster to ensure adequate oxygen flow. This rapid breathing taxes the heart, forcing it to speed up to provide enough blood for oxygen transport. The result is a vicious cycle, where stress prompts shallow breathing, which in turn creates more stress.

The remedy: Take relaxed abdominal breaths to combat stress. Here's how to make sure you're breathing deeply: Rest your hand below your belly button; you should feel your belly expand as you inhale. Invite the air all the way down to the deepest portion of the lungs, where oxygen exchange is most efficient. As you exhale, you should feel your belly contract again, along with the feeling of stress leaving your body.

Tips for a Healthy Spine

The following five easy tips will help you to minimize complications from any back conditions you may have, while helping to prevent future painful episodes.

1. Let your spine relax while sleeping. While you're sleeping, all the structures in your spine that have worked hard all day finally have an opportunity to relax and be rejuvenated. Using the right mattress and pillow will support the spine so the muscles and ligaments can be stress-free and have a chance to become refreshed.

In a recent MSAA patient-education program, Dr. Ben Greenberg shared his thoughts on sleep. "Outside of watching what we eat and remaining active, I think the three most important things we can do for health

are to maintain adequate and good-quality sleep, adequate hydration, and a positive outlook. People underestimate the need for good quality, uninterrupted sleep and its impact on cognition, energy, mood, and overall health."

2. Choose your shoes carefully. Whether walking for exercise or to get somewhere, the shoes you wear have a big effect on your back. They should be well-balanced, flexible, and most certainly comfortable. Good shoes not only provide protection for your feet, but also a supportive base that helps the spine and body remain in alignment.

3. Enjoy the benefits of massage. Many people love a good massage to relax their muscles and relieve stress. Therapeutic massages not only improve flexibility and decrease tension; they can also improve blood flow and increase the level of endorphins in your bloodstream, which are chemicals in the body that make us feel good.

4. Sit up straight – with support. The discs in your lower spine are loaded three-times more while sitting than standing, so long periods of sitting can often create or aggravate a painful back condition. Moreover, when sitting in an office chair, many people slouch and lean forward, and this poor posture usually leads to muscle tension and pain in the lower back and legs. Place a foam ball between the back of the chair and just below your shoulder blades to support your thoracic spine. Your thoracic spine is the upper portion of your back, made up of the twelve vertebrae that run from the base of your neck to just above your waistline.

This picture demonstrates the proper placement of an 8-inch foam ball that can be purchased anywhere. By placing the foam ball in the middle of the upper back, the chest instantly expands and the spine is lengthened while being supported. This technique can be used anytime prolonged sitting is in your day. I use one during my commute and it creates a comfortable and efficient posture for deep breathing and spinal health.



5. Specifically exercise your abs and back.

One of the most important components of good spine health is exercise. Specifically, performing abdominal and back exercises will go far in helping to keep your spine healthy. A physical therapist or other health specialist is able to recommend a simple routine that is best for you, and these exercises can often be performed in seven minutes as part of a daily routine. If your back and abdominal muscles are not in good shape, this may create additional pressure on the spine, which is already under the stress of supporting your entire body. When these muscles are well maintained, they help support the spine and minimize the chance of injury.

Follow these simple guidelines to protect your back and help keep it in good shape:

- **Standing...** keeping one foot about four inches apart from the other, with knees slightly bent, takes the pressure off your lower back.
- **Sitting...** sitting with your knees slightly higher than your hips provides good support for your lower back.

- **Reaching...** if able to do so safely, stand on a stool to reach things that are above your shoulder level, to avoid straining your back.
- **Moving Heavy Items...** pushing is easier on your back than pulling. Use your arms and legs to start the push. If you must lift a heavy item, please ask someone to help.
- **Lifting...** if able to do so safely, kneel down on one knee with the other foot flat on the floor as near as possible to the item you are lifting. Lift with your legs, not your back, keeping the object close to your body at all times.
- **Carrying...** breaking down a larger load into smaller items to carry, and carrying these lighter or smaller items in each

hand, may be easier to handle than one large item. If you must carry one large object, keep it close to your body. Of course, if it is at all risky or you feel any type of strain, please ask someone to help.

