

The magazine of the National Multiple Sclerosis Society

# Momentum®

SUMMER 2013

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Multiple Sclerosis  
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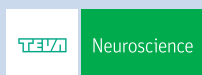
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National MS Society  
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900 South Broadway  
Suite 200  
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**[elisa.beerbohm@nmss.org](mailto:elisa.beerbohm@nmss.org)**



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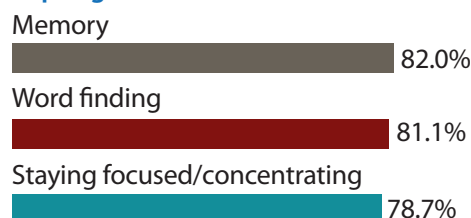
## Readers report on MS and cognition

More than 850 people responded to  
our survey on cognition, and the vast  
majority said that they have ongoing  
cognitive challenges. The most popular  
ways of managing these issues, by a  
landslide, were to write things down  
and make lists. Many people also rely  
on calendars and smartphone apps.  
Stay tuned for more suggestions from  
experts in an upcoming **Momentum**  
article on cognition.

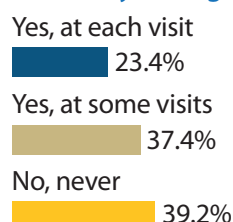
### Do you regularly experience difficulty with memory or thinking?



### Top cognitive difficulties:



### Does your neurologist ask about or evaluate your cognitive abilities?





# Momentum

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something that MS  
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— Kerrie, Multiple Sclerosis

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# Momentum<sup>®</sup>

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PHOTO BY JOSHUA ROPER

Rex Parker (second from left) trained for Bike MS using a free custom training plan from an interactive website called Training Peaks. p. 34

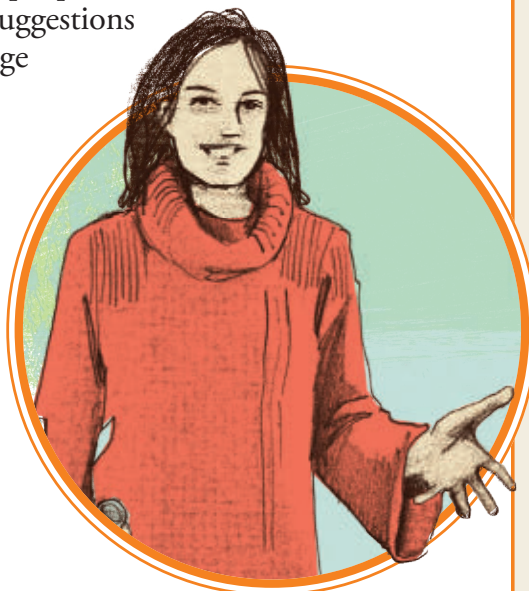
## FEATURE STORIES

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Should you reveal your MS to your friends, family and colleagues? Experts—and people who've been down that path—offer suggestions to help you successfully manage your disclosure decision.  
by Andrea Sachs

### 34 Training Days

Prepare yourself for Bike MS with these handy training tools and tips.  
by Kathleen Hagan



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by Cyndi Zagieboylo

Illustration:  
Kate Miller

Cover photo:  
Joshua Roper



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Wake-up.  
Shower.  
Take my MS pill\*  
Orange juice.  
Muffin.  
Out the door.

\*AUBAGIO® (teriflunomide) is a once-daily oral prescription medicine used to treat relapsing forms of multiple sclerosis (MS).

Pill shown not actual size.

AUBAGIO® (teriflunomide) is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS).

#### IMPORTANT SAFETY INFORMATION

**Do not take AUBAGIO if you have severe liver problems. AUBAGIO may cause serious liver problems, which can be life-threatening.** Your risk may be higher if you take other medicines that affect your liver. Your doctor should do blood tests to check your liver within 6 months before you start taking AUBAGIO and once a month for 6 months after you start taking AUBAGIO.

Tell your doctor right away if you develop any of these symptoms of liver problems: nausea, vomiting, stomach pain, loss of appetite, tiredness, yellowing of your skin or whites of your eyes, or dark urine.

**Do not take AUBAGIO if you take a medicine called leflunomide.**

**AUBAGIO may harm your unborn baby. Do not take AUBAGIO if you are pregnant or are of childbearing age and not using effective birth control.** You should have a pregnancy test before you start taking AUBAGIO. After stopping AUBAGIO, continue using effective birth control until you have tests to make sure your blood levels of AUBAGIO are low enough. If you become pregnant while taking AUBAGIO or within 2 years after you stop taking it, tell your doctor right away and enroll in the **AUBAGIO Pregnancy Registry** at 1-800-745-4447, option 2, which collects health information about you and your baby.

**If you are a man taking AUBAGIO whose partner plans to become pregnant,** you should stop taking AUBAGIO and talk with your doctor about reducing the levels of AUBAGIO in your blood quickly. If your partner does not plan to become pregnant, use effective birth control while taking AUBAGIO.

**AUBAGIO may stay in your blood for up to 2 years after you stop taking it.** Your doctor can prescribe a medicine that can help remove AUBAGIO from your body quickly.

**Before taking AUBAGIO, talk with your doctor if you have**

- Liver or kidney problems
- A fever or infection, or if you are unable to fight infections
- Numbness or tingling in your hands or feet that is different from your MS symptoms
- Diabetes
- Serious skin problems when taking other medicines
- Breathing problem
- High blood pressure

## It's your day

Living with MS can be challenging. Whether it's dealing with relapses or having to take time out for treatment, life with MS means adapting to new routines.

AUBAGIO is a once-daily pill that can play an important role in your treatment plan for relapsing multiple sclerosis (RMS). AUBAGIO is a disease-modifying therapy, or DMT, used to treat RMS.

In a 2-year clinical trial of 1088 people, AUBAGIO 14 mg demonstrated a significant positive effect vs placebo on the 3 measures of MS disease activity—relapses, disability progression, and MRI brain lesions (Gd-enhancing T1 lesions). In the same trial, AUBAGIO 7 mg demonstrated a significant positive effect vs placebo on 2 of the 3 measures, but not on disability progression.

Do not take AUBAGIO if you have severe liver problems, are pregnant or are of childbearing age and not using effective birth control, or are taking a medication called leflunomide.

Routine Monitoring is Recommended before Starting and During Therapy.

**Ask your doctor if AUBAGIO is right for you.**



**Visit [TellMeAboutAubagio.com](http://TellMeAboutAubagio.com)**

AUBAGIO® is available in 14 mg and 7 mg tablets.

It is not known if AUBAGIO passes into breast milk. Talk with your doctor to decide if you should take AUBAGIO or should breastfeed—you should not do both at the same time. Also talk with your doctor if you take or are planning to take other medicines (especially medicines for treating cancer or controlling your immune system) or if you take or are planning to take vitamins or herbal supplements.

Before starting AUBAGIO, your doctor should check your white blood cell count and perform a tuberculosis skin test.

You should not receive certain vaccinations during and for 6 months after treatment with AUBAGIO.

**AUBAGIO may cause serious side effects, including**

- Reduced white blood cell count. This may cause you to have more infections
- Numbness or tingling in your hands or feet that is different from your MS symptoms
- Kidney problems
- High potassium levels in your blood
- Serious skin problems
- Breathing problems (new or worsening)
- High blood pressure

**The most common side effects of AUBAGIO include**

- Abnormal liver test results
- Hair thinning or loss
- Diarrhea
- Flu
- Upset stomach
- Burning or prickling feeling in your skin

These are not all the side effects of AUBAGIO. Tell your doctor about any side effect that bothers you or that does not go away. For more information, ask your doctor or pharmacist.

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



## Medication Guide

**AUBAGIO**  
(*oh-BAH-gee-oh*)  
(teriflunomide)  
tablets

## Rx Only

Read this Medication Guide before you start using AUBAGIO 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 AUBAGIO?

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

- **Liver problems:** AUBAGIO may cause serious liver problems that may lead to death. Your risk of liver problems may be higher if you take other medicines that also affect your liver. Your doctor should do blood tests to check your liver:
  - within 6 months before you start taking AUBAGIO
  - 1 time a month for 6 months after you start taking AUBAGIOCall 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
- **Harm to your unborn baby:** AUBAGIO may cause harm to your unborn baby. Do not take AUBAGIO if you are pregnant. Do not take AUBAGIO unless you are using effective birth control.
  - If you are a female, you should have a pregnancy test before you start taking AUBAGIO. Use effective birth control during your treatment with AUBAGIO.
  - After stopping AUBAGIO, continue using effective birth control until you have blood tests to make sure your blood levels of AUBAGIO are low enough. If you become pregnant while taking AUBAGIO or within 2 years after you stop taking it, tell your doctor right away.
  - **AUBAGIO Pregnancy Registry.** If you become pregnant while taking AUBAGIO or during the 2 years after you stop taking AUBAGIO, talk to your doctor about enrolling in the AUBAGIO Pregnancy Registry at 1-800-745-4447, option 2. The purpose of this registry is to collect information about your health and your baby's health.
  - **For men taking AUBAGIO:**
    - If your female partner plans to become pregnant, you should stop taking AUBAGIO and ask your doctor how to quickly lower the levels of AUBAGIO in your blood.
    - If your female partner does not plan to become pregnant, you and your female partner should use effective birth control during your treatment with AUBAGIO. AUBAGIO remains in your blood after you stop taking it, so continue using effective birth control until AUBAGIO blood levels have been checked and they are low enough.

**AUBAGIO may stay in your blood for up to 2 years after you stop taking it. Your doctor can prescribe a medicine to help lower your blood levels of AUBAGIO more quickly. Talk to your doctor if you want more information about this.**

#### What is AUBAGIO?

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

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

## Who should not take AUBAGIO?

### Do not take AUBAGIO if you:

- have severe liver problems
- are pregnant or are of childbearing age and not using effective birth control
- take a medicine called leflunomide

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

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

- have liver or kidney problems
- have a fever or infection, or you are unable to fight infections
- have numbness or tingling in your hands or feet that is different from your MS symptoms
- have diabetes
- have had serious skin problems when taking other medicines
- have breathing problems
- have high blood pressure
- are breastfeeding or plan to breastfeed. It is not known if AUBAGIO passes into your breast milk. You and your doctor should decide if you will take AUBAGIO or breastfeed. You should not do both at the same time.

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

Using AUBAGIO and other medicines may affect each other causing serious side effects. AUBAGIO may affect the way other medicines work, and other medicines may affect how AUBAGIO works.

Especially tell your doctor if you take medicines that could raise your chance of getting infections, including medicines used to treat cancer or to control your immune system.

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

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

#### How should I take AUBAGIO?

- Take AUBAGIO exactly as your doctor tells you to take it.
- Take AUBAGIO 1 time each day.
- Take AUBAGIO with or without food.

### What are possible side effects of AUBAGIO?

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

- See "What is the most important information I should know about AUBAGIO?"
- **decreases in your white blood cell count.** Your white blood cell counts should be checked before you start taking AUBAGIO. When you have a low white blood cell count you:
  - **may have more frequent infections.** You should have a skin test for TB (Tuberculosis) before you start taking AUBAGIO. Tell your doctor if you have any of these symptoms of an infection:
    - fever
    - tiredness
    - body aches
    - chills
    - nausea
    - vomiting
  - **should not receive certain vaccinations during your treatment** with AUBAGIO and for 6 months after your treatment with AUBAGIO ends.
- **numbness or tingling in your hands or feet that is different from your MS symptoms.** You have a greater chance of getting peripheral neuropathy if you:
  - are over 60 years of age
  - take certain medicines that affect your nervous system
  - have diabetesTell your doctor if you have numbness or tingling in your hands or feet that is different from your MS.
- **kidney problems.** Tell your doctor if you have pain in your side (flank pain).
- **high potassium levels in your blood.** Tell your doctor if you have nausea that does not go away or a racing heartbeat.

- **serious skin problems.** Tell your doctor if you have any skin problems such as redness and peeling.
- **new or worsening breathing problems.** Tell your doctor if you have shortness of breath or coughing with or without fever.
- **high blood pressure.** Your doctor should check your blood pressure before you start taking AUBAGIO and while you are taking AUBAGIO.

The most common side effects of AUBAGIO include:

- increases in the results of blood tests to check your liver
- hair thinning or loss (alopecia)
- diarrhea
- flu
- nausea
- burning or prickling feeling in your skin (paraesthesia)

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 AUBAGIO. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-332-1088.

#### **How should I store AUBAGIO?**

- Store AUBAGIO at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep AUBAGIO and all medicines out of reach of children.

#### **General information about the safe and effective use of AUBAGIO.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AUBAGIO for a condition

for which it was not prescribed. Do not give AUBAGIO 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 AUBAGIO. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about AUBAGIO that is written for healthcare professionals.

For more information, go to [www.aubagio.com](http://www.aubagio.com) or call Genzyme Medical Information Services at 1-800-745-4447, option 2.

#### **What are the ingredients in AUBAGIO?**

Active ingredient: teriflunomide

Inactive ingredients in 7 mg and 14 mg tablets: lactose monohydrate, corn starch, hydroxypropylcellulose, microcrystalline cellulose, sodium starch glycolate, magnesium stearate, hypromellose, titanium dioxide, talc, polyethylene glycol and indigo carmine aluminum lake.

In addition, the 7 mg tablets also contain iron oxide yellow.

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


Genzyme Corporation  
500 Kendall Street  
Cambridge, MA 02142  
A SANOFI COMPANY

September 2012a

TER-MG-SA-SEP12



## Let us hear from you!

 **editor@nmss.org** or send mail to Momentum Editor, National MS Society, 733 Third Avenue, 3rd floor, New York, NY 10017. We need your name and address, but we won't print your name if you so request.

### Bullied as a volunteer

Thank you for your article, "Handling the office bully" (Spring 2013). Unfortunately, bullying happens to volunteers as well. After eight years of donating my heart, soul and time to a national organization, I was chased away by bullies in management, who goaded me into situations and called me aggressive when I defended myself. I was left with no option but to leave the volunteer position I loved. It has been almost a year and the psychological effects still have me bewildered, hurt and isolated.

Name withheld, via email

### Speed diagnosis—and treatment

I was shocked after reading the Research Now item on "Misdiagnosing MS" (Winter 2012–2013). Per the article, 95 percent of 122 doctors had encountered at least one patient misdiagnosed with MS. I was diagnosed in 2001 and, believe me, it was no easy road. After four years, five MRIs and increasingly worsening symptoms, my neurologist finally determined a diagnosis and prescribed a

disease-modifying therapy, as well as medication to assist with my fatigue and spasms.

While waiting for that diagnosis, I was still going to a job (from which I was eventually fired due to my medical problems) and fighting my symptoms, all the time not knowing if MS was truly the cause or if I was suffering from another debilitating illness.

Diagnosis is the first step to treatment. Rather than making a patient wait several years for a diagnosis while suffering through each day, physicians must be more aggressive in determining if MS is the true cause of the problem, and do it more quickly.

D. R. Boland, via email

Editor's note: Thank you very much for sharing your experiences. We agree that making the diagnosis of MS as quickly and accurately as possible is important so that the appropriate treatment(s)

can be initiated as early in the disease process as possible. The Society's Clinical Care Network (at **[nationalMSSociety.org/MSClinicalCare](http://nationalMSSociety.org/MSClinicalCare)**) continues to develop resources for physicians in this area, such as the free Multiple Sclerosis Diagnosis and Management App.

### Reflective of me

As a 34-year-old African-American professional female diagnosed with MS in 2011, I was excited to read about the National MS Society's commitment to inclusiveness ("Embracing diversity in the MS movement," Spring 2013).

Before I was diagnosed, I was told that MS was not a "black" disease. When I Googled MS and African-Americans, I found a few: Richard Pryor, Montel Williams and singer Tamia, but not many others. I still have trouble finding faces of color

## If You or Someone You Know Has MS

Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with MS. Talk to a healthcare professional or contact the National MS Society to learn about this and other ways to help manage Multiple Sclerosis.

### Address Drop, Add or Change

Enclose your label and request in the Join the Movement envelope on page 34. Alternately, you may email **[mailinglist@nmss.org](mailto:mailinglist@nmss.org)** or call 1-866-675-4787.

## Tell Momentum

Whether you're a student,  
or the parent of a student  
with MS, how do  
you handle school?

**nationalMSSociety.  
org/backtoschool**

in many MS-related social media outlets and newsletters. While these networks have been supportive and provide great information and advice, I am still in search of a community that is more reflective of me.

Karima, via email

### Another veteran's perspective

I want to thank Donnie Horner for sharing his perspectives on being diagnosed with multiple sclerosis while serving on active duty ("From military man to MS activist," Spring 2013). Thank you for your service. I also have MS.

I was in command of nuclear-tipped intercontinental ballistic missiles (ICBMs) on strategic alert duty during the Cold War, including the Cuban missile crisis and the Vietnam War. I believe my MS was aggravated by my period of active duty. My first neurological signs of MS occurred in 1973, six years after I left, which falls

within the Veterans Affairs (VA) requirement of an MS diagnosis within seven years after release for acknowledging a service-connected disability.

However, my official diagnosis wasn't established until 1997, 24 years later. The doctors and hospital staff who initially assessed my neurological symptoms 40 years ago didn't have today's diagnostic tools.

Improving my mobility on a fixed income is hardly possible without a formal VA acknowledgment of a service-connected disability. Donnie Horner was diagnosed with MS while on active duty and is eligible. VA neurologists concede that today I have MS. And yet, I am still waiting for my acknowledgment.

Michael E. Lichtenstein  
Captain, USAFR (Honorably  
Discharged), via email

Editor's note: The Society has been working with Capt. Lichtenstein to follow up. If you are a veteran with any questions about MS or access to services, call an MS Navigator at 1-800-344-4867.



