

The magazine of the National Multiple Sclerosis Society

# Momentum

WINTER. 2012-13

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ONE  
SIZE  
*doesn't*  
FIT  
ALL

# Not Your Friend's MS

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National  
Multiple Sclerosis  
Society

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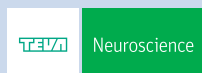
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## Readers report on happiness

Nearly 350 people responded to our  
survey on happiness, and almost  
three-quarters report being very happy  
(25.4%) or somewhat happy (48.2%).

The top strategies people use for  
boosting their happiness include  
expressing gratitude (59.9%); staying  
connected with their social network  
and loved ones (58.1%); and practicing  
kindness toward others (53.6%).

On those days when life with MS is  
particularly challenging, people turn to  
all manner of support: prayer, laughter,  
naps and Elvis movies showed up in  
your responses. For many, the power  
of positive thinking plays a role. As  
one person put it, "I remind myself  
that tomorrow is a new day."

### How has your MS diagnosis affected your happiness?

I've learned to seize the moment  
(48.8%)

I've taken more control of my health/  
life (29.2%)

I feel depressed about my future/  
abilities (42.1%)

I'm about as happy as I always was  
(13.7%)



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# Momentum

The magazine  
of the  
**National  
Multiple Sclerosis  
Society**

Winter 2012–13  
Volume 6, Number 1



People with  
MS may need to try  
many approaches before  
finding the right fit. p.14

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MS is famously unpredictable, and no person's MS is exactly like anyone else's. How do you plan for a future when it's seemingly impossible to know what to expect? by Stephanie Watson

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Get the latest on MS research, advocacy efforts and more.  
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Cover Illustration:  
James Steinberg



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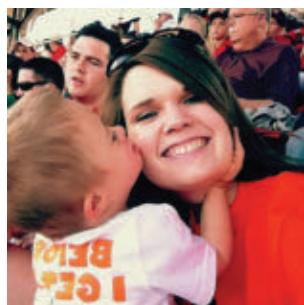
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## Let us hear from you!

✉ [editor@nmss.org](mailto: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.

## When the caregiver has MS

I read many articles addressing caregivers of people with MS. My question is, what if the **caregiver** has MS? I am a 57-year-old single woman with MS and am the sole caregiver for my elderly mother. Any advice or helpful hints would be appreciated. Just knowing I am not alone in this situation would be comforting.

Susan Alonso, Connecticut

## The right article

Kelly's Nieuwejaar's article about the word "caretaker" ("The wrong word," Fall 2012)—and how inappropriate it can sometimes seem—spoke louder

to me than any other article about MS I have ever read.

I am in a similar position to Kelly's husband, Khoren. I'm 41 and have had MS for 22 years. I can't work outside the house, so I remain at home with the kids while my wife, their mom, works full time. I do what I can around the house to take the load off my wife, and I contribute a little financially by working as a writer after everyone else has gone to bed.

But everything would crumble without the love, support and strength of my wife. It's fair to say that she, like Kelly, **is** a caretaker, but the type of very special caretaker only a loving wife could be.

Thank you for publishing her story.

Tony Dear, via email

## More ways to read

Stephanie Watson's article ("11 online resources for the visually impaired," Fall 2012) listed the National Library Service's free program for people with 20/200



## Momentum wants to know

about your creative pursuits

**nationalMSSociety.org/artandMS**

or worse vision. The program is open to many additional people with MS, since it includes anyone with a disability "preventing the reading of standard printed material." You need a medical certification, but it can be signed by a doctor, nurse or social worker.

I get double/blurred vision when I read longer materials. If I give in to temptation and read the newspaper, I'm usually wiped out the next day. My local librarian suggested this program and it's great.

Martha Figueroa, via email

## Making an impact

It is so nice to read stories of inspiration because it means so much to me that there are people with MS who are still trying. They are not only trying for themselves; they are paving a path for all of us.

I would like to think I am one of those positive individuals who has MS. It has been difficult, not only for me but for my family and friends. Yet I am comforted by the thought that

## 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 MS.

## 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.

there is a reason I am still alive and I hope I can find my voice of advocacy. I just need to find a way to make an impact. By pushing myself to keep moving, I am living!