- **Sleeping...** sleeping on your back puts 55 pounds of pressure on your back. If appropriate for you, placing a couple of pillows under your knees cuts the pressure in half. Lying on your side with a pillow between your knees also reduces the pressure.
- **Weight Control...** additional weight puts a strain on your back. If able, individuals should try to keep within 10 pounds of their ideal weight for a healthier back.
- **Quit Smoking...** smokers are more prone to back pain than nonsmokers; this is because nicotine restricts the flow of blood to the discs that cushion your vertebrae.

Remember!

These guidelines are the same whether you have full mobility and need no assistance, or if you use a cane, walker, or wheelchair. If the latter, please consult a physical therapist or a corrective exercise specialist in your area to ensure that your assistive device is specifically adjusted to fit your body size, allowing you to enjoy the benefits of optimal postural alignment. Sit and/or stand tall! Be proud of the beautiful, smart, and strong person you are. Lengthen your spine and align with a healthy lifestyle.

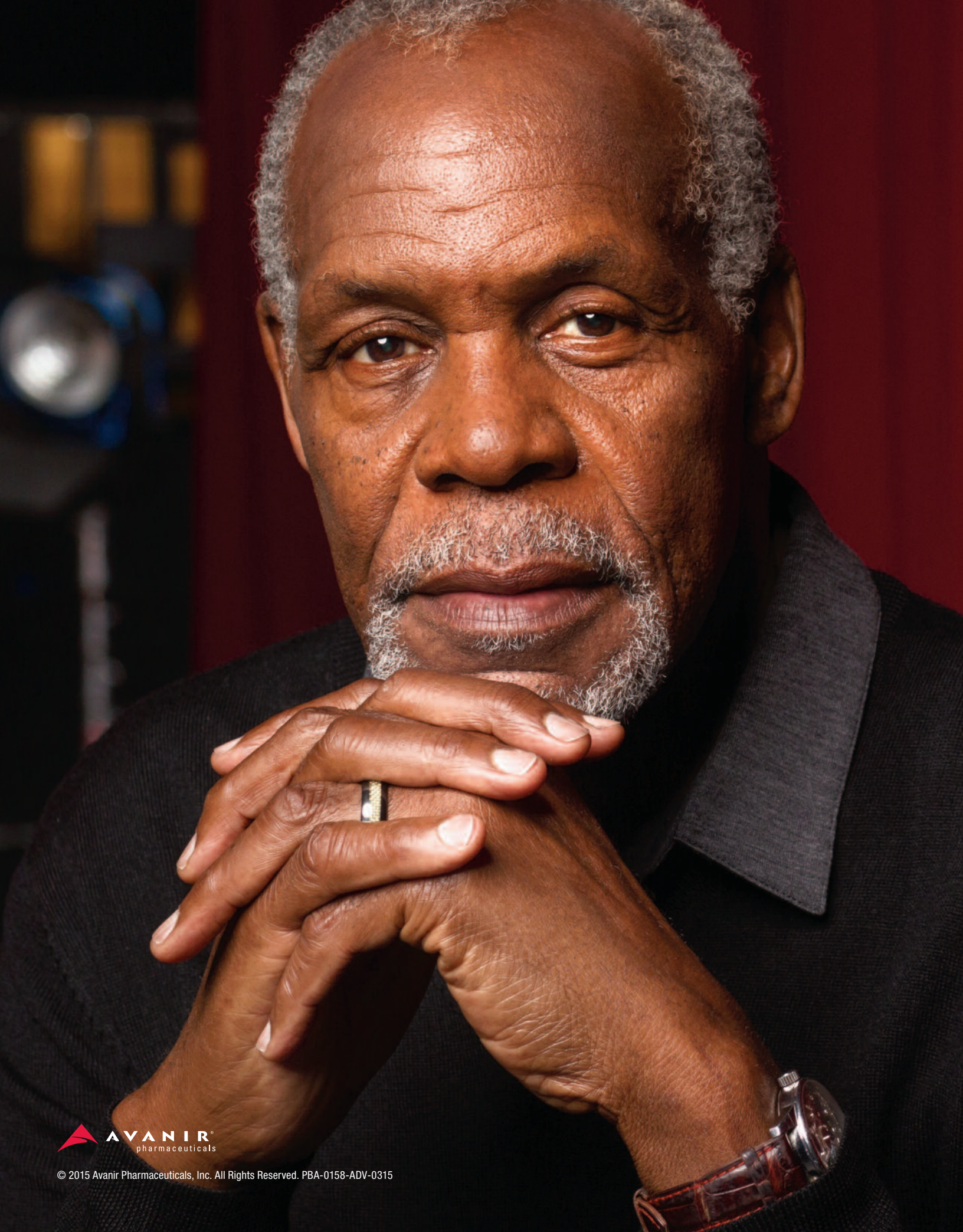
In Summary

MSAA Chief Medical Officer Dr. Jack Burks explains, “This article is a must-read for people with MS and others who are trying to navigate the complex waters of nutrition and health. It also includes very helpful tips on exercise and posture.

“Providing a foundation for healthy eating, this information may be beneficial in many ways. However, knowing which diet is best for your individual situation may be difficult. The table detailing each diet may help you to choose the diet – or the components of different diets – that is best for you. A nutritionist with MS expertise may help guide your decisions. The take-home message for me is this: paying more attention to diet may help your general health as well as your MS. Reducing your intake of processed food and salt are great places to start. In addition, exercise and better posture can make a big difference.”

Dr. Bromley adds, “The best medicine for your body is a healthy lifestyle. Implementing changes very gradually is the key – and increases the likelihood of success! Very restrictive diets and high-intensity exercise, although good for some people, are difficult to adhere to.

“Improving nutrition, increasing water intake if needed, getting outdoors, decreasing stress, and finding enjoyable activities to get adequate exercise, have all been shown to assist the body in running efficiently. Small steps can really add up, ultimately giving you control over how you feel. You can do it!” ■



**“Sudden outbursts of crying or laughing
can be a sign of fine acting.**

But if you have MS, it could be **PBA.”**

—Danny Glover