## IN A FLASH!

Read us on the Web!

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## Coming this Fall:

A brand new look and feel for **Momentum**! Plus, a focus on education and MS.



## MS activists unite at Public Policy Conference

As part of the National Multiple Sclerosis Society's annual Public Policy Conference, more than 300 MS activists went to Washington, D.C., on March 6 to urge Congress to preserve funding for MS research and drug approval.

After hearing from speakers including Sen. Byron Dorgan (N.D.)—the former co-chair of the Congressional MS Caucus—and political pollster Celinda Lake, MS activists were briefed

on the importance of funding for the National Institutes of Health (NIH), the Congressionally Directed Medical Research Programs (CDMRP) and the Food and Drug Administration (FDA). The NIH has directed about \$725 million to MS research in the past five federal funding cycles, and the CDMRP has supported more than \$20 million of MS research.

Funding for the FDA is vital to help ensure speedy approval of effective therapies. In the current

challenging political and budget environment, MS activists' presence in Washington is critical to remind Congress about our community's needs and to share personal stories about why funding must continue.

Advocacy will continue year-round, so make sure you are signed up as part of the MS Activist Network ([nationalMSSociety.org/MSActivist](http://nationalMSSociety.org/MSActivist)) and take action when you receive alerts. ■



PHOTO BY JOE SHYMANSKI

## Share your motto on World MS Day

Young people across the globe who are affected by multiple sclerosis will have their say on World MS Day, Wednesday, May 29.

In a multinational effort to raise awareness of the disease, via [WorldMSDay.org](http://WorldMSDay.org), six young people with MS from countries as diverse as Tunisia, Portugal, Argentina, India, Russia and the United States, will share their stories and the mottos by which they live. Other people who have MS or who care for people with the disease can upload their own



mottos, which can be read in five languages (Arabic, French, English, Portuguese and Spanish).

To share your own motto and discover more ways to participate, go to [WorldMSDay.org](http://WorldMSDay.org). ■



## High-contrast techniques for low-contrast vision

by Robin L. Phillips

**P**eople living with multiple sclerosis are affected by a spectrum of low-vision issues, but one of the most common is low-contrast vision acuity.

“When we talk about low-contrast vision, we are referring to vision in low-light environments, such as nighttime, as well as the ability to detect edges of objects,” says Elliot M. Frohman, MD, PhD, professor of neurology and ophthalmology, and director of the Multiple Sclerosis and Neuroimmunology Division at the University of Texas Southwestern Medical Center. “Distinguishing edges is extremely important, especially for seeing in three dimensions.” And seeing in three dimensions is what gives people depth perception,

The “holy grail” of high-contrast color schemes is dark black against bright white. But a purely black-and-white environment isn’t always practical.

allowing them to judge distances. Without depth perception, everyday tasks such as driving or cooking can be risky.

Joyce Cohen, who has lived with MS for 26 years, has become an expert at dealing with her low-contrast vision, as she uses a wheelchair and is partially blind. “It impacts everything you do and every possession you own,” says the 66-year-

old from Omaha, Neb. “You have to learn ways to make things easier to see clearly, so you don’t trip over or break them.”

### Clarifying the issue

Loss of low-contrast acuity is often caused by bouts of optic neuritis—a common symptom of MS whose long-term effects have been underestimated. “After a bout with optic neuritis, it’s possible to return to 20/20 vision on high-contrast, black-on-white letter charts,” explains Dr. Frohman. “But low-contrast vision can take a devastating hit.”

Dr. Frohman says that people with MS who experience just one bout of optic neuritis can lose up to 40 microns of thickness in the retinal nerve fiber layer, the nerve tissue inside the eye that leads to the optic nerve. Forty microns is approximately four times the amount an average person loses in an entire lifetime. “However, people with low-contrast deficits can take advantage of their high-contrast acuity by making as many things as possible in their environment high-contrast.” He recommends seeing a specialist first. “A neuro-ophthalmologist who is experienced with MS can offer specific recommendations and tools that can benefit people with low-contrast issues.”

### Bright ideas

The “holy grail” of high-contrast color schemes is dark black against bright white. But a purely black-and-white environment isn’t always practical.



# LowVisionALERT

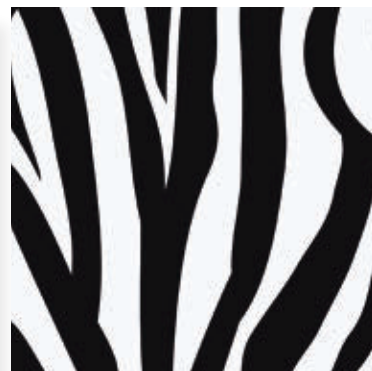
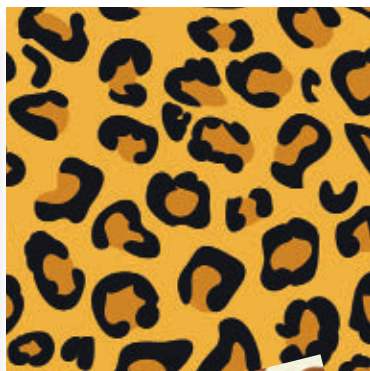


PHOTO BY THINKSTOCK

Strong patterns placed against solid colors can highlight sharp corners and edges in the home.



Christine Smith, OTR/L, MSCS, an occupational therapist who has specialized in MS for 18 years, offers some high-contrast solutions:

## 1. INCREASE LIGHTING ALL OVER.

“First, install bright lighting everywhere possible,” Smith advises. “Brighter lighting reduces shadows and increases contrast. Fluorescent light bulbs (including the newer, eco-friendly compact fluorescent bulbs) can produce really bright lighting in lamps and fixtures that weren’t designed for bright lights.” For example, a typical 60-watt incandescent bulb for a ceiling fan produces only about 604 lumens (a measure of brightness), whereas an 18-watt fluorescent bulb produces 1,170 lumens, and can work in just about any lamp or light fixture.

“Your lighting needs to be brighter and you need more of it,” Cohen agrees. “High-intensity, goose-neck lamps are great for task lighting, and they are cheap at office supply stores. Also, look critically at your bathroom, kitchen and bedroom, and

especially hallways. Install as much light in each space as you can.”

## 2. GET RID OF CLUTTER.

“It’s important to eliminate any cluttered visual space around your home,” Smith advises. “This could be from actual clutter, or it could be flooring with a design that is too busy, especially near transition areas such as stairs. Both can detract from seeing the contrasting edges of each stair.”

## 3. HIGHLIGHT SHARP EDGES AND CORNERS.

Use brightly colored duct tape to mark off areas where you’ll want to use extra caution, such as around edges or corners. “Another key to compensating for low-contrast deficits is to provide contrast not only with colors, but with patterns such as leopard prints or zebra stripes against solids,” Smith explains.

## 4. MAKE ELECTRONICS EASIER ON THE EYES.

“Changing a computer screen to a high-contrast color scheme and increasing the font [sizes] are easy ways to increase contrast,” says Smith. Look on your computer’s main menu for the control panel. From there, the “display” tab typically allows you to adjust your computer’s settings. For other home electronics, such as televisions, a number of other low-vision assistive tools and visual aids are available, such as large-button TV remotes that you can purchase to enhance contrast. Visit [AbleData.com](http://AbleData.com) and search for “high contrast” to find out what’s available.

## 5. COOK UP CONTRAST.

“A great idea is a cutting board that reverses,” explains Cohen. “One side is white and the other is black.” For example, white onions show up better on the black side, and dark green bell peppers show up better on the white side. To find examples, type in “low contrast cutting board” at **IndependentLiving.com** or **AbleData.com**.

Also contrast cookware with the color of your stove, Smith advises. “On light-colored stovetops, dark or black pots are better, and the reverse is true also. For some people, stainless steel cooktops contrast well with brightly colored pots. Many popular cast-iron brands are enameled in bold, fashionable colors.”

**“A great idea is a cutting board that reverses. One side is white and the other is black.”**

## 6. MAKE A FASHION STATEMENT.

Your personal style doesn't have to take a backseat to high-contrast needs. “My purse is all black, so I have a red wallet that shows up against the black purse lining,” offers Cohen. “Also, I have a metallic gold keychain and a bright purple cosmetic bag.”

### Simple solutions to a complex problem

Losing low-contrast vision can exacerbate other visual problems for people living with MS, and these issues can be complex. “All these suggestions may sound simple, but in reality they can make a huge difference in improving a person's ability to avoid falling or otherwise injuring themselves,” Dr. Frohman emphasizes. With some of these common sense solutions, you can better manage your low-contrast vision both in your home and in your office. ■

Robin L. Phillips, president of BlueRobin Communications LLC, is a freelance writer from Houston. She specializes in medical topics.

## Reach out for more

For more resources and information on low-contrast vision, call an **MS Navigator** at **1-800-344-4867**. The National MS Society's brochure, **Vision Problems**, also contains many helpful tips. Visit **nationalMSSociety.org** and search for “vision problems.”

The following organizations offer additional resources:

The Lighthouse  
**lighthouse.org**

Low Vision Center  
**lowvisioninfo.org**

National Federation of the Blind  
**nfb.org**



PHOTO BY THINKSTOCK







# The Disclosure Dilemma

by Andrea Sachs

Deciding if, when, how and who to tell about your MS is a big deal.

**K**aren Ball, the White House correspondent for the **New York Daily News**, had just returned home after two grueling trips abroad with the president. It was the summer of 1995 and, as usual, the capital was sweltering. But a few weeks later, Ball, then 33, found she couldn't walk in the heat without falling down. After bouncing from one doctor's office to another, she finally had an MRI, and was diagnosed with multiple sclerosis.

Ball knew next to nothing about MS, but she knew well that the press corps in Washington, D.C., thrived on gossip. "In that very insulated world in which I lived and worked, it would travel like wildfire once it became known," recalls Ball, now a freelance writer in Kansas City. So she immediately devised a plan. "I gave a disclosure statement to an assistant secretary with the White House press office, and I spun it strong. I was very careful in the way I worded [my disclosure]: 'It's not a big deal. They think I have a mild case. I'm going to be fine.'"

## A personal decision

While not everyone with MS needs to be quite as strategic as Ball was, many still must decide when—

and how—to have The Discussion: Who will they tell and how much will they say? The choices that people with MS make are myriad. "Some people are just an open book; some will not tell a single family member," says Tova Epstein, LCSW, a social worker at the Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Medical Center in New York City.

## Take your time

Those who have found the answer to their health puzzle after years of unexplained symptoms may have a strong impulse to tell the world. But since disclosure, once made, is irreversible, many experts advise thinking it over first. Says Rosalind Kalb, PhD, a clinical psychologist and vice president, clinical care, at the National MS Society, "We encourage people, if they can, to take a little time to sit with the information themselves and make a thoughtful, educated decision about who needs to know."

People often live in more than one realm: family, friends, dating and work. To the degree that those worlds are separate, people with MS may find themselves faced with the issue of disclosure



## Family

**When disclosing to young children, start with simple, basic information and add more complexity as they understand it.**

repeatedly. There's no one way to handle it, but a thoughtful plan may prevent later regrets.

### All in the family

A strong support network is key for coping with a chronic disease like MS, and for the majority of people, the family is the linchpin of that network. A spouse or partner, a sibling, or someone else in the family who was at their side during the search for a diagnosis, is often the person they tell first.

A harder call is deciding when to disclose to your children and what to say. "Think about how you talk with them about other complicated or confusing subjects," advises Dr. David Rintell, Ed.D., a psychologist at the Partners Multiple Sclerosis Center in Boston.

### Start simple

Dr. Kalb suggests using age-appropriate language to talk about MS. "I tell people to approach it like sex education," she says. "You start with simple, basic information, and add more complex information as your children develop the ability to understand it." With very young children, for example, you can explain that MS is not like the flu or chicken pox, and tell them they're not going to catch it and you can still hug and cuddle.

When discussing it with a young child, adds Dr. Rintell, "Make it concrete; make it specific to what

is observable, and don't go too far beyond that." For example, a parent could say, "Mom is having some trouble with her legs so she doesn't walk as well as before. But she's OK and can still take care of you."

Teenagers can understand much more about the illness. Still, he says, they should rely on their parents or healthcare providers for information; they're better off not researching MS on the Internet because they may come across unreliable or frightening information.

With grown children, the conversation is generally easier. Bob Sweitzer, 62, a retired transportation executive near Denver, immediately told his kids after he was diagnosed in 2004. "Our youngest of five was in college at the time," says Sweitzer. "The others were either in the latter stages of college or early stages of their own working careers. They were very supportive. And for the most part, they wanted to learn more."

Timing the disclosure is often determined by the severity of the illness. When MS causes changes in family routines, it's probably a good time to discuss what's going on. "If parents are very worried or depressed or anxious about all of this, their physical symptoms may not show, but their children are certainly picking up that something's amiss," says Dr. Kalb. "When you don't fill kids in, their imaginations typically come up with answers that are even scarier than reality."

Dr. Jennifer Finkel, the primary psychiatric consultant at the MS center at Mt. Sinai Medical Center, agrees. “If patients have obvious disabilities that even small children would notice, that warrants a discussion immediately. You can’t pretend that something’s not going on when it’s perceptible to anybody.”

### A friend in need is a friend indeed

Outside of the family, friends are usually the next stop in the process of disclosing. David Keer, a researcher in the federal government, found great comfort when he revealed his diagnosis to his friends: “I’ve lost a lot of friends to AIDS, so health is a very open discussion in my circle.”

## Friends

Let friends know you may want different things at different times.



“It is so important that there be a person in your life that you can be completely honest with,” says Epstein. “It is stressful enough dealing with symptoms.” Telling a friend about your health concerns can present a teachable moment—the opportunity to educate someone about the nature of MS. It also allows friends to ask questions, and find out how they can help.

Still, disclosure to friends doesn’t always go just as you wish: You tell them the news and they burst into tears. And guess what? You have to comfort them, just at the moment you need comforting yourself.

Says Dr. Rintell, “It’s important to signal to people that you really don’t want to hear negativity, or the story about the neighbor down the street who was diagnosed and days later was carried out of the house on a stretcher.” To evoke a more positive reply, Dr. Rintell suggests that people with MS model how they would like their friends to respond. “I’ve been diagnosed with MS, but I want you to know that I’m doing well. All that I need now from my friends are words of support.”

Know that what feels supportive may change as you adapt to your new reality. “I think it’s human nature to want different things at different times,” says Epstein, “and to let your friends know that.”

### The dating game

Dating, for anyone, means exposing oneself to a certain degree of vulnerability: Is this person the right one? Does this person really care about me? Add to that a diagnosis of MS, and the discomfort level can rocket.

Molly (not her real name), a 21-year-old college student in California, has learned this through experience; since she was diagnosed at 19, she has had several relationships fizzle after disclosing her MS. “It’s made me a little more hesitant and anxious,” she admits. “I’ve always thought it might be my age group; it’s a little more of a ‘me age.’ So it’s hard to figure out how to deal with something like this.”





## Dating

Some people tell their romantic partners about MS early in the relationship. Others wait until the time is right for them.

### Telling your romantic partner

In reality, says Dr. Kalb, there is sometimes reason to be concerned about disclosing to prospective romantic partners, regardless of age. “The fact is that some people will run to the hills,” she says. “It’s just extra baggage they don’t want to deal with. But many people don’t run. I’ve been working at the Society since 1980, and I have seen many couples get together with MS in the picture, with one or both of them, and it’s just one thing that a relationship has to deal with.”

On a date with someone you’re meeting for the first time, you have no obligation to share your medical status. “A first date is basically to find out if this person is worth spending any more time with,” Dr. Kalb says. “If you have a very visible symptom—you walk with a cane, for example—then you have a choice to explain what it is, or not. Once you’ve decided that this is a relationship that is worth putting some time and effort into, that’s when I think it is important to talk, not just about MS, but about anything about you that is important for that other person to know. You don’t build a very strong, sound relationship on secrets or half-truths or lies.”

Still, some people take a chance and tell someone early in the relationship. “Sometimes it doesn’t scare the person away,” says Epstein. “Sometimes it does.” Margo Wald Rubens, a divorced Detroit mother of three, met a man using an online dating service, and told him about her MS on their first date. “I liked him, and he was nice, and I thought, if we continue on together, I better tell him so he knows he can get out at any time. And he said, ‘No big deal to me.’” They were together until his death eight years later.

Dana Snyder-Grant, a Boston therapist, was also forthcoming about her diagnosis from the start. Snyder-Grant, 57, told her now-husband on their second date, when he asked her to go for a walk. “We started walking around the pond, and I pulled out my collapsible cane and it dramatically unfolded. And I said, ‘Meet my cane.’ And he asked, ‘Oh, what’s that for?’ and I said, ‘I have MS. I’ve had it 10 years now. This is what MS is. Symptoms can come and go. And it’s not going to kill me. It’s just a pain in the neck.’”

### Office politics

Fern Berman was used to living her life in the headlines. At the pinnacle of a successful career in public relations, Berman represented those at the top of the food chain—literally. Among her clients were Julia Child and the famous New York restaurant Le Cirque. Berman was also out as a lesbian, and her wedding was one of the first gay marriages covered

in **The New York Times**. But starting in 1993, when she was diagnosed with MS, Berman began a new lifestyle of keeping secrets.

“I lived in constant fear of my clients and colleagues discovering that I had MS,” says Berman. “I thought, ‘I’m dead. My career is over if they find out.’ I didn’t want people to think, ‘She’s really good, **even though** she has MS.’ I didn’t want it to be part of my identity.” But as Berman’s MS worsened, it became harder to shield that part of her life. “I felt beyond vulnerable. I wasn’t envisioning any future for myself.”