Jeanie Collitte, Ohio

### Too rosy a picture

The stories printed in **Momentum** tend to paint a rosy picture. They show wonderful pictures of family and friends, and all these tips and websites where we can get all kinds of help. The truth is we've probably already done the things suggested. We still struggle every single day just like everyone else, except we now have MS. The pictures, wonderful stories and websites really come short on how MS actually is.

Jean Allen, Washington

### We need more

Your recent article on family ("Many Forms of Family," Fall 2012), as far as gays and lesbians are concerned, is a joke. You make passing mention of two lesbians who, after doing some paperwork, felt protected from life's myriad unforeseeable events. As an attorney, I can tell you that they are dangerously unprotected. The article ignores the effects of anti-marriage equality laws on people with MS. Survivor benefits. Spousal coverage. Inheritance taxes. Pensions. There are 1,138 rights granted under federal marriage laws alone, many of which

concern health care, illness and survivorship.

Gay and lesbian couples, including gay and lesbian people with MS, pay more for less (and worse) in life and in healthcare. It's irresponsible to suggest that they simply need to do a little more paperwork and they will then be protected just as if they are a married heterosexual couple.

Timothy Laden Crum, JD,  
via email

Editor's note: Gay and lesbian couples face many significant challenges that this article didn't—and couldn't—address, given its broad focus. In no way did we intend to minimize the impact of those challenges on people's lives. Rather, we hope to provide more focused attention on these issues in future articles.

We are committed to providing coverage that is relevant to **all** our readers. We know that people from many different backgrounds—including (but certainly not limited to) the LGBT community, African-Americans, Hispanics, people with primary-progressive MS or pediatric MS—all face unique challenges in



### IN A FLASH!

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- Find back issues, too.

accessing care, and making plans for themselves and their loved ones. We hope Mr. Crum will keep reading **Momentum** to see how we move forward with our coverage.

### Coming this Spring: Hispanics and MS

- We'll look at issues specific to the Hispanic / Latino population, including language barriers and access to care—and where to turn for support.



# 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 YYSABRI increases the risk of progressive multifocal leukoencephalopathy (PML), a rare brain infection that usually causes death or severe disability, YYSABRI is generally recommended for patients that have not been helped enough by, or cannot tolerate, another treatment for MS. YYSABRI 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 YYSABRI:

- YYSABRI 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 YYSABRI. Even if you use YYSABRI 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 YYSABRI for a long time, especially longer than 2 years.
      - You have received certain medicines that can weaken your immune system before you start receiving YYSABRI.
- 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 YYSABRI treatment with you before you decide to take YYSABRI.
- If you take YYSABRI, 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–SA–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 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](http://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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I61061-14

Revised 01/2012

## 2012 program focuses on disruptive symptoms

Pain and sleep disorders caused by multiple sclerosis can have a profound effect on quality of life—not just for the person with MS, but for loved ones, as well.

Learn more about the root causes of pain and sleep disorders, and their best management strategies through the 2012 **North American Education Program (NAEP): Managing Pain and Sleep Issues in MS**, produced by the Society in collaboration with the MS Society of Canada.

In the video portion, scientists and clinicians discuss strategies



for treating and managing pain and sleep disorders.

Christina and Elysa, two women who live with MS, share how they address their own pain and sleep issues. An accompanying booklet also provides information from current and completed studies on these often frustrating symptoms.

Call an MS Navigator® at 1-800-344-4867 to learn more about NAEP programming in your area. The program will also be available at **[nationalMSSociety.org/MSlearnonline](http://nationalMSSociety.org/MSlearnonline)** in April 2013. ■

## FDA approves new oral therapy for MS

On Sept. 12, the U.S. Food and Drug Administration approved teriflunomide (brand name Aubagio, Genzyme/Sanofi-Aventis), a once-daily pill for treating relapsing forms of multiple sclerosis. Aubagio is the second FDA-approved oral therapy that has been shown to reduce MS disease activity. Two doses were approved; the higher dose was also shown to slow progression of the disease.

Aubagio works by inhibiting the function of specific immune cells implicated in MS. Large clinical trials suggest that its effectiveness against MS relapses is similar to those of the first generation disease-modifying therapies.

Taking Aubagio may have risks, and prescribing information includes a boxed warning about possible liver damage and/or fetal harm. Discuss potential risks and benefits with your physician before making any treatment decision.