People with brain injuries or certain neurologic conditions like multiple sclerosis (MS), may experience frequent outbursts of uncontrollable crying or laughing called **P**seudo**B**ulbar **A**ffect (**PBA**).

In a recent national registry of more than 5,000 patients with a variety of neurologic conditions, 46% of the 1215 patients with MS had **PBA** symptoms.*

‘PBA FACTS’ is a FREE kit that explains the facts and science behind this treatable neurologic condition.

For your FREE **‘PBA FACTS’** kit, call
1-800-774-4117 or go to pbafacts.com.
Learn more and talk with your doctor.

**Choosing to cry or laugh
should be up to you, not **PBA.****



*PRISM was a nationwide registry of adult patients with brain injuries or certain neurologic conditions, including 1215 who had MS. PBA symptoms were defined as a Center for Neurologic Study Labillity Scale (CNS-LS) score ≥ 13 . This CNS-LS score may suggest PBA symptoms and merits further diagnostic assessment. Patients or caregivers completed the assessment. The CNS-LS has been validated in ALS and MS patient populations.

Learning about PML Risk when Testing Positive for JC Virus

By Dr. Jack Burks

MSAA's Chief Medical Officer



Q: I was diagnosed with relapsing-remitting multiple sclerosis in 1987. I am a 67-year-old female who is mobile, independent, and able to take care of myself without assistance.

Initially, I was placed on methotrexate for about four years. I was then placed on Avonex and tolerated the weekly intramuscular injections for about 13 years. The only side effect I experienced was the flu-like symptoms.

I have moderate kidney disease and was instructed not to take any over-the-counter pain relievers. I finally persuaded my neurologist to let me try Tecfidera. I began this new oral drug in August 2014. So far I have had no major side effects and all of my visits to the neurologist reveal normal follow-up exams.

In May 2015, my neurologist ordered a lab test to check for the JC virus. The result was positive for PML. I did not have lab work drawn to check for this virus prior to starting Tecfidera. At the present time, my CBC levels are within normal range and these will be checked monthly to see if the levels have decreased.

My questions and concerns are:

1. Is it possible that the JC virus was already in my body?
2. How will the virus affect my relapsing form of MS?
3. At what point in time will the virus affect my brain and my ability to live independently?

A: I am pleased that you are doing so well with your MS, are continuing to do well on Tecfidera® (dimethyl fumarate), and that your blood counts (CBC) are in the normal range. Your questions are all in reference to the JC virus and progressive multifocal leukoencephalopathy (PML), which if not discovered early, is a potentially fatal brain infection. PML is caused by an activation of the JC virus in people with weakened immune systems.