In the summer of 2012, Berman began walking with a cane. “People would ask me, ‘What’s wrong with you?’ and at first I would say, ‘Oh, I hurt my knee.’ Then finally I said to myself, ‘I’m not lying anymore.’”

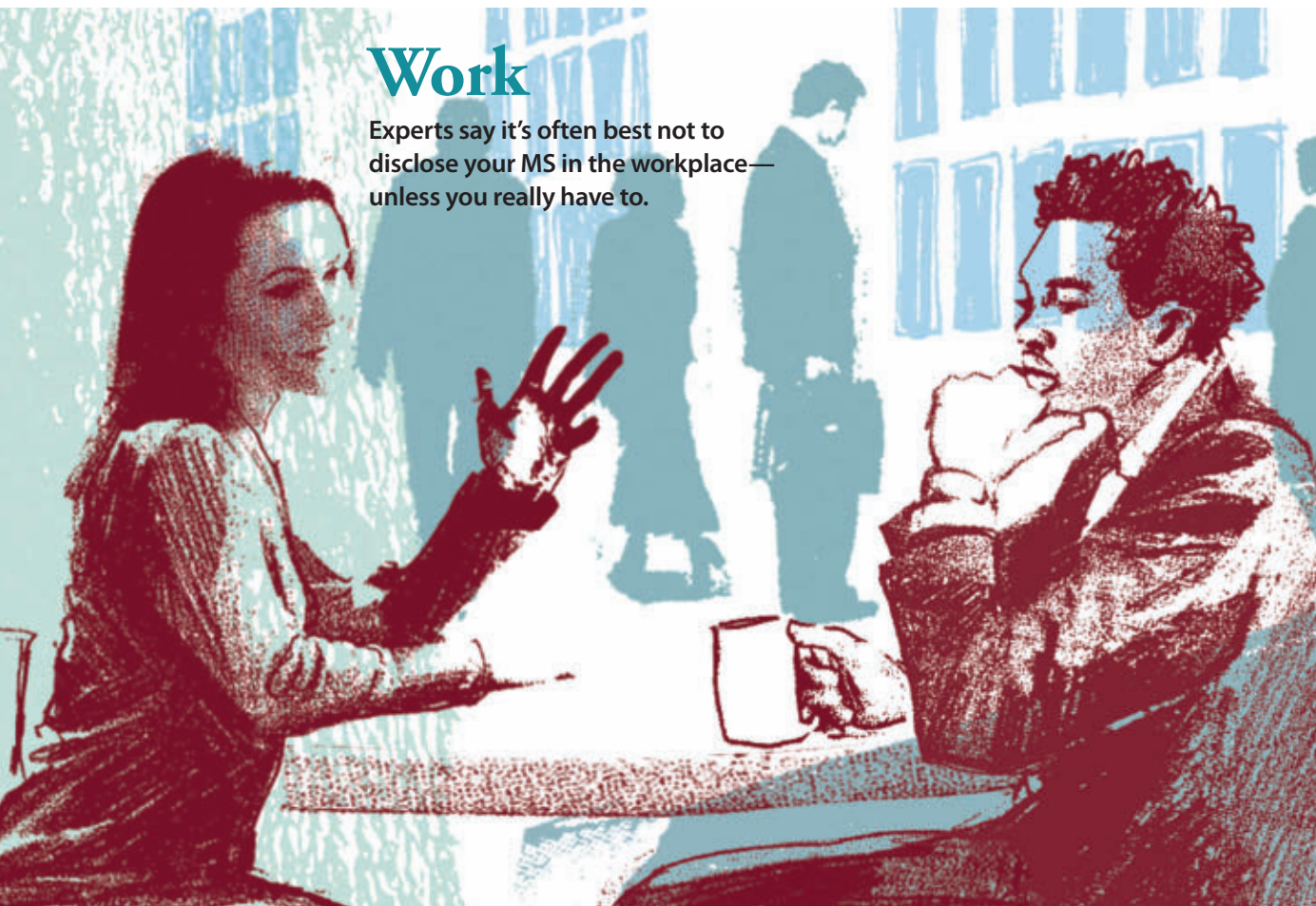
I started to tell people, ‘I have MS,’” she says. “I started telling more and more people the truth.” Though Berman left her high-powered job and New York City for a quieter life in Madison, Conn., she is now pursuing her passion for photography.

### Know your rights

For others, disclosing in the workplace is less dramatic but still requires finesse. The Americans with Disabilities Act (ADA), a federal law passed in 1990 and amended four years ago, provides some protections for those with MS who work for companies with 15 or more employees. But Linda Carter Batiste, a lawyer with the Job Accommodation Network (JAN), an agency supported by the U.S. Department of Labor’s Office of Disability Employment Policy, cautions that the law is

## Work

Experts say it’s often best not to disclose your MS in the workplace—unless you really have to.





“not a simple fix where you call somebody and they immediately come in and protect your rights in the workplace and you never miss a day of work.” For that reason, according to Barbara McKeon, the Society’s director of Employment Programs and Services in the New York City area, “We recommend that people consider not disclosing unless they have to. They might have a really good experience; their employer might be very understanding and very helpful. But on the other hand, it could go the other way and there’s no way for them to really know that.”

Much of the time, employees disclose to their employers when they need some sort of accommodation to do their job. This might include such adjustments as making the workplace accessible, modifying a schedule, allowing leave time or providing reserved, close-by parking space.

“Initially, you only need to let them know that you’re having trouble because of a medical condition and you need an accommodation,” Batiste explains. “Often, the employer doesn’t ask for any more information, and that’s the end of it.” But if you request an accommodation, the employer is allowed to ask for proof that you have a disability, which usually means your diagnosis and your limitations.

### No obligations

An employee who has visible symptoms but doesn’t require any kind of accommodation has no legal obligation to tell the employer. But if symptoms could lead an employer to misconstrue their significance—fatigue as laziness, or balance issues as substance abuse, for example—it might be better to disclose. Charles Goldman, a disabilities lawyer in Washington, D.C., warns employees with MS to proceed with caution. “I think we still live in a world where people are afraid of the unknown, and that comes into play when people have hidden disabilities such as MS.”

Much of the time, employees disclose their MS when they need some sort of accommodation to do their job.

Goldman learned that firsthand from Keer, the federal researcher, who became Goldman’s client after his employer refused him permission to work at home at times.

Although Keer ultimately won a settlement and has been working happily for 16 years at a more accommodating agency, he shudders at the memory of going up against his former employer.

Employees should know, says JAN’s Batiste, that “they are not 100 percent protected just because they happen to disclose. There may be times when someone discloses and an employer has a legitimate reason to terminate them, for example, if they cannot do their job anymore even with

accommodation.” The Society offers an online tool that can help a person decide if, when and how to disclose in the workplace. Visit [nationalMSSociety.org/workplacedisclosure](http://nationalMSSociety.org/workplacedisclosure) for more information.

### Be prepared

If an employee were getting ready to disclose, says Goldman, “We would say to them, first let’s work with someone to practice, such as someone at your local MS chapter, so you don’t have to hire a lawyer. You can practice what you’re going to say to whom and how you’re going to do it.” (For help finding a local employment program that can help you practice, call an MS Navigator at 1-800-344-4867 or JAN at 1-800-526-7234.) He adds, “You need to get your doctor lined up; let him [or her] know that he may be asked for medical information. You can’t just sort of put your toe in the water when you make disclosure. You’ve got to be prepared.” ■

Andrea Sachs is a senior reporter at **Time** magazine. Diagnosed with MS in 2009, she disclosed to her employer in 2012.



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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 certain

types of an irregular or abnormal heartbeat (arrhythmia), including a heart finding called prolonged QT, as seen on a test to check the electrical activity of your heart (ECG) before starting GILENYA. You should not take GILENYA if you take certain medicines that change your heart rhythm.

\*GILENYA can result in a slow heart rate when first taken. Your first dose will be given in a medical facility where you will be watched for at least 6 hours. If you stop taking GILENYA for more than 14 days after your first month of treatment, you will need to repeat this observation.

Please see additional Important Safety Information on next page.



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## Important Safety Information

GILENYA may cause serious side effects such as:

- **Slow heart rate, especially after your first dose.** An ECG will be performed before and 6 hours after your first dose. Your pulse and blood pressure should be checked every hour while you stay in a medical facility during this time. If your heart rate slows down too much, you might feel dizzy or tired, or feel like your heart is beating slowly or skipping beats. Symptoms can happen up to 24 hours after your first dose. After 6 hours, 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 watched by a health care professional. If you have any serious side effects after your first dose, especially those that require treatment with other medicines, you will stay in a medical facility to be watched overnight and for at least 6 hours after 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 watched overnight after you take your first dose. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor or go to the nearest emergency room right away if you have any symptoms of a slow heart rate. If you stop taking GILENYA for more than 14 days after your first month of treatment, you will need to repeat this observation.
- **Increased risk of serious infections.** GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test before you start GILENYA. Increased risk of infection was seen with doses higher than the approved dose (0.5 mg). Two patients died who took higher-dose GILENYA (1.25 mg) combined with high-dose steroids. Call your doctor right away if you have fever, tiredness, body aches, chills, nausea, or vomiting.
- **Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms.** Macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA; 3 to 4 months after you start GILENYA; and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- **Breathing problems.** Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.
- **Liver problems.** Your doctor should do blood tests to check your liver before you start GILENYA. Call your doctor right away if you have nausea, vomiting, stomach pain, loss of 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 breastfeed, as it is not known if GILENYA passes into breast milk. A pregnancy registry is available for women who become pregnant during GILENYA treatment. Call 1-877-598-7237 or visit [www.gilenyapregnancyregistry.com](http://www.gilenyapregnancyregistry.com) for more information.

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

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

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

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

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 medical condition or your treatment.

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

GILENYA may cause serious side effects, including:

1. **Slow heart rate (bradycardia or bradyarrhythmia) when you start taking GILENYA.** GILENYA can cause your heart rate to slow down, especially after you take 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 should stay in a medical facility 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 watched 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 watched.
- 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 watched overnight. You will also be watched 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 watched 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 emergency room right away if you have any symptoms of slow heart rate.

2. **Infections.** GILENYA can increase your risk of serious infections. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping treatment. Your doctor may do a blood test before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection:
  - fever
  - tiredness
  - body aches
  - chills
  - nausea
  - vomiting

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

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

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

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

**What is GILENYA?**

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

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

**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. Tell your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a blood test for chicken pox virus. You may need to get the vaccine for chicken pox and then wait 1 month before you start taking GILENYA.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes
- breathing problems, including during your sleep
- liver problems
- high blood pressure
- Are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.
  - Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
  - If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and for at least 2 months after you stop taking GILENYA.

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



For more information, you can call the GILENYA Pregnancy Registry at 1-877-598-7237 or visit [www.gilenyapregnancyregistry.com](http://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**, including prescription and non-prescription medicines, vitamins, and herbal supplements.

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

Using GILENYA and other medicines together may affect each other causing serious side effects. Especially tell your doctor if you take:

- Medicines for:
  - heart problems or
  - high blood pressure or
  - other medicines that may lower your heart rate or change your heart rhythm
- Vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines while you take GILENYA and for at least 2 months after you stop taking GILENYA. If you take certain vaccines, you may get the infection the vaccine should have prevented. Vaccines may not work as well when given during GILENYA treatment.
- Medicines that could raise your chance of getting infections, such as medicines to treat cancer or to control your immune system.
- ketoconazole (an antifungal drug) by mouth

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

#### **How should I take GILENYA?**

- Your first dose of GILENYA will be given in a medical facility where you will be watched 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.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- If you start GILENYA again after stopping for 2 weeks or more, you will start taking GILENYA again in your doctor’s office or clinic.

#### **What are possible side effects of GILENYA?**

GILENYA can cause serious side effects.

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

Serious side effects include:

- **Breathing Problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.
- **Liver problems.** GILENYA may cause liver problems. Your doctor should do blood tests to check your liver before you start taking GILENYA. Call your doctor right away if you have any of the following symptoms of liver problems:
  - nausea
  - vomiting
  - stomach pain
  - loss of appetite

- tiredness
- your skin or the whites of your eyes turn yellow
- dark urine

The most common side effects of GILENYA include:

- headache
- flu
- diarrhea
- back pain
- abnormal liver tests
- cough

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

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

#### **How do I store GILENYA?**

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

#### **General information about GILENYA**

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

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

For more information, go to [www.pharma.US.Novartis.com](http://www.pharma.US.Novartis.com) or call 1-888-669-6682.

#### **What are the ingredients in GILENYA?**

**Active ingredient:** fingolimod

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

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

GILENYA is a trademark of Novartis AG.

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Novartis Pharma Stein AG  
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Distributed by:  
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## Scientific prize may turn wishes to reality

by Vicky Uhland

**W**hen a family member was diagnosed with multiple sclerosis about 25 years ago, Chuck and Margery Barancik had many questions. So they immersed themselves in reading everything they could about MS and talking with the leading experts of the time. “We were deeply frustrated at the lack of available treatments, and concerned for the future,” Chuck says.

As the couple learned more about the disease and the research behind it, their questions began to take the form of a wish list. Why, they wondered, couldn’t someone discover a way to freeze this degenerative disease’s progress? What if a researcher could develop a vaccine for people who are at higher risk for MS—or even find a cure?

The Baranciks went beyond merely pondering these questions, however. For more than two decades, they have invested substantially in the National MS Society’s research portfolio. “We felt that we had the ability—and the responsibility—to help propel research forward,” Chuck says. Their contributions have led to significant advances in understanding MS and approaches to treatment. They also became MS activists: Chuck, a retired Chicago businessman,

What if a researcher could develop a vaccine for people who are at higher risk for MS—or even find a cure?

served on the Society’s research advisory committee, and Margery was a treasured member of the Greater Illinois Chapter’s board of trustees.

The Baranciks are proud to have sponsored early support for the Society’s acceleration of the MS drug development process through Fast Forward, which funds academic groups and emerging biotechnology and pharmaceutical companies involved in drug research.

“We’ve been very impressed

with the Society’s rigorous review process in awarding grants and we are especially pleased with its decision to increase funding for research,” Chuck says. He recognizes that researchers have made tremendous progress in developing drugs that reduce the frequency of MS attacks and alleviate symptoms, but “the magic bullet has not yet been discovered,” he says. “Advances are being made, but we all wish to see the pace accelerated.”

Because MS affects a relatively



PHOTO BY LORI SAX

**Margery and Chuck Barancik established a \$100,000 annual prize for innovation in MS research, the largest such prize ever.**

small percentage of the population, Chuck says, available funding for MS research doesn't always carry the sense of urgency he and Margery would like to see.

In an effort to fulfill their vision of finding a way to halt or cure MS, and to promote awareness of the disease, the Baranciks established the Barancik Prize for Innovation in MS Research.

The prize awards \$100,000 annually to “an exceptional scientist or a team of scientists whose work in MS research demonstrates outstanding innovation and originality.”

The goal of the Barancik Prize, which is the largest-ever MS research prize, is to attract more researchers to the field of MS; encourage and reward sound,

creative approaches; and promote greater public and institutional awareness of the disease. Meeting these goals will help address some of the immediate challenges that concern Chuck and all who are affected by MS: development of improved diagnostic tools; enhanced training for clinicians; treatments for progressive MS; and increased investment in MS research by the National Institutes of Health, pharmaceutical and biotechnology companies, academic institutions and the Society.

The first Barancik Prize winner will be announced in May, and nominations for future prizes will close Jan. 31 of each subsequent year. A 10-member selection committee made up of leaders in science, medicine and MS advocacy will evaluate the nominees for exceptional innovation and originality in MS research, the potential of their research to help treat or cure MS, and overall scientific accomplishments that establish them as future leaders in MS research.

Ultimately, Chuck hopes the prize will spur researchers to take a “shot in the dark” and develop innovative, scientifically sound answers to the wish list of questions about MS that he and Margery first posed nearly a quarter-century ago. ■

Vicky Uhland is a freelance writer and editor in Lafayette, Colo.

The Barancik Prize will attract more researchers to the field of MS; encourage and reward sound, creative approaches; and promote awareness.



The Baranciks hope the prize will help MS researchers, like the one pictured here, develop better diagnostic tools, among other objectives.

PHOTO BY BILL STANTON



Commercial fishing in Alaska is challenging, acknowledges Jeff Smith (pictured below). But it's what he lives to do.

## Living the Alaskan adventure

by Melissa DeV Vaughn

With a diagnosis of MS, Jeff Smith worried: Would he still be able to handle the demands of commercial fishing? Or was he finally facing something he couldn't fix?

Jeff Smith checked his watch, gunning his boat motor like a NASCAR driver as he waited for the 7 a.m. fishing period to open. After securing one end of his net to a buoy set in the water, he was soon under way, feeding the rest of the net from the boat's stern as he sped to the second buoy.

Now that these "sets" were made, he could earn his living, catching wild sockeye salmon from Alaska's Cook Inlet, where a series of snow-capped volcanoes dot the horizon and the brief sunsets turn the sky violet.

Commercial fishing in Alaska is hard work though, requiring demanding hours, brute strength and quick thinking. You're a net mender, boat mechanic, carpenter and electrician. You're sore, tired, smelly and often cold, and you have to keep your wits about you even when the seas are tossing you about like a ball in a bingo cage. It's all part of Smith's job as crew foreman.

There is a certain gratification that comes from a hard day's work, and from the time he was

a boy wandering the forests surrounding his Tallahassee, Fla., home, Smith has experienced that. After being honorably discharged as a U.S. Marine sergeant in 2005, he followed his skill sets, working as a plumber, mechanic and hunting guide. He has a knack for figuring out what's broken and fixing it.