For more information, visit **[nationalMSSociety.org/Aubagio](http://nationalMSSociety.org/Aubagio)**. ■

## Find a partner in your MS care—online

Find referrals online to healthcare providers experienced with MS, quickly and easily, through the Society's new **Partners in MS Care** program, available at **[nationalMSSociety.org/partners](http://nationalMSSociety.org/partners)**.

The Partners in MS Care program offers referrals to Centers for Comprehensive MS Care, which provide a spectrum of coordinated care for people with

MS. Over time, the program will also offer referrals to neurologists, mental health providers and rehabilitation therapists who have met certain criteria and with whom the Society has a collaborative relationship. To be a Partner in MS Care, a provider must demonstrate MS experience and knowledge, and meet or exceed standards established by the Society. ■





# Not Your Friend's MS

Multiple sclerosis is famously unpredictable, and no person's MS is exactly like anyone else's. How do you plan for a future when it's seemingly impossible to know what to expect?

by Stephanie Watson

**W**hen Sharon Dodge's neurologist told her she had multiple sclerosis in 1996, Dodge was in Europe, where her Navy pilot husband was stationed. "I think I seriously went into shock," she says—and not just from the news that she had a serious chronic illness. It was the thought of ending up like her father that sent her into a panic.

Dodge's father had been a 30-something airline pilot at the top of his career when he was diagnosed with MS. At that time, there were no disease-modifying therapies and no symptom-management treatments for the disease. "He went downhill fast," she recalls. "Every time he had an exacerbation, his body wouldn't recover." Within seven years of his diagnosis, Dodge's father was using a wheelchair. At age 48, he died from complications related to his MS.

Dodge was 30 when she was diagnosed with MS, eight years after her father's death. "All I could think was, 'Here I am, this young Navy wife with a 3-year-old.' It was a lot to swallow at first," she says. What she didn't realize at the time was that no two cases of MS are the same. Aside from their genetic predisposition, this father's and daughter's MS would turn out to have little else in common.

### Why everyone with MS is different

If you've been diagnosed with MS, you're probably already familiar with the four types of the disease:

- **Relapsing-remitting MS (RRMS):** MS begins as a relapsing-remitting disease about 85 percent of the time. RRMS is characterized by unpredictable periods of worsening (called relapses, exacerbations or attacks) followed by remissions. A remission may be complete, meaning that the person returns to his or her pre-relapse level of functioning, or partial, meaning that some of the symptoms are likely to be permanent.

- **Secondary-progressive MS (SPMS):** Within about 10 years, approximately 50 percent of those who are diagnosed with RRMS transition to SPMS, which is characterized by a steady (but not necessarily rapid) progression of disability without any remissions. Within about 25 years, a large majority of people make this transition. People with SPMS generally have fewer or no relapses as time goes on.

- **Primary-progressive MS (PPMS):** For about 10 percent of people, MS progresses right from the beginning, without any relapses or remissions. PPMS seems to differ from RRMS and SPMS in terms of its underlying disease process—it has less inflammatory action going on in the brain and spinal cord, and more tissue degeneration and destruction early on. These differences may be the reason that the current treatments for MS—which mainly target the inflammation—work much better in relapsing forms of MS than they do in PPMS.

- **Progressive-relapsing MS (PRMS):** A very small number of people (less than 5 percent) are diagnosed initially with a progressive form of the disease but then experience some relapses down the road.

Even within these types, MS doesn't always follow predictable patterns, explains Rosalind Kalb, PhD, a clinical psychologist and vice president of the National MS Society's Professional Resource Center. MRIs of the brains and spinal cords of people with MS show that no two patterns of damage are exactly alike, she adds. "It's rather random where the damage occurs, and that means the symptoms people have will vary, as well." For example, one person's fatigue might be a minor nuisance, while another's is severely disabling. A lesion in the spinal cord might lead to difficulty in walking for one person or bladder urgency in another.

The unpredictable nature of MS symptoms makes it hard to plan your life using the experiences of friends or family members with the disease as a template. “People with MS cannot follow somebody else’s path,” Dr. Kalb says.

### 20/20 foresight?

If only you could look into a crystal ball and see where your MS is headed 10, 15 or 20 years from now, you’d already know well ahead of time what resources you’ll need in the future. But there is no magical way to predict MS progression.