I will address each of your questions, but I first want to clear up a possible misperception. I doubt that your test result was “positive for PML.” I suspect your test result was “positive for antibodies to the JC virus,” which means you have been previously exposed to the JC virus. More than 50 percent of middle-aged adults are JC-virus antibody positive.

Therefore, the answer to your first question is yes, the JC virus was most likely already in your body.

For the second question, the JC virus will *not* likely affect your MS. For your third question, the JC virus is unlikely to ever affect your brain, because it will likely continue to lie dormant in your body, in places such as the bone marrow, where it is unlikely to cause harm. To cause PML damage, the JC virus must be activated and must get into the brain.

Certain diseases and drugs are associated with the activation of the JC virus – such as HIV/AIDS and the types of drugs used to treat cancer, which greatly suppress the immune system. These types of medications include Tysabri® (natalizumab), a disease-modifying therapy for MS approved by the United States Food and Drug Administration (FDA), as well as methotrexate, one of several medications approved for other conditions by the FDA, but still considered experimental in the treatment of MS.

In MS, we measure the JC virus antibody to help determine the risk of PML in people considering Tysabri. Your previous exposure to methotrexate would increase your risk of Tysabri-associated PML. As for Tecfidera, the risk of JC virus antibody-positive individuals getting PML while taking Tecfidera is very low, but not zero. Only two MS patients have been reported to develop PML while taking this medication. This risk may be increased if your white-blood cell count is low for a prolonged period of time. As you stated, your CBC is normal so far.

As more people with MS are treated over



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longer periods of time, we will know more about the risks of PML. For now, we do not have enough information to know the true risk, but generally speaking, your risk to develop PML is relatively low. However, continuing with blood tests and watching for symptoms is vital to an early diagnosis in the rare instances that PML does occur. Your neurologist or a specialist from an MS center can provide specific advice for your situation.

Q: I need bowel resolutions! I experience the loss of sensation of having a movement. My gastroenterologist doesn't seem to understand how this can affect me every day, physically and mentally. It's not constipation; it's just not knowing if or when I need to go

and then knowing when I'm done. This is so confusing and overwhelming! Do you have any suggestions to help with my situation?

A: Over the years of caring for people with MS, I have become distressed by the numerous misunderstood issues related to problems with bowel, bladder, and sexual problems. Lack of sensation related to bowel movements is one of the most challenging issues to manage. While you have sought help from your gastroenterologist (GI specialist), this has not provided any help to you. On a positive note, you do not presently have to cope with constipation, which is a good thing. My thoughts are:

1. Get a second opinion from another GI specialist.
2. Seek out a rehabilitation nurse who specializes in bowel issues for MS and/or trauma-induced paraplegics with bowel issues.
3. Train your bowels by establishing a bowel routine. For example, eat a healthy breakfast with hot tea or coffee each morning. About 30 minutes later, sit on a commode and concentrate on moving your bowels. The breakfast will hopefully stimulate your gastrocolic reflex, which may produce a more regular bowel movement (BM).
4. Ask the GI specialist about taking probiotics, stool softeners, or other medications, such as glycerin suppositories. These can help to stimulate bowel movements at regular intervals. I would use laxatives very sparingly.

Again, I am not a GI expert, but I have found that bowel rehabilitation nurses have many techniques that may help people with MS, often employing strategies found to be successful with patients who have suffered spinal-cord injuries. The common denominator is the loss of sensation and reduced control of bowel function. While bowel problems are a challenging symptom in MS, looking to experts such as bowel rehabilitation nurses and specialists at MS centers, can yield positive results and help to improve your quality of life. ■

Jack Burks, MD is the chief medical officer for MSAA. He is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies and advises patients, families, MS organizations, and healthcare groups. Dr. Burks is a clinical professor of neurology at the Florida International University in Miami and has authored textbooks, chapters, and articles on MS.

DO YOU HAVE A QUESTION?

Please submit your questions to:

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

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

PML Risk and Updates on New Therapies

Although Rare, the Risk for PML Still Exists

PML is a potentially fatal brain infection, caused by the activation of the JC virus (JCV), which is present in approximately 55 percent of individuals with MS. The JCV remains dormant in most individuals, but may become active in people with weakened immune systems – such as those taking a strong immunosuppressant.