That knack helped land him his first job as a fisherman. In 2007, when he had the summer off from college, he arrived in Alaska to guide tourist horse rides, but soon became intrigued at the prospect of working at a commercial fishing operation. Though he'd fished and boated recreationally all his life, he'd never done it vocationally. Undaunted, he showed up on the beach with his saddle, wearing a cowboy hat, and asked for work. Noting his uncanny ability to fix things, a crew operator hired him, and within days he was driving boats—something usually reserved for experienced fishermen. He returned nearly every summer after that and was



PHOTO BY MELISSA DEVAUGHN

regarded as a highly desirable crewman. But in the winter of 2010, Smith's speech began to slur and his left hand turned numb. Driving his motorcycle made his hands tingling and uncomfortable, and even tying his shoelaces became a challenge.

## Facing the future

The diagnosis of multiple sclerosis, coming after a battery of tests that included an MRI and spinal tap, floored Smith. He worried about his future: Would he still be able to handle the demands of commercial fishing? Was he finally facing something he couldn't fix?

"I definitely was worried about every aspect of fishing," says Smith, 32, from Laramie, Wyo., where he recently graduated college with a biology degree and aspirations of teaching so he can continue commercial fishing during his summers. "You pull up the nets, and you work with your hands. It's a job for hands, and my hands don't work."

When Smith returned to Alaska for the 2011 fishing season, he was determined not to let MS alter his life. He'd begun treatment, and while his dexterity had improved slightly, migraines brought on by his medication wracked him almost daily, leaving him nauseated and weak. On the boat, he'd routinely tough it out for the sets—the trickiest part of fishing properly—then have to slow the boat, lean over the stern and lose his breakfast

before returning to shore.

"My doctor and everyone told me not to go up there," Smith says. "They said any stress is bad for my MS. But what aspect of life is not stressful? Yes, it would make me more stressed to go to Alaska, but it's not more stressful than going to school and being worried about tests."

Joining Smith that year was his service dog Colt, who keyed into his every move. Colt was especially helpful when Smith felt dizzy or unbalanced, and the dog followed him wherever he went—from the shop, where he worked on spare boat parts,

to the shore, where he mended nets. Colt offered him the moral support he needed on the days he felt worst, curling up beside him in his cabin as he tried to sleep off the debilitating migraines.

"I couldn't have done it without him, and the work he did to help me is showing," Smith says. "He's getting gray around the muzzle."

Last summer, Smith returned to the shores of Cook Inlet. He'd changed to a different medication, which eased the migraines but came with its own issues. Monthly transfusions meant he'd have to travel from the remote fish camp to Anchorage to get

**"At least I've had adventures, gone places and done things that some people have only dreamed of," says Jeff Smith, shown here tossing salmon from one skiff to another.**





treatment. And some MS symptoms persisted. Often troubled with his balance and tiring quickly, Smith relied on Colt more than ever, while continuing to work long hours. He didn't want the disease to prevent him from doing his job, and that mental battle—adapting to his new reality—would be his biggest fight yet.

### A new reality

One day, fish camp owner Andy Hall spent a foul-weathered day on the water, preparing a new fishing site. With Smith in one boat and Hall in the other, the

two bickered over where and how to set the sites. The tension showed, and the crew picked up on the conflict. Hall, sensing that there was more going on than a power struggle between boss and foreman, told Smith, “Let’s go for a ride.” They took a work truck down the beach, pulled over and began to talk.

“I said, ‘We need your knowledge and abilities, but you’re not the strongest guy, physically, on the crew anymore,’” Hall says. “In the past you’ve been the guy who can think faster, move faster, lift more and tear the engine apart on the fly—you can do all these things that everybody else has to do with a lot of forethought and preparation.”

### Learning to change

Hall wanted Smith to understand what everyone on the crew already knew: “We need your brain, not necessarily your muscles. But you have to be willing to delegate and lead, you have to pass that knowledge on, to take on that new role.”

Afterwards, Hall says, a shift occurred. “His medical condition is forcing him to start relying on other attributes that he’s got,” Hall says. “And he’s lucky because he’s just as smart as he is strong. His instincts on the water are so far beyond most people’s that he has a tremendous amount to offer us even if he’s not the one driving the stakes or pulling the nets or filling the sand bags.”

Commercial fishing in Alaska is



PHOTO BY ANDY HALL

**Jeff Smith (left) and crewman Graham Zimmerman check their salmon nets.**

challenging, Smith acknowledges. But it’s who he is, and what he lives to do. So he accepts his limitations, and his new role as a mentor, but he won’t let MS define him.

“I miss tinkering in the shop, putting on a new motor or water pump. My hands won’t do it,” he says. “Now I supervise other people, to tell them how. Do I wish it were different? Yes, but this is what I need to do now.

“I will stop going to Alaska when it stops being fun. You have to do what you enjoy,” he says. If that day comes, he says he’ll get a traditional job with benefits to pay medical expenses.

In the meantime, he adds, “At least I’ve had adventures, gone places and done things that some people have only dreamed of.” ■

Melissa DeVaughn is a freelance writer and commercial fisher who lives in Chugiak, Alaska, in the off-season and on the shores of Cook Inlet, Alaska, while fishing.



PHOTO BY ANDY HALL



# Trail

Bike MS requires a commitment to train. Be sure to prepare properly for the big event.

by Kathleen Hagan

Andrew McCasker was a self-professed couch potato—until he decided to participate in a Bike MS ride. Inspired by his wife Leslie, who was diagnosed with multiple sclerosis 23 years ago, he dedicated himself to training by riding long distances multiple times per week, nine months before the event.

But McCasker realized he could have done more to prepare for the ride, which took place in the foothills of the Blue Ridge Mountains west of Washington, D.C. “I didn’t understand the nature of the terrain and the weather,” he says. “I was not prepared for the challenges posed by the hilly course and the hot temperatures.”

So he adjusted his training routine the following year. “This time, I trained on the same kind of terrain that the ride itself is

on,” he says. “I also made sure that I was eating and drinking enough to stay fueled and hydrated.”

Whether you’re a new or returning rider, the right training is key to a safe and successful Bike MS experience.

### How to begin

Dr. Angeli Mayadev, a physical medicine and rehabilitation physician in the MS Center at the Swedish Neuroscience Institute in Seattle, recommends starting training at least 12 weeks before the actual ride. However, as with any new exercise, talk to your healthcare provider first. Discuss strategies to manage MS symptoms such as heat intolerance, imbalance, weakness, fatigue or cognitive challenges. You may want a gentler schedule or more rest periods between training days. Develop a training routine that will work for you.

### Use the tools

All Bike MS participants are invited to use a free subscription to Training Peaks, an interactive website, where they can find custom training plans just for Bike MS cyclists, both novice and experienced, created by professional cycling coach Joe Friel. Use them to plan rides, record miles and keep track of diet.

Rex Parker of Boise, Idaho, who rode for the first time in 2012 in memory of his brother Rick, who had MS, found the program very valuable. “It helped me determine how far my rides should be each week,” he says. To set up your free Training Peaks account, go to [home.trainingpeaks.com/events/cycling/ms-society.aspx](http://home.trainingpeaks.com/events/cycling/ms-society.aspx).

### Slow and steady

Whether you plan to ride the whole Bike MS route or a shorter stretch, remember to listen to your body and not push yourself



# ningDays

Rex Parker (far right) and his team practice on the same terrain that they will ride for Bike MS.



The key to training for Bike MS is to develop a routine that will work for you.



Rest periods while training are important.



PHOTO COURTESY OF THE NATIONAL MS SOCIETY



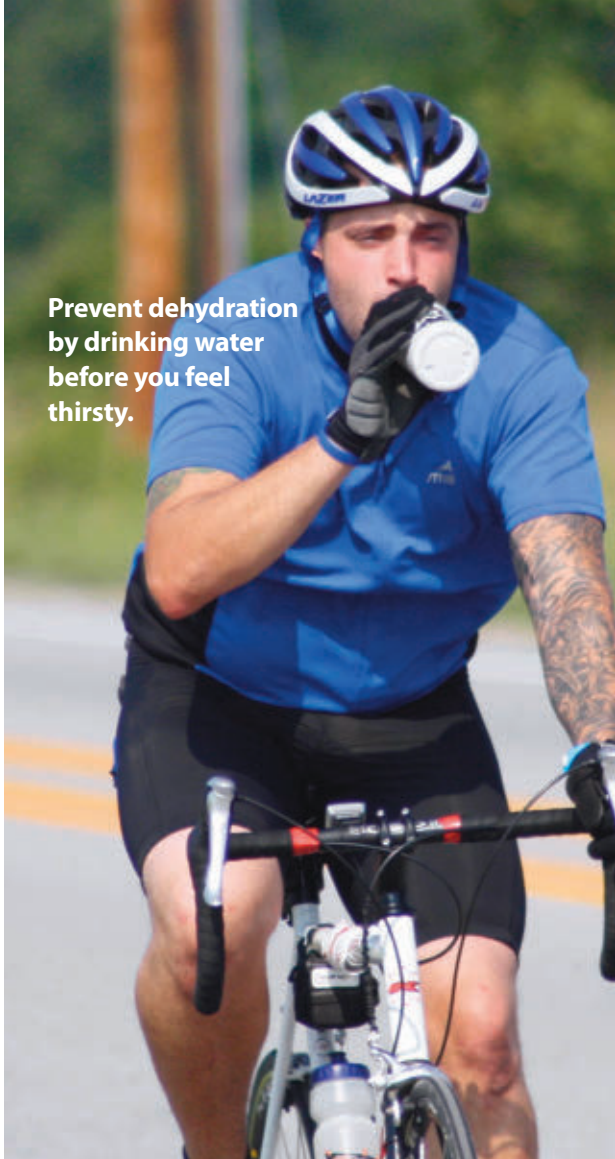


Rex Parker had his brother Rick's old 12-speed Schwinn professionally fitted so he could ride it in his honor for Bike MS.



Make sure to pace yourself as you're training.

Prevent dehydration by drinking water before you feel thirsty.



## Contribute to the cause

Andrew McCasker, 50, of the Greater Washington, D.C., area, spends almost as much time thinking about fundraising through Bike MS as he spends training. Last year, his team raised \$33,000 for multiple sclerosis research. He recommends drafting a very personal email to reach out to friends, family and acquaintances. "You need to get past the feeling that you are 'asking people for money' and instead know that you are asking them to contribute to a cause," he says. "Because that's what we're doing, and the fact that there has been progress in research makes it feel like the money is actually doing some good."

Rex Parker, 43, of Boise, Idaho, who was the top fundraiser for the Bike MS event in Idaho last year, uses a similar approach. "I rode in honor of my brother and was surprised by how excited others were by my personal story," he says.





too far. "Taking a day or two off does the body wonders. It helps tissue repair and rests the muscles and joints," says physical therapist Sue Kushner, MS, PT. "Sometimes, even giving your mind a rest can do you good."

Make sure to pace yourself training, as well. "For every hour you ride, take a break for five or 10 minutes and stretch," Dr. Mayadev says.

"Appropriate stretching is paramount to one's health and safety," Kushner says. "Stretch the hamstrings and quadriceps and also the upper and lower back muscles." For stretching ideas, go to [nationalMSSociety.org/stretching](http://nationalMSSociety.org/stretching).

Stretching is especially important for participants with progressive MS, who may experience muscle cramping and fatigue, says Dr. Mayadev. She also offers advice for cyclists who experience hand numbness: "Get bike gloves with padding and double tape the handlebars. That puts less pressure on the wrists."

### Stay cool

Another challenge for cyclists who have MS is becoming overheated, says participant Anna Strathman, diagnosed with relapsing-remitting MS in January 2011. "I drink enormous amounts of water and pour water over my body to try to keep my core temperature down as I ride,"

Stretching is especially important for participants with progressive MS, who may experience muscle cramping and fatigue.

says the Mono County, Calif., resident.

"Always drink water or beverages with electrolytes **before** you feel thirsty," Kushner says. "Because by the time you feel thirsty, you're already on your way to becoming dehydrated."

### The right bike

A properly fitting bike will make your ride safer and more comfortable, Dr. Mayadev says. To make sure the saddle and handlebars are at the correct height for your body, get your bike professionally fitted by a trainer or physical therapist.

That's what Parker did when he inherited his brother Rick's bike, an old 12-speed, steel-frame Schwinn from 1987. "That's what planted the seed," he says. "Riding in Bike MS seemed like the right way to honor his memory."

Parker had the seat adjusted both horizontally and vertically based on his body measurements, which helped relieve the upper leg pain and intermittent knee soreness he had been experiencing while riding.

For those with mobility challenges,

there are alternatives, such as tandem bikes and recumbent bikes. For the past five years, Gordy Myre, from Boise, Idaho, has ridden 50 miles of Bike MS using a hand bike—a three-wheel cycle that relies on upper body strength to pedal. "I have secondary-progressive MS, but I continue to do everything," says Myre, who was diagnosed 23 years ago. "The hand bike gave me the opportunity to get back out there."

### The lay of the land

Train on the same bike you plan to ride during the event and familiarize yourself with the course in advance. That way, you can learn what types of terrain you will encounter and train for them accordingly. "I recommend driving the course so you can see how hilly it is but also speak with the ride coordinators to get more information," Kushner says. Then, like McCasker, you'll be better prepared for your best ride on the big day.

To find an upcoming event near you, visit [BikeMS.org](http://BikeMS.org). ■

Kathleen Hagan is a Chicago-based editor who writes regularly for association and healthcare publications.

## For people with relapsing MS



### Indication

AVONEX® (interferon beta-1a) is approved by FDA to treat relapsing forms of multiple sclerosis (MS) to decrease the number of flare-ups and slow the occurrence of some of the physical disability that is common in people with MS. AVONEX is approved for use in people who have experienced a first attack and have lesions consistent with MS on their MRI.

### Important Safety Information

Before beginning treatment, you should discuss with your healthcare provider the potential benefits and risks associated with AVONEX.

**AVONEX can cause serious side effects.** Tell your healthcare provider right away if you have any of the symptoms listed below while taking AVONEX.

- ▶ **Behavioral health problems including depression, suicidal thoughts or hallucinations.** Some people taking AVONEX may develop mood or behavior problems including irritability (getting upset easily), depression (feeling hopeless or feeling bad about yourself), nervousness, anxiety, aggressive behavior, thoughts of hurting yourself or suicide, and hearing or seeing things that others do not hear or see (hallucinations).
- ▶ **Liver problems, or worsening of liver problems including liver failure and death. Symptoms may include** nausea, loss of appetite, tiredness, dark colored urine and pale stools, yellowing of your skin or the white part of your eye, bleeding more easily than normal, confusion, and sleepiness. During your treatment with AVONEX you will need to see your

healthcare provider regularly and have regular blood tests to check for side effects.

- ▶ **Serious allergic reactions and skin reactions. Symptoms may include** itching, swelling of the face, eyes, lips, tongue or throat, trouble breathing, anxiousness, feeling faint, and skin rash, hives, sores in your mouth, or your skin blisters and peels.

**AVONEX will not cure your MS** but may decrease the number of flare-ups of the disease and slow the occurrence of some of the physical disability that is common in people with MS. MS is a life-long disease that affects your nervous system by destroying the protective covering (myelin) that surrounds your nerve fibers.

The way AVONEX works in MS is not known. It is not known if AVONEX is safe and effective in children.

**Do not take AVONEX if you** are allergic to interferon beta, albumin (human), or any of the ingredients in AVONEX.

**Before taking AVONEX, tell your healthcare provider if you:**

- ▶ are being treated for a mental illness, or had treatment in the past for any mental illness, including depression and suicidal behavior

*(Continued on the following pages.)*

**Please see the following pages and brief summary of the Medication Guide for additional important safety information. This information is not intended to replace discussions with your healthcare provider.**



Susan O.  
Taking AVONEX  
*STILL SWIMMING*



## AVONEX slows down physical disability progression, helping you stay active longer

- ▶ At 2 years, people taking AVONEX were 37% less likely to have increased physical disability, compared with people who weren't treating their relapsing MS
- ▶ In a separate 3-year study, people taking AVONEX were 44% less likely to have a second flare-up, compared with people who weren't treating their relapsing MS
- ▶ With AVONEX PEN<sup>®</sup>, you can take action against relapsing MS with one click, once a week

Visit [AVONEX.com](http://AVONEX.com) today, or call 1-800-456-2255  
to order a free AVONEX information kit.

[AVONEX.com](http://AVONEX.com)

ONCE-  
A-WEEK **AVONEX**<sup>®</sup>  
(interferon beta-1a)  
IM INJECTION



## Important Safety Information (cont'd)

- ▶ have or had bleeding problems or blood clots, have or had low blood cell counts, have or had liver problems, have or had seizures (epilepsy), have or had heart problems, have or had thyroid problems, have or had any kind of autoimmune disease (where the body's immune system attacks the body's own cells), such as psoriasis, systemic lupus erythematosus, or rheumatoid arthritis
- ▶ drink alcohol
- ▶ are pregnant or plan to become pregnant. It is not known if AVONEX will harm your unborn baby. Tell your healthcare provider if you become pregnant during your treatment with AVONEX.
- ▶ are breastfeeding or plan to breastfeed. It is not known if AVONEX passes into your breast milk. You and your healthcare provider should decide if you will use AVONEX or breastfeed. You should not do both.

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

### AVONEX can cause serious side effects including:

- ▶ **Heart problems, including heart failure.**  
While AVONEX is not known to have any direct effects on the heart, a few patients who did not have a history of heart problems developed heart muscle problems or congestive heart failure after taking AVONEX. If you already have heart failure, AVONEX may cause your heart failure to get worse. Call your healthcare provider right away if you have worsening symptoms of heart failure such as shortness of breath or swelling of your lower legs or feet while using AVONEX.  
—Some people using AVONEX may have other heart problems including low blood pressure, fast or abnormal heart beat, chest pain, and heart attack or heart muscle problem (cardiomyopathy).