Doctors can use MRI scans to see if you have new or growing lesions on your brain or spinal cord. But even though MRI techniques have improved significantly over the years, they still can’t predict which twists and turns your disease will take down the road. “You can’t tell from any single MRI how somebody is going to do,” says Dr. Barbara Giesser, clinical professor of neurology at the David Geffen School of Medicine at UCLA.

Other tests, such as those for MS biomarkers in the blood or spinal fluid, are exciting areas of research, but haven’t advanced far enough to be predictive. But Dr. James Bowen, medical director of the Multiple Sclerosis Center at the Swedish Neuroscience Institute in Seattle, explains: “There’s nothing on the near horizon that’s going to let us do a scan or a blood test and say, ‘You can relax because you’re never going to have another attack.’”

There are, however, a few indicators that you might have a milder disease progression. Evidence suggests you might have a better outcome if you have fewer relapses in the first few years after you’re diagnosed, and you recover fully after each of those relapses. Other positive signs are relapses that are more sensory in nature (such as numbness and tingling) and fewer findings on your neurologic exams.

Doctors also know that certain groups of people have more rapid and disabling disease progression than others. For example, men and African-Americans tend to have more severe MS. “Those particular groups can have more spinal cord involvement, which can cause more symptoms,” Dr. Bowen explains.

With all the uncertainty that surrounds this disease, planning for the future with MS becomes a matter of hoping for the best while preparing for the worst. “None of us knows what the future will bring,” says Gail Hartley, MSN, NP, an MS nurse at the Arcadia Neurology Center in Arcadia, Calif. But it’s essential for those with chronic illness to plan ahead as best they can.

Sven and Bernadette Couch of Seattle both have MS. Now in their 40s, the couple has been taking things day to day without much thought to what the future might bring. “As I ran into difficulties, I found answers, but there was very little foresight,” Sven says. “I probably avoided conceding that one day I may not walk.”

While that approach may seem easier or less frightening, Dr. Kalb says it’s important for people with MS to be aware of the ways in which their disease could become disabling, so they can prepare in advance. “It’s OK to think about what might happen down the road,” such as needing a wheelchair to go long distances, she says. “Thinking about it won’t make it happen.”

### Adapting to MS changes

“To some degree, you have to come to peace with the uncertainty of it, which takes time,” Dr. Bowen says. “The other part is that you really have to be adaptive.”

Before you can adapt to the variability of MS, you need to understand the possible manifestations of the disease. “Along the entire MS journey, you want to be proactive,” Dr. Giesser explains. “When





you're diagnosed, start by getting informed. Get as much knowledge as you can to assimilate." Learn what symptoms you might experience, what treatment options you have and what a relapse feels like, she advises. But be sure to give yourself the time you need to process the diagnosis and the emotions that come with it.

When you are ready, talk to doctors and nurses. Ask a lot of questions about your disease. And read about MS in books, in medical journals and on reliable websites.

"The people who manage MS most comfortably are those who learn about the disease and the kinds of changes it might cause," Dr. Kalb says. "Then if something new or unusual happens, they feel like they've got some baseline awareness that this is probably related to their MS, and they can talk about it with their doctor. They are a little more prepared and less panicked."

Jinjer LeVan, who was diagnosed in 1991 at age 31, did exactly that, heading straight to a

medical library. "I did a lot of research about MS and neurodegenerative disease. I wanted to learn everything I could," she says.

Becoming more knowledgeable about MS will also help you communicate more effectively with your healthcare team. "As a person living with a chronic disease, it's up to me to manage my healthcare if I want to stay as healthy and active as I can," LeVan says. "Since I have other health issues, my healthcare team includes eight specialists besides primary care and my neurologist. If there's something not going right, then I get to the doctor I need and keep the others informed."

### Putting together a healthcare team

Because your neurologist is central to your treatment, it's imperative to choose one carefully. "It kind of takes a village," Dr. Giesser says.

"But the neurologist and the patient are the nucleus of the team." Partner with a doctor who sees enough MS patients to understand the disease inside and out. Your neurologist should have an accessible office and a bedside manner that puts you at ease when you discuss your treatment options.