While the risk is very low, an individual with a weakened immune system needs to be anti-JCV antibody positive (as identified through a blood test) to potentially develop PML. However, a person who is anti-JCV antibody negative could be exposed to the virus at any time.

PML has been linked to a small percentage of individuals with MS taking Tysabri® (natalizumab). For individuals who are anti-JCV antibody positive, the risk ranges from less than 1 in 1,000 during the first year of treatment, to 1 in 500 during the second year, and increases thereafter. As of fall 2014, approximately 517 cases of PML were reported with Tysabri, while more than 130,000 people have been treated with this medication.

Other disease-modifying therapies (DMTs) for MS have not been directly linked to this rare brain infection. However, a history of different immunosuppressant medications and even the long-term use of steroids can increase someone's risk of developing PML when taking other DMTs for MS.

To date, two cases of PML have been reported in individuals taking Tecfidera® (dimethyl fumarate), leading to a label change in late 2014 to include a warning about PML. Two cases were also reported in individuals taking Gilenya® (fingolimod), and in August 2015, a third case of PML was reported in a patient with relapsing MS who was treated with Gilenya. This individual did not have prior exposure to Tysabri treatment, but had been treated with chemotherapy and radiation treatment for a different condition in the past.

The good news is that PML is now often diagnosed at a much earlier stage of the illness, which greatly improves one's chance of not only surviving, but also experiencing little or no disability as a result. PML is identified through magnetic resonance imaging (MRI) and sometimes people are diagnosed prior to experiencing any symptoms.

However, individuals at a higher risk of developing PML should watch for symptoms, and if any occur, report this to their doctor immediately. According to the United States Food and Drug Administration (FDA), symptoms of PML are diverse and may include progressive weakness on one side of the body, clumsiness, vision problems, confusion, and changes in thinking, personality, memory, and orientation. Please see Ask the Doctor on page 36 of this magazine for additional details on the JC virus and PML.

Two Medications Move toward Approval

Daclizumab high-yield process (DAC HYP) is a new therapy that has been studied in relapsing-remitting multiple sclerosis (RRMS). It is a humanized monoclonal antibody against CD25, a receptor on T cells that is thought to become activated in MS. The DECIDE study compared DAC HYP 150mg injected subcutaneously once every four weeks, to intramuscular interferon once weekly. Treatment with DAC HYP versus interferon resulted in significant reductions in: the annualized relapse rate (ARR); the proportion of patients who relapsed; the number of new/enlarging T2 lesions; and the risk of confirmed disability. In spring 2015, the FDA accepted the application for review of DAC HYP in relapsing forms of MS. If approved, this will be marketed under the brand name Zinbryta™.

In June 2015, positive Phase III trial results were announced for the experimental medication **ocrelizumab**, a monoclonal antibody presently being studied for the treatment of relapsing forms of MS. Study participants received either 600 mg of ocrelizumab via intravenous (IV) infusion every six months, or the approved 44-mcg dose of Rebif® (interferon beta-1a), given via subcutaneous injection three-times weekly. In the OPERA I and OPERA II studies, ocrelizumab showed significant reductions in: the annualized relapse rate (ARR); the progression of clinical disability; and the number of lesions in the brain. Parent company Genentech plans to submit this data to the FDA in early 2016.

Glatopa Approved for Relapsing Forms of MS

On April 16, 2015, the FDA approved **Glatopa™ (glatiramer acetate injection)** for the treatment of individuals with relapsing forms of multiple sclerosis (MS), including those who have experienced a first clinical episode and have magnetic resonance imaging (MRI) features consistent with MS. Glatopa is manufactured by Sandoz, a Novartis company, and is the 13th medication to be approved by the FDA as a long-term, disease-modifying therapy for these forms of MS.

Glatopa is a generic version of Copaxone® (glatiramer acetate injection), which has been marketed by Teva Pharmaceuticals since its approval in the mid-1990s. This is the first generic version of a disease-modifying therapy for MS to be approved by the FDA. According to Sandoz, Glatopa is therapeutically equivalent to and substitutable for Copaxone. However, readers should note that Glatopa is only available in the once-daily 20-mg dose, whereas Copaxone also offers a three-day weekly administration of 40 mgs each. Both medications are given via subcutaneous (under the skin) self-injections.