- ▶ **Blood problems.** AVONEX can affect your bone marrow and cause low red and white blood cell, and platelet counts. In some people, these blood cell counts may fall to dangerously low levels. If your blood cell counts become very low, you can get infections and problems with bleeding and bruising.
- ▶ **Seizures.** Some patients have had seizures while taking AVONEX, including patients who have never had seizures before.
- ▶ **Infections.** Some people who take AVONEX may get an infection. Symptoms of an infection may include fever, chills, pain or burning with urination, urinating often, bloody diarrhea, and coughing up mucus.
- ▶ **Thyroid problems.** Some people taking AVONEX develop changes in their thyroid function. Symptoms of thyroid changes include problems concentrating, feeling cold or hot all the time, weight changes, and skin changes.

**Tell your healthcare provider right away if you have any of the symptoms listed above.**

The most common side effects of AVONEX include:

- ▶ **Flu-like symptoms.** Most people who take AVONEX have flu-like symptoms early during the course of therapy. Usually, these symptoms last for a day after the injection. You may be able to manage these flu-like symptoms by taking over-the-counter pain and fever reducers. For many people, these symptoms lessen or go away over time. Symptoms may include muscle aches, fever, tiredness, and chills.

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

**Please see the next page and brief summary of the Medication Guide for additional important safety information. This information is not intended to replace discussions with your healthcare provider.**

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Biogen Idec  
14 Cambridge Center  
Cambridge, MA 02142  
(800) 456-2255  
www.AVONEX.com

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ONCE-  
A-WEEK **AVONEX**<sup>®</sup>  
(interferon beta-1a)  
IM INJECTION

# Brief Summary of Medication Guide

## AVONEX® (a-vuh-necks) (interferon beta-1a) Injection for intramuscular use

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

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

**AVONEX can cause serious side effects.** Tell your healthcare provider right away if you have any of the symptoms listed below while taking AVONEX.

#### 1. Behavioral health problems including depression, suicidal thoughts or hallucinations.

Some people taking AVONEX may develop mood or behavior problems including:

- irritability (getting upset easily)
- depression (feeling hopeless or feeling bad about yourself)
- nervousness
- anxiety
- aggressive behavior
- thoughts of hurting yourself or suicide
- hearing or seeing things that others do not hear or see (hallucinations)

#### 2. Liver problems, or worsening of liver problems including liver failure and death. Symptoms may include:

- |                                      |  |
|--------------------------------------|--|
| • nausea                             | • yellowing of your skin or the white part of your eye |
| • loss of appetite                   | • bleeding more easily than normal                     |
| • tiredness                          | • confusion  |
| • dark colored urine and pale stools | • sleepiness   |

During your treatment with AVONEX you will need to see your healthcare provider regularly and have regular blood tests to check for side effects.

#### 3. Serious allergic reactions and skin reactions. Symptoms may include:

- itching
- swelling of the face, eyes, lips, tongue or throat
- trouble breathing
- anxiousness
- feeling faint
- skin rash, hives, sores in your mouth, or your skin blisters and peels

### What is AVONEX?

AVONEX is a form of a protein called beta interferon that occurs naturally in the body. AVONEX is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS). This includes people who have had their first symptoms of multiple sclerosis and have an MRI consistent with multiple sclerosis.

AVONEX will not cure your MS but may decrease the number of flare-ups of the disease and slow the occurrence of some of the physical disability that is common in people with MS. MS is a life-long disease that affects your nervous system by destroying the protective covering (myelin) that surrounds your nerve fibers.

The way AVONEX works in MS is not known.

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

### Who should not use AVONEX?

#### Do not take AVONEX if you:

- are allergic to interferon beta, albumin (human), or any of the ingredients in AVONEX. See the end of this Medication Guide for a complete list of ingredients in AVONEX.

### What should I tell my healthcare provider before using AVONEX?

#### Before taking AVONEX, tell your healthcare provider if you:

- are being treated for a mental illness or had treatment in the past for any mental illness, including depression and suicidal behavior
- have or had bleeding problems or blood clots
- have or had low blood cell counts
- have or had liver problems

- have or had seizures (epilepsy)
- have or had heart problems
- have or had thyroid problems
- have or had any kind of autoimmune disease (where the body's immune system attacks the body's own cells), such as psoriasis, systemic lupus erythematosus, or rheumatoid arthritis
- drink alcohol
- are pregnant or plan to become pregnant. It is not known if AVONEX will harm your unborn baby. Tell your healthcare provider if you become pregnant during your treatment with AVONEX.
- are breastfeeding or plan to breastfeed. It is not known if AVONEX passes into your breast milk. You and your healthcare provider should decide if you will use AVONEX or breastfeed. You should not do both.

### Tell your healthcare provider about all the medicines you take,

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

### How should I use AVONEX?

- Your healthcare provider should show you how to prepare and measure your dose of AVONEX and how to inject your AVONEX before you use AVONEX for the first time.
- Your healthcare provider or nurse should watch the first AVONEX injection you give yourself.
- AVONEX is given once a week by injection into the muscle (intramuscular injection).
- Inject AVONEX exactly as your healthcare provider tells you.
- Your healthcare provider will tell you how much AVONEX to inject and how often to inject AVONEX. **Do not** inject more than your healthcare provider tells you to.
- **Do not** change your dose unless your healthcare provider tells you to.
- Change (rotate) your injection site you choose with each injection. This will help decrease the chance that you will have an injection site reaction.
- **Do not** inject into an area of the body where the skin is irritated, reddened, bruised, infected or scarred in any way.
- AVONEX comes as a:
  - Vial with freeze-dried (lyophilized) powder
  - Prefilled syringe (can be used with the AVOSTARTGRIP™ titration kit)
  - Single-Use Prefilled Autoinjector Pen (AVONEX® PEN™)

Your healthcare provider will decide which one is best for you. See the Instructions for Use at the end of this Medication Guide for detailed instructions for preparing and injecting your dose of AVONEX.

- Always use a new, unopened AVONEX vial, prefilled syringe, or single-use prefilled autoinjector pen for each intramuscular injection.

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

#### AVONEX can cause serious side effects including:

- **See "What is the most important information I should know about AVONEX?"**
- **Heart problems, including heart failure.** While AVONEX is not known to have any direct effects on the heart, a few patients who did not have a history of heart problems developed heart muscle problems or congestive heart failure after taking AVONEX. If you already have heart failure, AVONEX may cause your heart failure to get worse. Call your healthcare provider right away if you have worsening symptoms of heart failure such as shortness of breath or swelling of your lower legs or feet while using AVONEX.
  - Some people using AVONEX may have other heart problems including:
    - low blood pressure
    - fast or abnormal heart beat
    - chest pain
    - heart attack or a heart muscle problem (cardiomyopathy)
- **Blood problems.** AVONEX can affect your bone marrow and cause low red and white blood cell, and platelet counts. In some people, these blood cell counts may fall to dangerously low levels. If your blood cell counts become very low, you can get infections and problems with bleeding and bruising.
- **Seizures.** Some patients have had seizures while taking AVONEX, including patients who have never had seizures before.

- **Infections.** Some people who take AVONEX may get an infection. Symptoms of an infection may include:
  - fever
  - chills
  - pain or burning with urination
  - urinating often
  - bloody diarrhea
  - coughing up mucus
- **Thyroid problems.** Some people taking AVONEX develop changes in their thyroid function. Symptoms of thyroid changes include:
  - problems concentrating
  - feeling cold or hot all the time
  - weight changes (gain or loss)
  - skin changes

### Tell your healthcare provider right away if you have any of the symptoms listed above.

The most common side effects of AVONEX include:

- Flu-like symptoms. Most people who take AVONEX have flu-like symptoms early during the course of therapy. Usually, these symptoms last for a day after the injection. You may be able to manage these flu-like symptoms by taking over-the-counter pain and fever reducers. For many people, these symptoms lessen or go away over time. Symptoms may include:
  - muscle aches
  - fever
  - tiredness
  - chills

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 AVONEX?

- Store AVONEX in the refrigerator at 36°F to 46°F (2°C to 8°C).
- **Do not** freeze AVONEX. **Do not** use AVONEX that has been frozen.
- **Do not** store AVONEX above 77°F (25°C).
- Keep AVONEX away from light.
- **Do not** use AVONEX past the expiration date.
- If you cannot refrigerate your AVONEX vials, you can store your AVONEX vials at 77°F (25°C) for up to 30 days. After mixing, the AVONEX solution should be used immediately, within 6 hours when stored refrigerated at 36°F to 46°F (2°C to 8°C).
- If you cannot refrigerate your AVONEX PEN and AVONEX prefilled syringes, you can store your AVONEX PEN and AVONEX prefilled syringes up to 77°F (25°C) for up to 7 days.

### Keep AVONEX vials, prefilled syringes, pens and all other medicines out of the reach of children.

### General advice about the safe and effective use of AVONEX.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. **Do not** use AVONEX for a condition for which it was not prescribed. **Do not** give AVONEX 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 AVONEX. If you would like more information, talk with your healthcare provider. You may ask your healthcare provider or pharmacist for information about AVONEX that is written for healthcare professionals.

### What are the ingredients in AVONEX?

**Active ingredient:** interferon beta-1a

#### Inactive ingredients:

- **Vial with freeze-dried (lyophilized) powder:** albumin (human), sodium chloride, dibasic sodium phosphate, and monobasic sodium phosphate.
- **Single-Use Prefilled Syringe:** sodium acetate trihydrate, glacial acetic acid, arginine hydrochloride, polysorbate 20 in water for injection.
- **Single-Use Prefilled Autoinjector Pen:** sodium acetate trihydrate, glacial acetic acid, arginine hydrochloride, polysorbate 20 in water for injection.

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

Manufactured by:  
BIOGEN IDEC INC.  
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Cambridge, MA 02142 USA  
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1-800-456-2255

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## The picture of health

by Vicky Uhland

Mary Pettigrew was a happily married, successful marketing director and event planner in Dallas when, in 2001 at age 35, she was diagnosed with multiple sclerosis. Within five years, lesions in her brain had affected her memory and cognition so much that she had to quit working full time and apply for disability benefits. If that weren't enough, in 2008, she underwent major surgery on her neck for cervical stenosis, leaving her unable to drive. Soon after, her husband told her he couldn't cope with how her disease had changed their lives and wanted a divorce.

Lonely, anxious and depressed, Pettigrew turned to music and writing for solace. She resumed her long-neglected piano practice and taught herself to play the acoustic guitar. She began composing songs and eventually, the lyrics morphed into poetry, which grew into short stories and outlines for television screenplays.

Today, Pettigrew no longer feels depressed. She's noticed an improvement in her memory, cognition and hand-eye coordination. There's no way of knowing for sure what role her creative endeavors played in these changes. But there's no question that her artistic endeavors have helped her to feel fulfilled once again.

The act of creating empowers the spirit—and maybe the body, too.

"I've discovered new passions, untapped talent, a connection with words and stories, that have bestowed an unfathomable gift for this new journey, this new chapter in life," Pettigrew says.

She's not alone. Many other people with MS believe that playing musical instruments, singing, or engaging in art, photography or creative writing has helped relieve mental, emotional and physical symptoms associated with the disease. A small but growing body of research backs this up.

### The science of art

"Art therapy nurtures the soul, the superego and the id, which is being challenged by disability," says Dr. Florian Thomas, director

of the Multiple Sclerosis Center at St. Louis University and professor of neurology at the university.

In fact, in 2008, Dr. Thomas and colleagues presented a study at the Multiple Sclerosis: Comprehensive Approaches to Complex Challenges conference, which assessed the psychosocial benefits of art. In the study, 12 adults with MS worked with clay, watercolors, collage, carving and mosaics in group sessions that lasted two hours a week for eight weeks.

"Participants reported that the experience of creating art and the weekly contact with others helped them focus on the more positive and enjoyable aspects of their lives," Dr. Thomas concludes. "This helped relieve depression and increased self-esteem regarding their creativity and ability to interact with and support others with MS."

Art therapy can also have positive physical effects. Dr. Thomas cites



An oil painting by Virginia Phillips. View the rest of her Red Umbrellas series at [VirginiaPhillips.com](http://VirginiaPhillips.com).



## Find the right tools

Some artist supply stores and online catalogs such as Dick Blick Art Materials ([dickblick.com](http://dickblick.com)) sell adaptive art tools. These include universal cuffs, which attach a paintbrush or pen to your wrist; lap boards for arts and crafts or writing; tabletop easels and potting wheels that can be used by people in wheelchairs or scooters; and easy-grip and jumbo paintbrushes, pencils, crayons and pastels.

Another option is to create or modify your own tools. Brian Grossman, a professional sculptor who was diagnosed with primary-progressive MS in 1984, has developed a variety of solutions that allow him to continue creating his alabaster

and bronze sculptures, despite limited mobility, and reduced dexterity and strength in his left hand and arm.

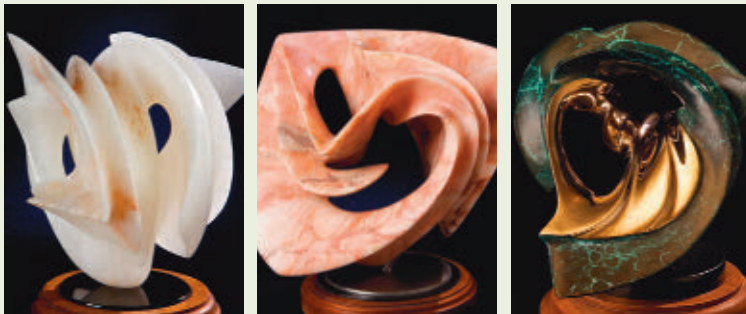
Grossman has outfitted his large studio in Boulder, Colo., so that all of his tools are within easy reach. He also has constructed magnetized extenders to help him pick up dropped items. To accommodate his reduced dexterity, Grossman puts guards

on dangerous tools like grinders, and he protects his hands with rubber gloves lined with cotton.

Grossman estimates he has created and sold more than 1,000 pieces of sculpture in the last 37 years. "Even if my legs hurt, even if I can only carve for half an hour at a time, I would never, ever give up my artwork," he says. "My artwork is who I am. Without my artwork, I would not be here at all."



Brian Grossman



Brian Grossman's distinctive sculptures reflect the unique journey of his life. He's produced hundreds of original sculptures using Colorado alabaster, many of which have been cast in bronze.

a study from 2010, published in the **Journal of Rehabilitation Research & Development**, showing that the repetitive movement inherent in using a paintbrush, snapping a camera shutter, typing, playing an instrument or participating in other art activities strengthens the synapses in the brain, which can improve hand-eye coordination. "Physically, in terms of hand-eye coordination, art therapy is the logical extension of putting 20 pegs into 20 holes," he says.

There's also evidence that distracting activities, such as engaging in art, helps alleviate pain, and that physical exercise, which can include the development of art skills like painting or sculpting, may improve cognition.

Other studies have found that art therapy reduces anxiety and stress in people with various physical, psychological and behavioral conditions. Experts agree that more studies relating specifically to MS are needed.

### Music, sweet music

Like the visual arts, music has myriad psychological benefits. In 2006, **Expert Review of Neurotherapeutics** examined seven case reports and seven studies of music therapy, and concluded that singing or playing an instrument correlated with greater self-acceptance and lower rates of anxiety and depression among people with MS.

Playing, singing or listening to certain songs can boost your

mood or help you relax, while drumming can release pent-up anger, says Donna Washington, associate professor and coordinator of the music therapy program at Howard University in Washington, D.C.

Washington is a classically trained singer who was diagnosed with MS 22 years ago. “Making music was the only thing that saved me during my bouts of depression,” she says. “Music gives me beauty, strengthens me and gives me power. And it’s inexpensive and I don’t have to do much to get it.”

Washington says that music has physical benefits as well. Walking while singing creates a rhythm that can help improve gait, she says, while remembering words and melodies can boost attention span. What’s more, MRI scans of healthy people show that singing affects parts of the brain that help with memory and speaking and that are not otherwise easily accessed.

## Art for yourself—and others

You don’t have to be a professional, or have formal training, to benefit from art—or for others to benefit from your creations. Matt, a guidance counselor in Westchester County, N.Y., who asked that his last name not be used, began hiking and photographing scenery soon after he was diagnosed with MS in 2007. He donates the proceeds from the sale of his photographs to advance MS research. “Even though it

sucks that I have MS, this keeps me from getting down and makes me think I can actually do some good,” he says.

Jennifer Schwartz Wright, a board-certified art therapist and interim director of the Art Therapy Studio in Cleveland, says the act of creation helps people with MS in four key ways. First, it gives a sense of control. “Every decision people make in their artwork is their own, which is very empowering when they have losses due to illness,” she says. It also helps people express themselves without words, which Wright says can be an incredible release. In addition, “art materials are nourishing and beautiful and tactile—the opportunity to touch and manipulate them stimulates the senses,” she says. And finally,

creating art gives people the opportunity to interact with others, who may have had similar experiences.

## The power of the group

“The social component of art therapy can’t be underestimated,” Dr. Thomas says. While creating art in isolation can produce all of the benefits shown in studies, art therapy groups like those offered by the National MS Society add another dimension.

Michelle Keating, RN, who helps coordinate the Society’s Creative Art Experience Talk MS Group in St. Louis, says the group’s monthly meetings are as much about socialization and discussing the challenges and solutions of living with MS as they are about art. “The advantage

## TOMORROW—A MANTRA

A poem by Mary Pettigrew

Tomorrow...

Things will be different, things will be ok  
Everything will be simpler, a clean slate and a brand new day.

If I tell these things to myself, will my fear subside?

Tomorrow...

Breathing will come easier, smiles of happiness overcome my face  
Crying tears will be those brought from joy,  
I'll know that love will once again find a proper place.