In addition to your neurologist and one or more neurology nurses, and depending on your MS, your treatment team may include a:

- **Primary care physician** to oversee general healthcare needs.
- **Physical therapist** to improve your strength, balance and mobility, and to teach you strategies to relieve fatigue.
- **Occupational therapist** to improve upper-body strength and range of motion, and to recommend accessibility tools (such as button and zipper hooks) to simplify everyday tasks.

- **Psychologist or psychiatrist** to provide counseling or medications, and to help you adjust to the emotional challenges of living with a chronic medical condition.
- **Social worker** to help you locate and coordinate community resources.
- **Speech-language pathologist** to help you communicate effectively and address any difficulties with swallowing.
- **Vocational counselor** to address employment issues.
- **Urologist** to treat bladder issues and other urinary system problems.
- **Ophthalmologist** to address vision issues.
- **National MS Society MS Navigator®** for referrals to healthcare providers in your area.

Depending on your location, you might have access to a specialized MS center that incorporates all, or at least most, of these professionals. People who live in more rural areas can work with their neurologist or primary care physician to assemble a virtual team of specialists, or even look into telemedicine (see “Telemedicine reaches out,” pg. 41).

No matter what your MS is like, it helps to be an active participant in your treatment. Take advantage of every visit with your neurologist and the other healthcare professionals on your team. Ask questions about anything that is unclear or that has been worrying you. If possible, bring someone with you to your visits. “Some patients are good at asking questions, but it’s hard for them to listen and pay attention because of cognitive changes or anxiety,” Hartley says. “So it’s very important to have a friend or family member with you, someone else who can help listen.” That person can take notes so you can focus on what your healthcare provider is saying.

## Putting together an MS plan

No matter the type or severity of your MS, you should start thinking about your future. Discuss it with your family and write down a plan for each of these areas:

**Financial decisions.** Thanks to better treatments, people with MS can live well into their retirement years. That means you’ll need not only funds set aside for basic living expenses, but also extra savings to cover future care needs. Work with a financial planner to ensure you’re saving enough. An elder law attorney can help people of any age handle wills, trusts and estate planning. It’s also a good idea to designate someone—a family member or friend—who can handle your finances in the future, should you become unable to do so.

**Employment decisions.** Start thinking about your job, especially if it requires physical labor, but don’t assume you need to hand in your resignation. “Having a diagnosis doesn’t make you disabled,” Hartley says. “If a person can stay at work rather than going on disability, I strongly recommend they do that.” Working longer will help you build financial security and hold onto your employer-sponsored health insurance.

Thanks to the Americans with Disabilities Act (ADA), an employer can’t fire someone because of his or her MS. A company with 15 or more employees also must make reasonable changes to a job or work environment to accommodate a person’s changing capabilities. That might involve allowing 15-minute breaks for a person with fatigue, or equipping a desk with ergonomic equipment.

In the late 1990s, when LeVan’s symptoms worsened, her employer made the adjustments she needed to stay on the job. “They were so wonderful,” she recalls. “It started with easy things like getting me a foot rest to prop up my feet, when I experienced a lot of tingling and pain, and

a headset so I didn't have to worry about dropping the phone in mid-conversation. As my symptoms and needs changed, so did the accommodations that were made for me, such as: a private office so I could shut my door and take mini-naps when needed; moving my office closer to a bathroom; and designating a parking space for me so I didn't have to walk as far, and extra space to allow for my low vision. They made other adjustments to make my job easier, like allowing me to telecommute when possible and adjust my hours when needed."

**Insurance decisions.** If you do have to leave or change your job, make sure you include your health insurance needs in your decision-making. If you have employer-based health insurance, talk to your employer (or plan administrator) about your right to keep that coverage for at least 18 months at your own expense. Federal COBRA law guarantees the right to continuation coverage to anyone insured by employers of 20 or more, and other laws provide comparable provisions for those ending employment with very small businesses, the armed services or government.

The cost of continuation coverage can be hefty, but will be more affordable after the Affordable Care Act's subsidies begin for any individual whose income is at or below 400 percent of the federal poverty level (about \$43,000 for a single person), starting in 2014. At that time, individuals no longer eligible for employer-based coverage will also have the choice of buying their own policy, even if they have MS or another pre-existing condition. No-cost expertise will be available to help you and your family make informed choices about insurance options.

**Living arrangements.** If your mobility needs change, consider making modifications to your home, such as adding ramps or lifts, installing grab bars and redesigning the bathroom and kitchen for greater accessibility. If you're living in a multistory home, think about eventually moving into a more

accommodating living environment, such as a one-story house or condo.