Sandoz has a 24-hour phone line at **855-GLATOPA** or **(855) 452-8672**. You may also visit **glatopa.com** for additional details.

For more information on these and other topics, please go to **mymsaa.org** and select “News from MSAA.” **For any MS-related questions**, please contact MSAA’s Client Services Specialists via email at **MSquestions@mymsaa.org**, via phone at **(800) 532-7667, extension 154**, or via our interactive one-on-one chat feature. ■

ACTHAR

ANOTHER WAY TO TREAT MS RELAPSES IN ADULTS



ACTHAR MAY HELP SPEED RELIEF OF YOUR MS RELAPSE

TALK TO YOUR DOCTOR, AND LEARN MORE AT ACTHARMSRELAPSE.COM/STORIES WHERE YOU CAN HEAR PEOPLE SHARE THEIR EXPERIENCE WITH ACTHAR

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

USES

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

IMPORTANT SAFETY INFORMATION

You should not take Acthar if you have:

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

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

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

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

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

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

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

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

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

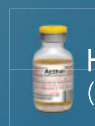
- Increased risk of infections
- Increased blood pressure
- Irritability
- Symptoms of Cushing's syndrome
- Cardiac hypertrophy (thickening of the heart muscle)
- Weight gain

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

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

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

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



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

Important information about H.P. Acthar® Gel.

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

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

Acthar can cause serious side effects, including:

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

What is H.P. Acthar Gel?

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

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

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

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

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

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

How is H.P. Acthar Gel given?

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

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

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

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

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

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

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

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

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

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

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

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

How should I store H.P. Acthar Gel?

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

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

Active ingredient: Corticotropin.

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

General information about H.P. Acthar Gel.

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

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

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



Aquatic Exercise Video Available Online and on DVD

By Peter Damiri

Vice President of Programs and Services

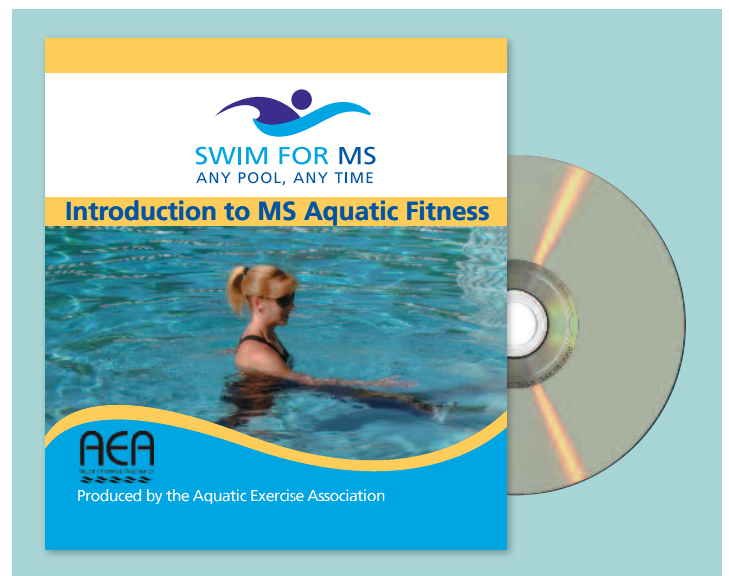
Posted on the Swim for MS online Aquatic Center, *Introduction to MS Aquatic Fitness* is MSAA's latest educational video. This valuable resource demonstrates a wide variety of shallow-water exercises designed specifically for the MS community. Produced in partnership with the Aquatic Exercise Association and Genzyme, a Sanofi company, the instructional video showcases numerous aquatic exercises aimed at improving function, performance of daily activities, and general health and wellness. The video is also available to order as a free DVD copy.

To make the instruction as inclusive as possible, activities are performed at various impact levels offering options to personalize the workout. Following the 30-minute demonstration, the program concludes with a sample workout routine that runs through all of the exercise activities and their variations.