If I tell these things to myself, will my fear subside?

Tomorrow...

I'll get out of bed and shower, I'll put on something pretty to wear  
I'll leave the comforting hideout of my house, bathe in sunlight, inhale fresh air.

If I tell these things to myself, will my fear subside?  
my fear will subside...

fear will subside...

will subside...

subside...

of the group experience is camaraderie and sharing,” she says. “Nobody feels any different than anyone else.” Keating, who was diagnosed with MS in 1981, has coauthored a soon-to-be-published study that shows that knitting, beading, collage making and watercolor painting in a group that is overseen by arts instructors improves participants’ self-esteem, hope and belief that they can function with and control their MS.

People can get the benefits of socialization in other ways, if art groups are not an option. Virginia Phillips, a Valparaiso, Ind.-based interior designer and painter who was diagnosed with primary-progressive MS in 1998, uses a scooter and doesn’t like to drive. She now relies on her friends to transport her to places where she can take the photos she uses as a basis for her oil paintings.

“We have lunch and a lot of fun,” she says. Friends also visit regularly to see her paintings, and once a week she paints and interacts with other artists at a local venue that hosts art classes and special events.

“I think without the creative urge to see what’s going to come out of my paintbrush, I’d be more in the doldrums,” Phillips says. “There’s always a perfect painting out there—I get up every morning looking for it.” ■

Vicky Uhland is a freelance writer and editor in Lafayette, Colo.

## How to become an artist

**A**re you interested in art, music or writing but are afraid that you’re just not creative enough or have too many physical limitations? Here are some suggestions to help you overcome those common stumbling blocks.

● **PLAY AROUND.** “I always told everyone I was a terrible artist and not very creative, but then I found out I was pretty good at photography,” says Matt (last name withheld), who became a shutterbug after being diagnosed with MS six years ago. “Explore until you find something you enjoy and that suits you. You might be bad at painting, but have a gift for sculpting or acting.”

To tap into your inner artist, try a collage, suggests Susan Gibbons, an artist and photographer in Long Island, N. Y., who was diagnosed with MS in 1999. Cut out images from magazines, newspapers, brochures or fliers and glue them to a poster board or sheet of paper. “Find a theme like, ‘How am I feeling today?’ or ‘What will my life be like in five, 10, 15 years?’”

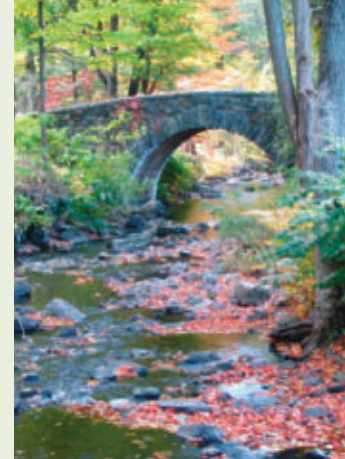
● **TAKE A CLASS OR JOIN A GROUP.** Classes at community colleges or art studios are good ways to learn the basic skills that give you the confidence to be creative. Sound too intimidating? Check with the Society at 1-800-344-4867 to see if a chapter near you has an art therapy or art support program, or join a community group that specializes in your favorite creative endeavor.

● **READ A BOOK.** Art therapist Jennifer Schwartz Wright recommends **The Artist’s Way** by Julia Cameron. It is a practical, step-by-step guide to discovering your creativity.

● **HIRE A THERAPIST.** Find certified art and music therapists through the Art Therapy Credentials Board ([atcb.org](http://atcb.org)) or the American Music Therapy Association ([musictherapy.org](http://musictherapy.org)).

● **START SMALL.** Mary Pettigrew, a poet with MS, says an easy way to begin writing is to keep a journal. “You don’t have to be flowery with the words. Even if you watched TV all day, write that down.” With practice, the quantity and quality of your writing will increase.

If you’d like to play a musical instrument, music therapist Donna Washington says the easiest ones to learn are the tambourine, xylophone or autoharp. If finger dexterity is an issue, she suggests strumming with a popsicle stick.



One of Matt’s many photos



# Early treatment matters.

In clinical studies, early treatment with BETASERON® (interferon beta-1b) helped significantly delay the time to a second flare-up (conversion to clinically definite MS) compared with placebo.<sup>1</sup>

## INDICATIONS

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

## IMPORTANT SAFETY INFORMATION

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

**BETASERON can cause serious side effects, including:**

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

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

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

dangerous impulses, hallucinations, other unusual changes in behavior or mood.

**Other possible serious side effects with BETASERON include:**

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

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

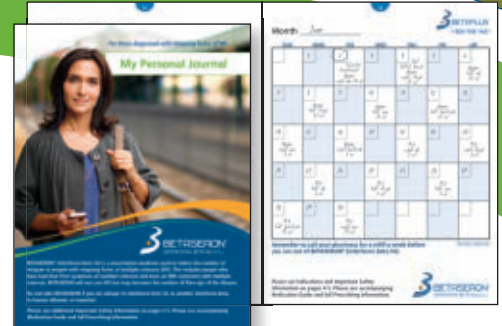
**Flu-like Symptoms.** BETASERON can cause flu-like symptoms including fever, chills, tiredness, sweating, muscle aches when you first start to use it. These symptoms may decrease over time.

# So does ongoing support.

The BETAPLUS® support program brings BETASERON patients free 24/7/365 telephone access to MS-trained BETA Nurses, dedicated insurance assistance, an app that can help them track and plan their injections, and timely information and tools.

## Visit **BETASERON.com** today

Sign up for BETAPLUS and get e-mails and information that could help you make a decision about RRMS therapy—plus a free personal journal to help you plan and track your treatment.



Taking medicines for fever and pain relief on the days you are using BETASERON may help decrease these symptoms.

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

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

### Risk to Pregnancy:

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

### Most Common Side Effects:

The most common side effects of BETASERON include low white blood cell count, increases in your liver enzymes, headache, increase in your muscle

tension, pain, rash, problems sleeping, stomach pain, weakness. These are not all the possible side effects of BETASERON.

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

### Please see brief summary of Medication Guide on the following page.

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

**Reference: 1.** Kappos L, Polman CH, Freedman MS, et al. Treatment with interferon beta-1b delays conversion to clinically definite and McDonald MS in patients with clinically isolated syndromes. *Neurology*. 2006;67:1242-1249.



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# BETASERON®

(interferon beta-1b)  
injection 0.3 mg

6800505BS  
521-154-0002-13

## Brief Summary of Medication Guide

### Betaseron® (bay-ta-seer-on) Interferon beta-1b (in-ter-feer-on beta-one-be)

This information does not include all the important information about Betaseron. For more information about Betaseron go to [www.BETASERON.com](http://www.BETASERON.com).

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

##### Betaseron can cause serious side effects, including:

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

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

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

- **depression or suicidal thoughts.** Call your healthcare provider right away if you have any of the following symptoms, especially if they are new, worse, or worry you: thoughts about suicide or dying, new or worse depression, new or worse anxiety, trouble sleeping (insomnia), acting aggressive, being angry, or violent, acting on dangerous impulses, hallucinations, other unusual changes in behavior or mood.

#### What is Betaseron?

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

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

#### Who should not take Betaseron?

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

#### What should I tell my healthcare provider before taking Betaseron?

##### Before you take Betaseron, tell your healthcare provider if you:

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

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

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

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

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

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

It is important for you to change your injection site each time you inject Betaseron. This will lessen the chance of you having a serious skin reaction at the site where you inject Betaseron. Avoid injecting Betaseron into an area of skin that is sore, reddened, infected or has other problems.

- **flu-like symptoms.** Betaseron can cause flu-like symptoms including: fever, chills, tiredness, sweating, muscle aches when you first start to use it

These symptoms may decrease over time. Taking medicines for fever and pain relief on the days you are using Betaseron may help decrease these symptoms.

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

The most common side effects of Betaseron include: low white blood cell count, increases in your liver enzymes, headache, increases in your muscle tension, pain, rash, problems sleeping, stomach pain, weakness.

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

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

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

##### Keep Betaseron and all medicines out of the reach of children.

##### General information about the safe and effective use of Betaseron.

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

#### What are the ingredients in Betaseron?

Active ingredient: interferon beta-1b

Inactive ingredients: albumin (human), mannitol

Diluent contains sodium chloride solution.

Manufactured by:



**Bayer HealthCare**

Bayer HealthCare Pharmaceuticals Inc.  
Montville, NJ 07045

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## How I empowered myself with food

by Elizabeth Yarnell, ND, CLT

**W**hen I was diagnosed with multiple sclerosis at age 29 in 1999, the last thing I was thinking about was what I was eating. After all, what could a degenerative disease that affected the myelin sheaths on the nerves in my brain have to do with what was going into my mouth?

Quite a bit, it turned out. Since then, I've become increasingly aware of how the food I eat makes me feel.

I spent my 20s as a girl on the go, catching meals at restaurants or fast-food joints, or simply skipping meals altogether. I lived alone and stocked my apartment with such staples as Diet Coke, Crystal Light and gummy bears. My friends joked about my habit of downing Tums as if they were Tic Tacs. Even before my diagnosis, I suffered from chronic constipation interspersed with diarrhea.

My new fiancé (now husband) was the first one to suggest that my diet was less than admirable. A competitive athlete, he was already cooking with organic, whole foods and was aghast at my processed-food lifestyle. At first I resisted his efforts. After all, food was just sustenance. Then, after my diagnosis, I started learning more. MS became a wake-up call to take care of myself through caring about my diet.

### We are what we eat

The human body functions through a complex mechanism of chemical and electrical interactions, and vitamins, minerals and nutrients play supporting roles as catalysts, balancing agents and igniters. Like running a car without ever replenishing the oil or power-steering fluid, when the body does not get what it needs, things start to go awry.

I came to the conclusion that the best diet to keep my own “engine” running was one of clean, whole foods—mostly plant-based—rather than a steady diet of processed foodstuffs. I started to eat a Mediterranean-style diet of fresh vegetables, olive oil, garlic and fish. My interest then carried me even further: In 2006, I became a certified nutritional consultant, and in 2011, a naturopathic doctor.

### What I eat

As I remade my diet, I developed a new vocabulary with words like essential fatty acids, monosaturated and unsaturated fats, antioxidants and phytonutrients (see “A few words to know,” p. 50). I ate fatty fish like tuna and salmon for their omega-3 oils; avocados brought delicious monounsaturated fats; and fresh fruits, leafy greens and vegetables offered fiber,

I spent my 20s as a girl on the go, catching meals at restaurants or fast-food joints, or simply skipping meals altogether. I lived alone and stocked my apartment with such staples as Diet Coke, Crystal Light and gummy bears. My friends joked about my habit of downing Tums as if they were Tic Tacs.



PHOTO BY THINKSTOCK

nutrients and antioxidants. Instead of potato chips, I began snacking on nuts and seeds to ensure

a steady stream of essential fatty acids to my body. I learned that mushrooms are full of B

vitamins, and that kale offers a lot of nutrients important to overall health, such as iron, vitamins C, K and A—and it's anti-inflammatory to boot. Winter squash, sweet potatoes, broccoli, beets, onions and bell peppers all made appearances in my new eating plan, each bringing its own spectrum of vibrant nutrients—and beautiful colors—to the table.

## What I don't eat

I decided to take my quest for clean nutrition all the way and dedicated myself to avoiding as many chemicals and preservatives as possible. For me, whole, unprocessed foods were the way to go. Processed and packaged foods are often stripped of their natural nutrients, and can contain additives and artificial preservatives.

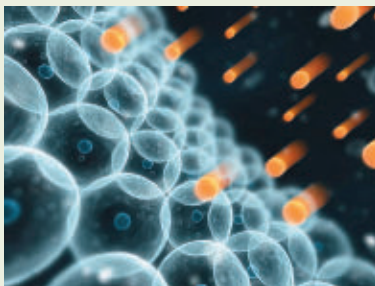
I wondered what else could I avoid that might help me feel stronger and healthier, more in control of my health. The list became longer and longer as I realized how many ingredients in everyday convenience foods are made in a chemist's laboratory.



## A few words to know

Fats are an essential part of our diet, but it's important to know which fats contribute to good health. **Polyunsaturated fats** contain essential fatty acids—"essential" meaning your body can't make them so you must get them from your food. These include omega-3s, which are found in certain fish such as salmon or mackerel, flax seeds and walnuts. While they have been shown to lower risk factors for cardiovascular disease in the general population, study results on the benefits of omega-3s for multiple sclerosis have been mixed. In addition, any possible impact of taking them in combination with disease-modifying medications has not been well studied.

**Antioxidants** are nutrients that help protect cells from potentially toxic "free radicals." Free radicals, or "oxidants," can cause damage to cells in the body, including the central nervous system. Small clinical trials of different antioxidants are already under way in people with MS. Visit [nationalMSSociety.org/research](http://nationalMSSociety.org/research) or call 1-800-344-4867 for the latest results.



**Free radicals, or "oxidants," can cause damage to cells in the body, including the central nervous system.**

**Phytonutrients**, while not essential in the diet, are nutritionally beneficial components of plants generally thought to promote good health. For example, **carotenoids**, the red, orange and yellow pigments found in carrots, sweet potatoes and bell peppers, have been shown to help protect against some cancers, heart disease and age-related macular degeneration.

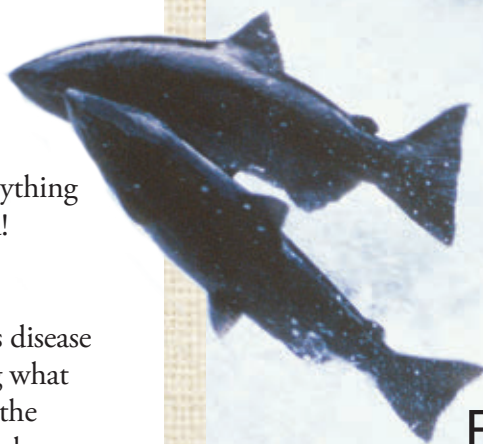


Essentially, I avoid everything that isn't an actual food!

### Choosing to eat well

MS is such a capricious disease that I feel like choosing what goes into my mouth is the one variable I can control. Since going down this path, the length of time between my MS flare-ups has expanded considerably. I used to get one about once a year. Now, my last exacerbation was in 2002. My bowels have cleared and stabilized, and my skin has a healthy glow. The longer I continue to shun my former ways and eat wholesomely and cleanly, the stronger, more energetic and healthier I feel even as I age into my mid-40s. While I can't prove that diet is the reason for these improvements, I don't see any reason not to keep eating healthily. In the MS world we inhabit, so much is unknown that it can be easy to slip into dark thoughts about an uncomfortable future. Eating well helps me feel that I have some control over this future. And what do I have to lose? I have to eat anyway, so I might as well eat to benefit my body as much as I can! ■

Elizabeth Yarnell, ND, CLT, a nutritional consultant and speaker, is the author of **Glorious One-Pot Meals: A Revolutionary New Quick and Healthy Approach to Dutch-Oven Cooking**. Visit her website at [ElizabethYarnell.com](http://ElizabethYarnell.com).



## Fresh wild salmon burgers with quinoa

This recipe contains many healthy nutrients, such as omega-3s in the wild salmon and protein in the quinoa. A side of mashed avocados adds an extra nutritional boost.

- 2 eggs
- 1 medium zucchini
- 2 teaspoons of horseradish
- 1 tablespoon of chopped basil
- ½ teaspoon of sea salt
- Freshly cracked black pepper to taste
- 1 lb. skinless salmon
- ¾ cup quinoa (Find this either in the grains section or hot cereals section of most supermarkets.)
- 1 tablespoon of coconut oil
- 1 teaspoon of sesame oil

- 1** Beat the eggs in a medium mixing bowl until blended. Trim the ends off the zucchini and quarter it. Pulse the quarters in a food processor until diced. Add to the bowl of eggs with horseradish, basil, salt and pepper.
- 2** Cut the salmon into large chunks and pulse in the food processor until diced (do not process into a paste). Add to the egg-zucchini mixture and mix in quinoa to make a mixture that will hold together in patties.
- 3** On a cast-iron griddle or skillet, heat 1 tablespoon of coconut oil with 1 teaspoon of sesame oil. Place the patties into the oil, flipping when needed until cooked through.

Serve with sliced tomatoes, either on a bed of lettuce or a bun, and a side of mashed avocados sprinkled with sea salt.



# What could a blood test mean for someone with relapsing MS?



TYSABRI is for adults with relapsing forms of multiple sclerosis (MS) to slow worsening brain infection that usually causes death or severe disability, it's generally recommended for patients

## Indication:

TYSABRI is a prescription medicine approved for adult patients with relapsing forms of MS to slow the worsening of disability and decrease the number of flare-ups (relapses). Because TYASBRI increases the risk of progressive multifocal leukoencephalopathy (PML), a rare brain infection that usually causes death or severe disability, TYASBRI is generally recommended for patients that have not been helped enough by, or cannot tolerate, another treatment for MS. TYASBRI does not cure MS and has not been studied for longer than two years or in patients with chronic progressive MS.

## Important Safety Information about TYASBRI:

- **TYSABRI increases your chance of getting a rare brain infection that usually causes death or severe disability called PML.** PML usually happens in people with weakened immune systems. No one can predict who will get PML. There is no known treatment, prevention, or cure for PML.
- Your chance may be higher if you are also being treated with other medicines that can weaken your immune system, including other MS treatments. Therefore, you should not take certain medicines that weaken the immune system at the same time you are taking TYASBRI. Even if you use TYASBRI alone to treat your MS, you can still get PML.
  - Your chance of getting PML increases if you have been exposed to JCV, the virus that causes PML. Your doctor may do a blood test to check if you have been exposed to JCV.
  - If you have been exposed to JCV, your chance of getting PML increases even more if:
    - You have received TYASBRI for a long time, especially longer than 2 years.
    - You have received certain medicines that can weaken your immune system before you start receiving TYASBRI.