**Personal care decisions.** Assess whether MS is interfering with your ability to do everyday tasks, such as grocery shopping, cooking and cleaning. You may also need help with personal care, such as showering and dressing. Think about and discuss with your family what care options you prefer as your condition changes—including housekeeping help, in-home care, adult day programs or assisted living—and price out the various options so you'll have a good estimate of how much money you'll need to save. (See "When, why and how to hire in-home help," pg. 54.)

And don't be afraid to admit you need extra help when the time comes. "I've always been very independent," says Bernadette Couch. She resisted getting assistance until relatives finally noticed that she and Sven were overwhelmed by their home responsibilities. "Our family said, 'Hey, you guys need help.' They realized that we needed help before we did." Now, the couple has a cook who helps with meals, as well as volunteers who clean their house and take out the garbage.

### Getting control

Part of the reason Sharon Dodge is doing so well is that she has access to much better therapies today than her father did in his lifetime. Decades ago, treatments were very limited. "He had zero options," Dodge says. "My dad tried some crazy stuff—snake venom, hyperbaric oxygen, bee-sting therapy. There wasn't anything out there that he didn't try. He was a desperate man."

Although there still isn't an ultimate cure for MS, there are now several disease-modifying drugs that can slow the disease progression, manage symptoms and reduce relapses. Dodge doesn't have to resort to desperate measures like her father did. A disease-modifying drug helps to keep her MS in check. "Taking the shots is my insurance," she says.



Yet these drugs will only help if you take them. It's crucial to start disease-modifying medicines as soon as possible to ward off future damage, experts say. "The Society and the Consortium of Multiple Sclerosis Centers agree that as soon as patients are diagnosed with relapsing-remitting MS, they should be offered a disease-modifying therapy," Hartley says. "We know that the earlier we start treatment, the better people do in the long run."

"Most of our patients are on some treatment to decrease the disease activity," Dr. Bowen says. "We tend to take a fairly aggressive treatment approach, regardless of whether they have a milder or more aggressive case."

Beyond taking disease-modifying drugs, you can take a number of other actions to ensure you continue feeling your best.

**Pay attention to the signs.** Your body isn't always going to accommodate your daily routine, so you need to accommodate your body. After more than a decade of living with MS, Dodge has become very aware of her capabilities. "I've really learned what I can and cannot do, and what my limits are," she says. Learn when your energy levels tend to peak each day; schedule errands and activities around those high-energy periods; and rest when you feel the most tired. Ask for help when you need it.

**Eat a healthy diet.** There is no specific "MS diet." But universal healthy diet recommendations also apply to people with MS. "People should follow the basic high-fiber, low-fat diet that's good for everybody," Dr. Kalb recommends. "But if there are foods that make you feel better or don't make you feel as well, modify your diet accordingly."

**Exercise.** While there is no specific fitness routine recommended for those with MS, "staying active protects your heart, strengthens your bones, helps prevent obesity and diabetes, improves your

muscle strength and gives you more energy," Dr. Giesser says.

Sue Kushner, MS, PT, associate professor in the School of Physical Therapy at Slippery Rock University in Slippery Rock, Pa., agrees. "Exercise such as strengthening, stretching and balance activities, and coordination routines can certainly help with function, mobility and overall fitness." Kushner says people with MS also need to exercise for general health. "Just because you have MS doesn't mean you're exempt from the normal health risks that everyone else faces, including diabetes, heart disease and obesity."

Dodge does yoga, rides her bike and runs a few times a week. "I always feel better after I exercise," she says. "If you're looking for an MS-friendly exercise program that won't wear you out, try swimming, tai chi or yoga."

**Relieve stress.** Stress is toxic to good health, especially when you have MS. Many people say their symptoms get worse when they feel overwhelmed. "When I have more stress, I can feel myself deteriorating," says Bernadette Couch. She and Sven unwind by relaxing on their back porch, exercising or taking a ride in the car. Others use meditation to tame stress (see "Meditation—more than just 'om,'" pg. 38).

### Connect with others

While you're caring for your body, look after your emotional health, too. When you feel overwhelmed, seek out support from friends and family. "It's a very volatile disease. Emotionally, it's like a roller coaster," Sven says.