As part of the Swim for MS initiative, MSAA has created its comprehensive, online Aquatic Center through a collaborative

Aquatic fitness expert Monique Acton demonstrates shallow-water exercises addressing balance, strength, mobility, and aerobic endurance in the Introduction to MS Aquatic Fitness video.

sponsorship with Genzyme to help increase awareness, understanding, and availability of water-based exercise programs as a positive wellness opportunity for the MS community. We encourage you to watch *Introduction to MS Aquatic Fitness* and to look for additional resources such as booklets, tip sheets, webinars, inspirational videos, and more – all found on the online Aquatic Center at **SwimForMS.org**. ■



Ways To Learn, Explore and Find Healthcare Insurance

With open enrollment for the Health Insurance Marketplace under the Affordable Care Act (ACA) and Medicare coming soon, MSAA encourages people with MS and their care partners to visit our specialized website section, My Health Insurance Guide, and learn more about how to select a health insurance policy. With the goal of making complex



MSAA's My Health Insurance Guide site includes a glossary of common insurance terms plus many more important resources.



information easy to understand, My Health Insurance Guide includes a useful glossary of common insurance terms, helpful questions to ask when looking at plan coverage, steps for appealing a denial, downloadable brochures, webinars, and an award-winning video titled “What You Need To Know About The Affordable Care Act.” This web portal also breaks down the many levels of Medicare, outlining original Medicare, Plan D for prescription coverage, Medicare Advantage Plans, and supplemental Medigap policies. For more information, please visit mymsaa.org/healthinsurance.

In addition to the resources offered by MSAA, the federal government provides a dedicated website at healthcare.gov. Managed by the United States Centers for Medicare and Medicaid Services,

healthcare.gov is not only the hub for Marketplace enrollment, but also contains a wealth of information, publications, videos, and more, all designed to help consumers better understand their health insurance coverage and options. Resources on this site include *From Coverage to Care – A Roadmap to Better Care and a Healthier You*, which is a 44-page easy-to-read publication and an 11-part video series. This provides a step-by-step breakdown of key information related to understanding coverage, finding providers, and preparing for the office visit once a consumer enrolls in the Marketplace.

The healthcare.gov website also offers a very useful online resource titled, “See Plans and Prices,” which allows consumers to enter

and preview plans in the Marketplace, even during times when open enrollment is closed. After entering your zip code, a disclaimer screen appears, explaining that this tool is not an application for Marketplace coverage and plan information may change when enrollment begins. Once entered into the portal, a wealth of healthcare plans appear with options to search by premium costs, coverage categories (bronze, silver, gold, etc.), types of plans (HMOs, PPOs, etc.), and other important considerations.

While on the site, visitors can delve deep into specific plans to find listings of in-network providers, prescription medication coverage (including key MS medications for treatment

and symptom management), hospital services, wellness programs, etc. with pricing on the monthly premium, estimated deductible, maximum out-of-pocket costs, and copays.

Please visit MSAA's My Health Insurance Guide at mymsaa.org/healthinsurance, along with healthcare.gov and other reputable websites. You may also call **(800) 532-7667, extension 154**, to speak with one of MSAA's Client Services Specialists. The more you know, the better prepared you will be to find affordable healthcare – which is vital in assisting individuals with MS receive the healthcare and prescriptions needed for optimal health. ■

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Sustaining Gifts

Improving Lives Today... and Every Day!

By Kimberly Goodrich

Vice President of Development



Thanks to our generous donors, Mary received a cooling vest through MSAA. Now she is able to enjoy going to her grandson's baseball games and spend time in her garden. Tamara received a rolling walker that allows her to walk farther and with less fatigue, meaning she has been able to enjoy family trips for the first time in years. The equipment program is one of MSAA's core programs providing items that increase a person's safety, dignity, and mobility, as well as improve his or her overall quality of life. Our goal at MSAA is to continue growing this program in order to meet the increasing demand for these items. This requires that we not only do more, but that we do it better.

As a nonprofit organization, MSAA works hard to be sure we are using the dollars given by our donors in the most effective ways possible. This means we are always looking for ways to increase the efficiency of our operations, stretching your generous gifts to reach more and more people each day. Lately we have heard a lot about "sustaining" gifts and the many benefits this type of giving can have – not only for an organization and those

Mary's indoor cooling vest was provided to her thanks to the thoughtfulness of MSAA's many sustaining donors.

it supports, but also for the donors themselves.

What is a sustaining gift? Essentially, a sustaining gift is a donation automatically given at regular intervals, such as monthly, quarterly, or annually. These gifts can be set up in advance and given directly via electronic funds transfer (EFT) or credit card.