Your risk of PML is greatest if you have all 3 risk factors listed above. If you haven't been exposed to JCV, you could still be at risk of getting PML due to the possibility of a false negative result or future exposure to JCV. Because of this risk, you may want to be retested periodically. Your doctor should discuss the risks and benefits of TYASBRI treatment with you before you decide to take TYASBRI.

- If you take TYASBRI, it is important to call your doctor right away if you have any new or worsening medical problems (such as a new or sudden change in your thinking, eyesight, balance, or strength or other problems) that have lasted over several days.

**TYSABRI® has helped many people who have relapsing MS.** But it can also increase the chance of getting a serious brain infection called PML, which usually causes death or severe disability. It's important to understand that there are 3 known risk factors for PML — exposure to the virus that causes PML (the JC Virus), a longer period of TYSABRI treatment (especially beyond 2 years), and the use of certain medications that weaken the immune system. A blood test has been created that can help identify one of these risk factors (the JC Virus). It's important to remember that there may be other risk factors for getting PML during TYSABRI treatment that we don't know about yet. Also, you could still be at risk, regardless of your test results. The administration of the test only takes a few minutes. It could give you and your doctor the insight you need to make a more informed decision about TYSABRI.

**Learn more about the JC Virus Test at [www.TysabriTest.com](http://www.TysabriTest.com). Then talk to your doctor about the benefits and risks of TYSABRI.**



disability and reduce number of flare-ups. Since TYSABRI increases the risk of PML, a rare unable to tolerate or respond well to another therapy. See TYSABRI Risk Information below.

Tell all of your doctors that you are getting treatment with TYSABRI.

- TYSABRI is available only through the TOUCH® Prescribing Program (TOUCH), which is a restricted distribution program. Only prescribers, patients, and infusion centers enrolled in the TOUCH can prescribe, receive, and infuse TYSABRI. In order to receive TYSABRI, you must talk to your doctor and agree to all of the instructions in the TOUCH.
- You should not receive TYSABRI if you have PML or are allergic to TYSABRI or any of its ingredients.
- TYSABRI is not recommended if you have a medical condition that can weaken your immune system, such as HIV infection or AIDS, leukemia or lymphoma, organ transplant, or others, or if you are taking medicines that weaken your immune system.
- Tell your doctor about all of the medicines you take or have taken.
- Tell your doctor if you are pregnant or are trying to become pregnant or if you are breastfeeding or plan to breastfeed. TYSABRI can pass into your breast milk. It is not known if the TYSABRI that passes into breast milk can harm your baby.
- Serious side effects with TYSABRI include an increase in your chance of getting an unusual or serious infection, because it can weaken your immune system.
- Other serious side effects with TYSABRI include allergic reactions (e.g., hives, itching, trouble breathing, chest pain, dizziness, wheezing, chills, rash, nausea, flushing of skin, low blood pressure), including serious allergic reactions (e.g., anaphylaxis) and infections. Serious allergic reactions usually happen within 2 hours of the start of the infusion, but can happen any time after receiving TYSABRI. Tell your doctor or nurse right away if you have any symptom of an allergic reaction. You may need treatment if you are having an allergic reaction.
- TYSABRI may cause liver damage. Symptoms of liver damage include yellowing of the skin and eyes (jaundice), unusual darkening of the urine, nausea, feeling tired or weak, or vomiting. Blood tests can be done to check for liver damage. Call your doctor right away if you experience any symptoms of liver damage.
- Common side effects include headache, urinary tract infection, lung infection, pain in your arms and legs, vaginitis, stomach area pain, feeling tired, joint pain, depression, diarrhea, and rash. Tell your doctor about any side effect that bothers you or does not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088. **Please see the brief summary of the patient medication guide on the following page.**



## MEDICATION GUIDE

TYSABRI® (tie-SÁ-bree)  
(natalizumab)

Read the Medication Guide given to you before you start **TYSABRI** and before each infusion. There may be new information. This Medication Guide does not take the place of talking to your doctor about your medical condition or your treatment. Ask your doctor or nurse if you have any questions.

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

- **TYSABRI increases your chance of getting a rare brain infection that usually causes death or severe disability. This infection is called progressive multifocal leukoencephalopathy (PML).** If PML happens, it usually happens in people with weakened immune systems.
- No one can predict who will get PML.
- There is no known treatment, prevention, or cure for PML.
- Your chance of getting PML may be higher if you are also being treated with other medicines that can weaken your immune system, including other treatments for Multiple Sclerosis (MS) and Crohn's disease (CD). You should not take certain medicines that weaken the immune system at the same time you are taking **TYSABRI**. Even if you use **TYSABRI** alone to treat your MS or CD, you can still get PML.
- Your chance of getting PML increases if you have been exposed to JCV. JCV is a common virus that is harmless in most people but can cause PML in people who have weakened immune systems, such as people taking **Tysabri**. Most people who are exposed to JCV do not know it or have any symptoms. This exposure usually happens in childhood.
- If you have been exposed to JCV, your chance of getting PML increases even more if:
  - You have received **TYSABRI** for a long time, especially longer than 2 years
  - You have received certain medicines that can weaken your immune system before you start receiving **TYSABRI**.

Your doctor may do a blood test to check if you have been exposed to JCV before you start receiving **TYSABRI** or during your treatment. There may be other risk factors for getting PML during **Tysabri** treatment that we do not know about yet.

- Your risk of getting PML is greatest if you have all 3 risk factors listed above. Your doctor should discuss the risks and benefits of **TYSABRI** treatment with you before you decide to receive **TYSABRI**.
- **TYSABRI** is available only through a restricted distribution program called the TOUCH® Prescribing Program. In order to receive **TYSABRI**, you must talk to your doctor and understand the benefits and risks of **TYSABRI** and agree to all of the instructions in the TOUCH® Prescribing Program.
- If you take **TYSABRI**, it is important that you call your doctor right away if you get any new or worsening medical problems (such as a new or sudden change in your thinking, eyesight, balance, or strength or other problems) that have lasted over several days. Tell all of your doctors that you are getting treatment with **TYSABRI**.

See “**What are the possible side effects with **TYSABRI**?**” for other serious side effects with **TYSABRI**.

### What is **TYSABRI**?

**TYSABRI** is a prescription medicine approved for:

#### 1. Adult patients with relapsing forms of Multiple Sclerosis (MS) to:

- Slow the worsening of disability that is common in patients with MS and,

- Decrease the number of flare-ups (relapses)  
Because of the chance of getting PML, **TYSABRI** is generally recommended for patients that have not been helped enough by, or cannot tolerate another treatment for MS.

#### 2. Adult patients with moderate to severe Crohn's disease:

- To reduce signs and symptoms of Crohn's disease.
- In patients who have not been helped enough by, or cannot tolerate usual Crohn's disease medicines and medicines called tumor necrosis factor (TNF) inhibitors.
- **TYSABRI** does not cure MS or Crohn's disease.
- **TYSABRI** has not been studied for use longer than 2 years.
- **TYSABRI** has not been studied in patients with chronic progressive MS.
- It is not known if patients older than 65 years have a different response to **TYSABRI**.
- **TYSABRI** is not approved for use in patients under age 18.

#### **TYSABRI** is only:

- prescribed by doctors who are enrolled in the TOUCH® Prescribing Program
- infused at an infusion center that is enrolled in the TOUCH® Prescribing Program
- given to patients who are enrolled in the TOUCH® Prescribing Program

#### Who should not receive **TYSABRI**?

Do **not** receive **TYSABRI** if you:

- have PML
- are allergic to **TYSABRI**

#### **TYSABRI** is not recommended if you:

- have a medical condition that can weaken your immune system such as HIV infection or AIDS, leukemia or lymphoma, or an organ transplant, and others.
- are taking medicines that can weaken your immune system. Talk with your doctor about all of the medicines you take or have taken.

If you have questions about any of the above, talk to your doctor.

#### What should I tell my doctor and nurse before receiving each infusion of **TYSABRI**?

Tell your doctor and nurse about all of your medical conditions. Tell them if you:

- have any new or worsening medical problems (such as a new or sudden change in your thinking, eyesight, balance, or strength or other problems) that have lasted several days
- have had hives, itching or trouble breathing during or after an infusion of **TYSABRI**
- have a fever or infection (including shingles or any unusually long lasting infection)
- are pregnant or plan to become pregnant
- **are breastfeeding or plan to breastfeed. **TYSABRI** can pass into your milk.** It is not known if the **TYSABRI** that passes into breast milk can harm your baby
- Tell your doctor and nurse about all of the medicines you are taking, including prescription and non-prescription medicines, vitamins and herbal supplements.
- Know the medicines you take. Keep a list of them with you to show your doctor and nurse. The nurse may ask to see this list before every **TYSABRI** infusion.

#### How do I receive **TYSABRI**?

- **TYSABRI** is given once every four weeks through a needle placed in a vein (IV infusion).
- You must follow all the instructions of the TOUCH® Prescribing Program. Before you can begin to receive **TYSABRI**, your doctor or nurse will:
  - explain the TOUCH® Prescribing Program to you
  - have you sign the TOUCH® Prescriber/Patient Enrollment Form
- Before every **TYSABRI** infusion you will be asked a series of questions to confirm that **TYSABRI** is still right for you.

- Call your doctor who prescribes **TYSABRI** right away to report any medical problems that keep getting worse and last several days.

#### What are the possible side effects of **TYSABRI**?

**TYSABRI increases your chance of getting a rare brain infection that usually causes death or severe disability. This infection is called progressive multifocal leukoencephalopathy (PML).** If PML happens, it usually happens in people with weakened immune systems. (see “**What is the most important information I should know about **TYSABRI**?**”)

Other serious side effects with **TYSABRI** include:

- **Infections.** **TYSABRI** may increase your chance of getting an unusual or serious infection because **TYSABRI** can weaken your immune system.
- Allergic reactions including serious allergic reactions. Symptoms can include:
  - hives
  - chills
  - itching
  - rash
  - trouble breathing
  - nausea
  - chest pain
  - flushing of skin
  - dizziness
  - low blood pressure
  - wheezing
- Serious allergic reactions usually happen within 2 hours of the start of the infusion, but they can happen at any time after receiving **TYSABRI**.
- Tell your doctor or nurse right away if you have any symptom of an allergic reaction, even if it happens after you leave the infusion center. You may need treatment if you are having an allergic reaction.
- **Liver damage.** **TYSABRI** may cause liver damage. Symptoms can include:
  - yellowing of the skin
  - unusual darkening and eyes (jaundice)
  - of the urine
  - nausea
  - feeling tired or weak
  - vomiting

Blood tests can be done to check for liver damage. Call your doctor right away if you have symptoms of liver damage.

Other side effects with **TYSABRI** include:

- headache
- feeling tired
- urinary tract infection
- joint pain
- lung infection
- depression
- pain in your arms and legs
- diarrhea
- vaginitis
- rash
- nose and throat infections
- stomach area pain

Tell your doctor about any side effect that bothers you or that does not go away. These are not all the side effects with **TYSABRI**. Ask your doctor for more information.

#### General information about the safe and effective use of **TYSABRI**.

This Medication Guide provides a summary of the most important information about **TYSABRI**. If you would like more information or have any questions, talk with your doctor or nurse. You can ask your doctor or nurse for information about **TYSABRI** that is written for healthcare professionals. You can also call 1-800-456-2255 or visit **www.TYSABRI.com**.

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

#### What are the ingredients in **TYSABRI**?

Active ingredient: natalizumab

Inactive Ingredients: sodium chloride, sodium phosphate, monobasic, monohydrate; sodium phosphate, dibasic, heptahydrate; polysorbate 80, and water for injection.

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

Manufactured by: Biogen Idec Inc.,  
14 Cambridge Center, Cambridge, MA 02142 USA  
Distributed by: Elan Pharmaceuticals, Inc., South San Francisco, CA 94080  
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**Sara Bernstein**, Editor,  
**Research Now**

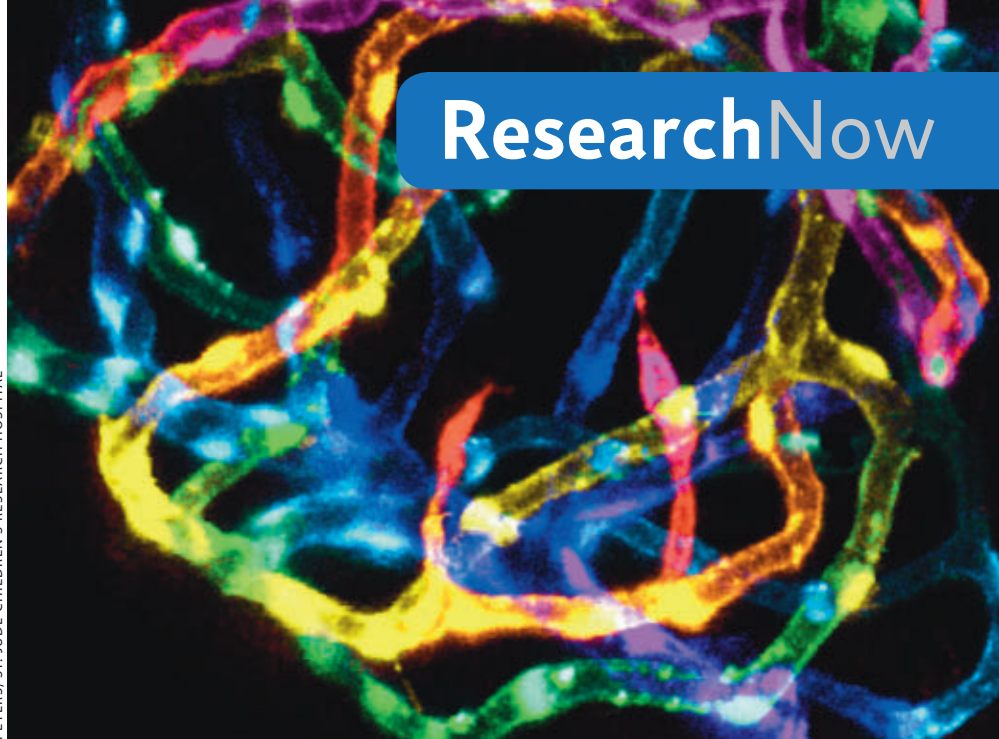
**Cathy Carlson**, Associate  
Vice President, Research  
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The National MS Society is proud to be a source of information about MS. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

COURTESY OF DR. MICHAEL R. TAYLOR AND DR. JENNIFER L. PETERS, ST. JUDE CHILDREN'S RESEARCH HOSPITAL



Researchers created this image of the developing zebrafish brain by labeling brain cells with fluorescent proteins and then using a confocal microscope to snap 3-D images of them. The translucent nature of this model makes it easy to observe how the brain functions and how these processes go awry in diseases such as MS.

## MS research under the sea

by Sara Bernstein

**T**he pursuit of all promising avenues is leading multiple sclerosis researchers to interesting places—including the depths of the ocean. Yes, zebrafish and sea anemones are being used to study the origins of MS and to develop novel strategies for stopping the disease in its tracks and restoring function. Here is a sample of such work from grantees funded by the National MS Society.

### Zooming in on zebrafish genes

Zebrafish are ideal for studying the early stages of disease development, including MS. Why? Because these small, freshwater fish lay hundreds of eggs at weekly intervals, which means researchers can get information about large numbers of genes simultaneously. The embryos are also translucent,

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And visit **[nationalMSSociety.org/research](http://nationalMSSociety.org/research)** regularly for full coverage on everything from research breakthroughs to clinical trials near you.



PHOTO BY THINKSTOCK

## Sea anemones are now the basis of a novel therapeutic strategy for MS.

making it easy to observe the formation of myelin (the substance that surrounds nerves and is a major target for the immune attack in MS) and other processes.

Dr. William Talbot (Stanford University Medical Center, Stanford,

Calif.) is screening zebrafish genes to identify those that may control myelin formation. Dr. Talbot's team has received several grants from the Society to complete this work. The group has identified a string of mutations that may

be important in the development of MS.

One mutation is in the gene that instructs *kif1b*, a “motor protein” that helps nerve cells transport other proteins so they can function normally. Dr. Talbot's team has shown that normal *kif1b* is required for myelin to form properly around nerve fibers and for the proper development of nerve fibers themselves. These findings suggest that disruption of this protein in MS may reduce the capacity for myelin formation and repair in MS (**Nature Genetics** 2009;41:854).

Dr. Talbot and his colleagues are continuing their search using zebrafish models for the genes that are crucial to myelin formation. The discovery of such genes could lead to a new understanding of how to stop MS damage and devise strategies for restoring function.

Dr. Bruce Appel (University of Colorado, Aurora) also is using zebrafish in his work. He is studying the genes that regulate how myelin-making cells wrap myelin around nerve fibers. His team is also evaluating whether mice, whose myelin closely matches that of people, have these same genes. With funding from the Society, his team found eight genes that had not been previously linked with the development of myelin-making cells (**Developmental Dynamics** 2010;239:2041).

Now the Society's funding of his work has been leveraged to



obtain funding from the National Institutes of Health. The team recently published results on the gene that instructs “pescadillo,” a protein crucial to the growth of myelin-making cells. Pescadillo was originally discovered in zebrafish and has subsequently been identified in mice and humans as well. Dr. Appel’s team found that the pescadillo-directing gene is required for the proper number of myelin-making cells to form, and for other myelin-related genes to function normally (**PLOS One** 2012;7:e32317).

These experiments should extend our knowledge of the molecular mechanisms that guide the myelin-making process, and inform efforts to find ways to repair myelin damaged by MS.