How do these gifts benefit the nonprofit organization? Knowing that regular gifts are happening allows us to plan better for future needs, such as the increase in cooling requests that happens each summer. However, the primary benefit is a savings in postage, mailing, and administrative costs. When you join MSAA's Sustaining Partners monthly giving program, you will no longer receive mail solicitations – this means more of your contribution goes toward improving the lives of individuals with MS!

How does this help the donor? It's easy! Once it's set up, no work is required on your

part. You too will save on postage and time. A cumulative tax receipt is issued at the end of each year and you can easily increase, decrease, pause, or stop your gifts at any time.

Many people find they are able to give more generously when they spread their gift throughout the year. A regular gift of just \$10 per month adds up to a very generous \$120 for the year. And that \$120 can provide

a shower chair and a safety grab bar that keeps someone safe in his or her own home.

We encourage you to consider becoming a Sustaining Partner of MSAA and share in the benefits this program offers. To learn more about joining our Sustaining Partners monthly giving program, please visit our website at support.mymsaa.org/sustainer or call **(800) 532-7667** and ask for the Development Department. ■

THE PRESIDENT'S *Circle*

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

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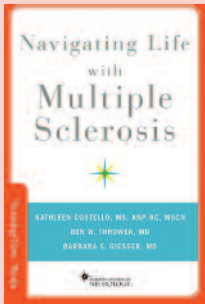
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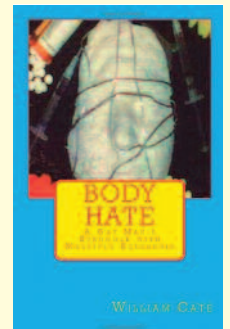
Navigating Life with Multiple Sclerosis
by Kathleen Costello, MS, ANP-BC, MSCN;
Ben W. Thrower, MD; and Barbara S. Geisser, MD
Oxford University Press | *MCAA Book #331*

Written by three top experts in the field, this book is designed to be a practical guide for meeting the challenges of this life-long disease. Chapters cover such topics as what MS is and how it affects the nerves, how MS is diagnosed and the symptoms it causes, as well as treatments, lifestyle, pregnancy and children, research, and planning for the future.

**Body Hate:
A Gay Man's
Struggle
with Multiple
Sclerosis**

by William Cate
Long Time Ago
Books

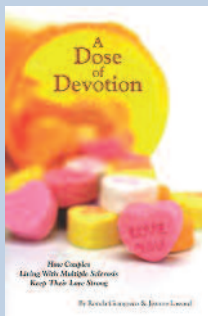
MCAA Book #424



William Cate was a punk rocker from Boston. He was an energetic and aggressive drummer in a band that was close to a recording contract, when suddenly he was diagnosed with MS. In this autobiography, the author talks candidly about his sexual orientation, the changes he has made in his career, and his unexpected battles with MS.

MCAA's Lending Library

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



A Dose of Devotion: How Couples Living With Multiple Sclerosis Keep Their Love Strong

by Ronda Giangreco and Jeanne Lassard

CreateSpace Independent Publishing | *MCAA Book #387*

Twelve couples who have confronted the challenges of MS with grace, humor, and courage are featured. However, the book goes beyond these heartwarming stories; it is a blueprint for how all marriages can thrive in the face of adversity.

Through wisdom, insight, and inspiration, the authors hope to reduce the high number of marriages that end after a diagnosis of MS.

Are You an Artist with MS?

Submit Your Best Work for MSAA's 2016

Art Showcases

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

Submit your two-dimensional works in oil, watercolor, acrylic, pastels, pencil drawings, or digital artwork. Artwork will only be accepted from individuals who have MS.

The **MS Ability Showcase** is open to all themes; however, submitted artwork to the **Four Seasons Showcase** must depict a specific season or holiday.

Submissions will be featured on mymsaa.org in March 2016 in recognition of MS Awareness Month.

Deadline to submit art is December 18, 2015. For complete guidelines, visit support.mymsaa.org/artshowcase

Road Less Traveled
David Desjardins, Union, ME

For more information, contact:
Angel Serrano, MSAA
375 Kings Highway North
Cherry Hill, NJ 08034
Email: showcase@mymsaa.org
Phone: (800) 532-7667, ext. 117



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Lexie & teammates at her one-day Swim for MS event



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