### More potential treatments

A sea anemone common in the Caribbean is known by the scientific name **Stichodactyla helianthus**. In 1995, researchers administered extracts of this anemone to mice, resulting in a toxic reaction. Upon examining this reaction, the team discovered that a protein fragment called “ShK” in the extract blocked ion channels (**Toxicon** 1995;33:603). Ion channels are tiny pores that allow charged particles—sodium, potassium and calcium ions, for example—to pass in and out of a cell. These channels are made up of protein molecules that assemble to form a water-filled tunnel across the cell’s protective membrane.

Dr. K. George Chandy (University of California, Irvine) and his colleagues have focused on ion channels on the surface of immune T cells, which allow T cells to become activated and are thought to lead the immune-system attack against the nervous system. Dr. Chandy discovered a key channel, Kv1.3, and modified ShK molecules to create an experimental treatment, called ShK-186, to block this channel.

In a unique pilot project supported by the Society, Dr. Chandy’s team found that by selectively blocking Kv1.3 and preventing T cell activation, ShK-186 can prevent experimental autoimmune encephalomyelitis (EAE, an MS-like disease) in rats and treat ongoing disease (**Molecular Pharmacology** 2005;67:1369). Dr. Chandy’s team formed a company, Airmid Inc., to develop Kv1.3 blockers as a strategy for MS and similar diseases. Kineta Inc. acquired this portfolio in July 2009. In August 2012, Kineta announced that it had received regulatory approval in the Netherlands to begin studying ShK-186 in human trials.

This novel approach may lead to a therapy that can prevent the activation of immune cells responsible for MS attacks, while leaving the rest of the immune system intact. Research under the sea continues to provide exciting findings that could help us reach the goal of a world free of MS. ■

## Harry Weaver Award fuels bright minds in MS research

by Elinor Nauen

**E**ngaging the best and brightest minds is crucial to stopping multiple sclerosis in its tracks, restoring function and ending the disease forever. To do this, we have to attract these minds to the field of MS research. One way the Society accomplishes this is with the Harry Weaver Neuroscience Scholar Award.

Named after the Society’s director of research from 1966–77, this five-year career development grant is given to scientists with a promising future in MS research. Some \$12.5 million has been distributed to 44 individuals and their institutions since the award began in 1981.

### Bringing gender research to the forefront

The 1997 Weaver Award supported Dr. Rhonda Voskuhl’s



research on gender differences in MS, specifically regarding whether sex hormones and chromosomes

play a role in MS. In the late 1990s, “People were first getting interested in gender differences in



MS, so it was a good time to be doing this. I was one of the few at the time. The Weaver Award helped me bring this research avenue to the forefront,” she says.

It also helped her win other grants and eventually, an endowed chair. Dr. Voskuhl is now a professor in the department of neurology at UCLA and program director of the UCLA Multiple Sclerosis Program. One outcome of her work is that two different hormone treatments are currently being tested in three clinical trials. She was the first researcher to show that estrogen treatments may protect the nervous system in MS. Now, with funding from the Society’s Fast Forward initiative to expedite the MS drug development process, Dr. Voskuhl’s team is collaborating with ACADIA Pharmaceuticals to determine whether a novel estrogen-like compound can protect the nervous system from damage in mice with experimental autoimmune encephalomyelitis, (EAE, an MS-like disease).

## Toward new understanding of the disease process

Dr. Anne Cross, section head of neuro-immunology at Washington University and co-director of the John Trotter MS Center in St. Louis, also believes the



Weaver Award helped her get her current position. “It gave me credibility when I didn’t have that many papers on MS,” she says, adding, “I think the award helped keep me in the MS field. It certainly helped solidify my wish to continue working on MS.” Dr. Cross received her Weaver Award in 1990, when she was studying the trafficking of white blood cells from the bloodstream into the central nervous system. These days her primary focus is on better ways to image the central nervous system. “I would like to be able to accomplish something similar to a biopsy but noninvasively,” she explains. “It would be nice to visualize what’s going on at the microscopic level and how treatments are having an effect—without hurting the patient.” Dr. Cross is incoming chair of the Society’s Research Programs Advisory Committee.

Bruce Trapp, PhD, a 1986 Weaver awardee, is now chair of the department of neurosciences at Cleveland Clinic Lerner Research



Institute and a professor at Case Western Reserve University. Dr. Trapp’s work changed the face of MS research by showing that nerve fibers are damaged by the disease. His current research aims are twofold: to obtain a better understanding of cell development

and myelin formation in the nervous system, and to understand how myelin and myelin-forming cells are destroyed in autoimmune and inherited diseases. His 1986 Weaver Award funded a study of MS tissue. “Now we have the most sophisticated brain autopsy setup in the world at the Cleveland Clinic, a direct descendant of that early work.”

Dr. Philip L. De Jager, associate professor of neurology at the Brigham & Women’s Hospital and Harvard Medical School, is in the final year



of his 2008 award. His research is focused on understanding how genetic variation affects neuroimmunologic function and susceptibility to MS, and how one goes from having a genetic risk to developing MS. The grant enabled his team to take a close look at one genetic variant and a broad look at many others, to see what causes MS-related alterations in immune responses. “The Weaver Award offered me the flexibility to pursue the original question and grow that question to launch a much broader and more systematic assessment of the consequences of genetic variation in MS,” he notes. “It gives me time to develop innovative research projects and get preliminary data to the point where National Institutes of

Health resources might be forthcoming.”

Dr. Ari J. Green, assistant clinical director of the Mission Bay MS Center at the University of California, San Francisco, is in his first year of the Weaver Award.



His research addresses how MS affects the visual system, using advanced imaging to investigate the retina and optic nerve and how they're damaged by the disease—and thus better understand injury to nerve fibers of the brain and central nervous system.

“I can't express how honored I am to receive the Harry Weaver Award,” he adds. “My hope is to build on what other Weaver awardees have done and to help develop better approaches and treatments for patients.”

All these top-notch investigators are positive about the progress they see in MS research, mentioning advanced technology, emerging therapies to help protect and repair the nervous system, and increased understanding about the types and origins of MS. “It's absolutely an exciting time to be engaged in MS research because we can witness the difference we're making in people's lives,” says Dr. Green. ■

Elinor Nauen is a health writer based in New York City.

## Weaver awardees drive progress

Several National MS Society Harry Weaver Neuroscience Scholar Award recipients have gone on to earn **The John Dystel Prize for Multiple Sclerosis Research**. The prize, which is awarded jointly by the Society and the American Academy of Neurology, recognizes outstanding contributions to research in the understanding, treatment or prevention of MS.

- Dr. Richard M. Ransohoff (Cleveland Clinic Foundation) was a Harry Weaver Scholar in 1987 and earned the 2012 John Dystel Prize for pioneering work in MS that led to new insights on immune activity in the brain and spinal cord.
- Dr. David A. Hafler (Yale University) received a Weaver Award in 1985 and the Dystel Prize in 2010 for fundamental discoveries related to MS in fields such as immunology and genetics, and for bringing clinical importance to basic science findings.
- Dr. Stephen L. Hauser (University of California, San Francisco) earned a Weaver Award in 1987, and in 2008 was honored with the John Dystel Prize for his pioneering studies on genetic susceptibility to MS, and for his role in translating findings on the role of immune B cells in MS into clinical trials.
- Dr. Bruce D. Trapp (Cleveland Clinic Foundation) received a Weaver Award in 1986, and was chosen as the 2003 John Dystel prize recipient for his major contributions to our understanding of brain tissue destruction and repair in MS. These findings changed the face of MS research and have had significant implications for the development of new therapies.

The John Dystel Prize is made possible through a special contribution from the Society's John Dystel MS Research Fund. Society National Board member Oscar Dystel and his late wife Marion established this fund in 1994 in honor of their son John Jay, an attorney whose promising career was cut short by progressive disability from MS. John died of complications of the disease in June 2003. To learn more, visit [nationalMSSociety.org/dystelprizewinners](http://nationalMSSociety.org/dystelprizewinners).

### Collaborating on progressive MS

by Timothy Coetzee, PhD

**P**rogressive forms of multiple sclerosis continue to elude effective treatment, increasing our collective urgency to do something now. That's why we've joined forces with the MS Societies of Canada, Italy, the Netherlands, the United Kingdom and the MS International Federation to create the International Progressive MS Collaborative.

The mission of the Collaborative is "to expedite the development of therapies for effective disease modification and symptom management in progressive MS."



While focused and singular, the mission is coupled with significant challenge. We know a lot about treating relapsing-remitting forms of the disease, but we have a long way to go in understanding what's

different about progressive MS and how to treat it.

The Collaborative is tackling this challenge by rallying the global MS research community to help identify the major barriers and potential solutions. This multi-country collaboration of researchers helped us identify key needs for accelerating research in progressive MS. These include:

- **New laboratory models for progressive MS.** Scientists need a way to replicate progressive MS in the lab so that they can sort out what contributes to the disease and potential solutions. We need new tools so that researchers can move more quickly to solve progressive MS.
- **New drug discovery strategies.** Discovering new treatments for progressive MS will require a new approach. We need to see if we can repurpose existing drug treatments, and also find new tools for identifying innovative therapies.
- **Improved clinical trial strategies.** The strategies used to find treatments for relapsing-remitting MS are not going to work for progressive MS. Trials in relapsing-remitting MS often rely on counting relapses or using MRI scans to detect immune activity; the fact that there is no easy way to identify progression quickly is one reason why drug development for progressive MS is lagging. New approaches are needed to test potential treatments faster and with fewer patients.

- **New symptom-management and rehabilitation strategies.**

While we're focused on finding effective disease-modifying treatments for progressive MS, we're also committed to finding useful treatments for symptoms associated with progressive MS and to developing better rehabilitation strategies that can improve quality of life.

New approaches are needed to test potential treatments faster and with fewer patients.

By focusing on these key areas, the work of the Collaborative will mobilize the global research community to do something about progressive MS. Together, we will take action and fund innovative and collaborative research initiatives around the world.

We've got some big challenges ahead of us. By working together globally, we will discover the answers and accelerate solutions for people living with progressive forms of MS. ■



Timothy Coetzee, PhD, is chief research officer of the National MS Society.



## New MS therapy expands options

by Sara Bernstein

In March, oral Tecfidera™ (dimethyl fumarate, Biogen Idec—formerly “BG-12”) joined the ranks of first-line, disease-modifying therapies approved by the U.S. Food and Drug Administration to treat relapsing forms of multiple sclerosis. This makes it the third oral therapy approved for relapsing MS and the tenth disease-modifying treatment available in the U.S. Taken orally in capsule form twice daily, it expands the range of treatment options now available to people with relapsing MS.

### Skin deep

The first use of dimethyl fumarate as a medicine was a leap of faith. German biochemist Walter Schweckendieck took a dose of a related compound, fumaric acid, in 1959, believing that a deficiency of the substance was causing his psoriasis, a skin condition mediated by the immune system. It worked, and although his theory was never proven, fumaric acid showed its effectiveness to treat psoriasis in clinical trials and was approved in 1994 in Germany to treat the disease (Fumaderm®, fumaric acid esters, Fumapharm AG).

### Fumarate for MS

Decades later, dermatologist Dr. Peter Altmeyer informed his

colleague, neurologist Dr. Horst Przuntek, that he had noticed that MS symptoms seemed reduced in a couple of people whom he was treating with Fumaderm for psoriasis. The conversation led to a small study in which disease activity on MRI scans was reduced in 10 people with MS who were taking Fumaderm (**European Journal of Neurology** 2006;13: 604).

Biogen Idec acquired the company Fumapharm in 2006, and began developing BG-12, a drug similar to Fumaderm, for treatment of MS. Fumaderm contains the Tecfidera ingredient dimethyl fumarate, and it also contains fumeric acid esters. Biogen Idec specifically created a new, different formulation of dimethyl fumarate alone, which provides a lower dose and comes in coated capsules intended to make it more tolerable to the digestive system.

Small studies led to two large-scale phase III studies called DEFINE and CONFIRM, which were conducted in people with relapsing-remitting MS. In the DEFINE trial, which involved 952 people, there was a significant reduction after two years in relapses experienced by those who were taking BG-12, compared with those on placebo. In the CONFIRM study, which involved more than 1,400 people, the average number of MS relapses in a year was reduced by 44 percent versus the placebo in people taking BG-12 twice daily.

The most common adverse events in these trials were facial flushing and gastrointestinal disturbances such as diarrhea, nausea and upper abdominal pain. In trials, the incidence of these events was highest during the first month of treatment, decreasing thereafter. BG-12 also reduced blood lymphocyte (white blood cell) counts, but no significant or severe infections were reported. Liver enzyme tests were elevated, but there were no reports of significant liver injury or failure. Before starting treatment, the FDA recommends that a person's healthcare provider assess a recent (within six months) blood cell count and repeat the count annually.

### Looking inside

Although its exact mechanism of action is not known, Tecfidera is thought to inhibit immune cells and their messenger signals. Some research also has suggested that Tecfidera may have antioxidant properties that could be protective against damage to the brain and spinal cord. Further research is necessary to fully explore this potential. ■

To read more about Tecfidera and other disease-modifying therapies available for MS, visit [nationalMSSociety.org/aboutMS](http://nationalMSSociety.org/aboutMS) and click “Treatments.”

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### IMPORTANT SAFETY INFORMATION

Do not take AMPYRA if you have ever had a seizure, or 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. 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.

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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 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.

**Please see the full 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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

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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](http://www.AMPYRA.com) or call 1-800-367-5109.

### What are the ingredients in AMPYRA?

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

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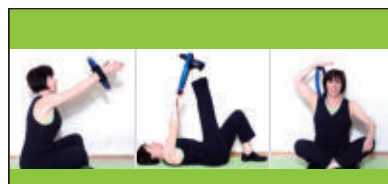


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Multiple Sclerosis  
Society

## Making your life with MS a work of art

People have an astonishing number of ways to cope with the hand that life deals them. Often, when someone is diagnosed with multiple sclerosis, they'll find new meaning in well-loved hobbies and activities. As you've read in this issue of **Momentum**, people who have relied on music, painting, poetry or some other art form throughout their lives have found it instrumental in facing the challenges of MS. That's true of Tom, a fabulous artist I know who became quadriplegic as a result of MS and couldn't paint for some time.

Like anything else, you won't know if you enjoy creating or appreciating art unless you try it.

Through technology, though, he learned to resume his passion. He told me that it was a miracle—that it opened up his life again.

I've known many others who didn't feel creative before their MS diagnosis, but turned to journaling afterward, and it helped them feel better. That's not surprising to me. One of the things we know from our collaboration with Shawn Achor

in the Everyday Matters initiative is that journaling gives people a happiness advantage. Just like the visual and performance arts, it's a way to express yourself, and that's a uniquely human need. It's what makes us individual. And it can help you feel powerful around MS.

If you're like me, though, you may not think of yourself as artistic in any way. In my family, I'm more of an art encourager. My house is filled with originals—paintings, photos, ceramics—from family members and other people I know whom I want to encourage. And each is meaningful to me because I have a piece of that person's essence. The way I see it, art appreciation is another way to be artistic.

Sometimes, art is more about experiencing a moment than possessing or even admiring a beautiful object. We acknowledge this in our home once a year, at our holiday dinner. My brother and sister-in-law make a fancy gourmet meal and we all contribute. My niece creates an original recipe for the occasion. Between courses, we display our talents. Some things are predictable: My mother recites poetry, and my brother sings hymns. But there are usually some surprises, too—someone juggling, or acting out the scene of a play. Not everyone stands up and

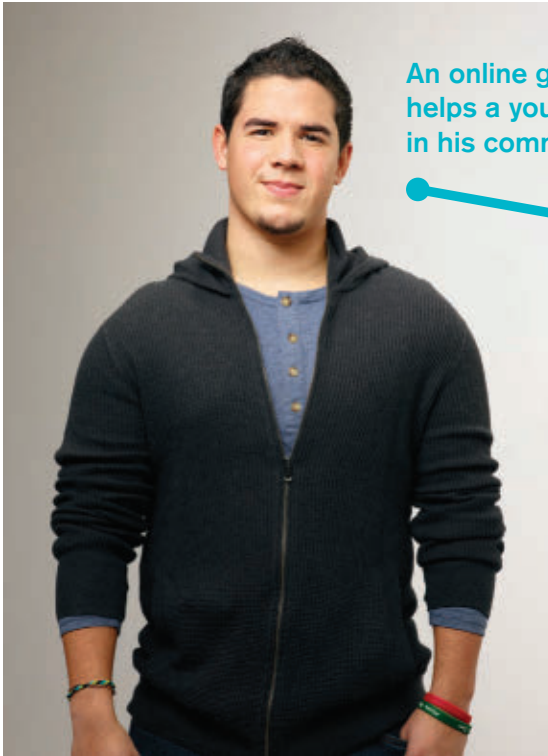
does something, but everyone participates by laughing, cheering or groaning.

Like anything else, though, you won't know if you enjoy creating or appreciating art unless you try it. You might find something that resonates with you; or like Tom, you may have to work through a new reality to be able to express yourself. There are so many ways to participate. Art is everywhere—it's at museums and parks, in public libraries and private kitchens. There are opportunities to try something out through a community program or by asking others to share their talents with you. And if accessibility issues are what's stopping you, contact the National MS Society for support to try and figure it out. We're here to help you discover—or rediscover—your most powerful, engaged life. ■



Cyndi Zagieboylo  
President & CEO  
National MS Society  
733 Third Avenue, 3rd Floor  
New York, NY 10017  
✉ [Cyndi@nmss.org](mailto:Cyndi@nmss.org)





An online group for young people with MS helps a young man in New York find other people in his community.



His neurologist starts recommending online support as a resource for her MS patients.

MS KILLS CONNECTION >

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Every Connection Counts at [MSconnection.org](http://MSconnection.org)

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