"You can only ride the wave and do what you can. You can't question it or fight it, because that takes a lot of energy," Bernadette adds.

Over the years, Sven and Bernadette have learned to lean on each other. "I think we lend each other a great deal of emotional support," Sven says.

It can be difficult to discuss your condition, even with people closest to you, but that's exactly what you should do. LeVan says communicating with your family is essential. "The worst thing to do is not say anything and think that you're sparing them. You're not—because the family's picking up that there's something wrong, and they don't know what it is," she says. "You can't just stay silent and hope it goes away. You have to communicate and let them know what's going on."

A psychologist, psychiatrist or counselor should be a first line of support. Their job, in part, is to help you develop coping skills for whatever life throws at you. Your emotional health should get the same attention as any other symptom. Joining a support group or online community for people with MS can provide an outlet for your fears and frustrations. Some groups focus on specific populations, such as young adults, parents with MS, care partners or African-Americans. "You can share support. You can share ideas and problem-solving strategies. You can laugh and cry together," Dr. Kalb says.

Above all, try to keep a positive attitude, even though that may be difficult when you're living with such an unpredictable disease. Dodge says she has always tried to look on the bright side, even though she watched her father die from disease complications.

"It's important to know that you can live your life well with this disease," she says. "In the beginning, with the fear from having watched what happened to my dad, I definitely thought that was going to be me someday. So I've been surprised that it's **not** me," she says. Today at age 46—almost the age at which her father passed away—"I've already lived longer with my diagnosis than my dad—and, most importantly, I've lived quite well," she says. ■

Stephanie Watson is a freelance health writer based in Atlanta.

## RESOURCES

For referrals to healthcare professionals in your area, or for advice on financial, employment or accessibility planning, call an MS Navigator® at 1-800-344-4867 or visit **[nationalMSSociety.org](http://nationalMSSociety.org)**.

Connect with the MS community and groups that share your interests at **[MSconnection.org](http://MSconnection.org)**.

**Also:** Learn about your employment rights at **[ada.gov](http://ada.gov)**, or call 800-514-0301.

Social Security disability insurance and Supplemental Security Income information: **[www.ssa.gov](http://www.ssa.gov)**.

Medicaid eligibility information: **[www.medicaid.gov](http://www.medicaid.gov)**.

Pre-Existing Condition Insurance Plans: **[www.healthcare.gov/law/features/choices/pre-existing-condition-insurance-plan](http://www.healthcare.gov/law/features/choices/pre-existing-condition-insurance-plan)**.

Continuing coverage through COBRA: **[www.dol.gov/ebsa/cobra.html](http://www.dol.gov/ebsa/cobra.html)**.

### Books

Rosalind Kalb, PhD; Barbara Giesser, MD; and Kathleen Costello, ANP-BC

#### **Multiple Sclerosis for Dummies**

John Wiley & Sons, 2012

Pat Kennedy, RN, CNP, MSCN

#### **The Can Do Multiple Sclerosis Guide to Lifestyle Empowerment**

Demos Health, 2012

Phillip D. Rumrill Jr., PhD; Mary L. Hennessey, PhD; and Steve W. Nissen

#### **Employment Issues and Multiple Sclerosis**

Demos Health, 2008

Visit **[nationalMSSociety.org/books](http://nationalMSSociety.org/books)** for more information and links to many more titles.

## Indication and Important Safety Information

### 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.

- 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, and 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, 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.
- 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, 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
- 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.

*(Continued on the following pages.)*

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



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**Talk with your doctor to see if AVONEX PEN is right for you.**

<sup>a</sup> A 6-week study to see if people who had previously used AVONEX prefilled syringe for at least 12 weeks were able to successfully use AVONEX PEN. People took AVONEX using the prefilled syringe the first week and then switched to AVONEX PEN for the next three weeks. Results were based on patient and physician questionnaires.

<sup>b</sup> People were asked to complete a multiple choice questionnaire on their last day of the study, rating their overall experience with AVONEX PEN compared to the prefilled syringe.

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## Important Safety Information (cont'd)

### 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.

For additional important safety information, please see the brief summary of the Medication Guide on the following page.

Visit **AVONEX.com/PEN** to learn more.



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ONCE-  
A-WEEK **AvONEX**®  
(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.

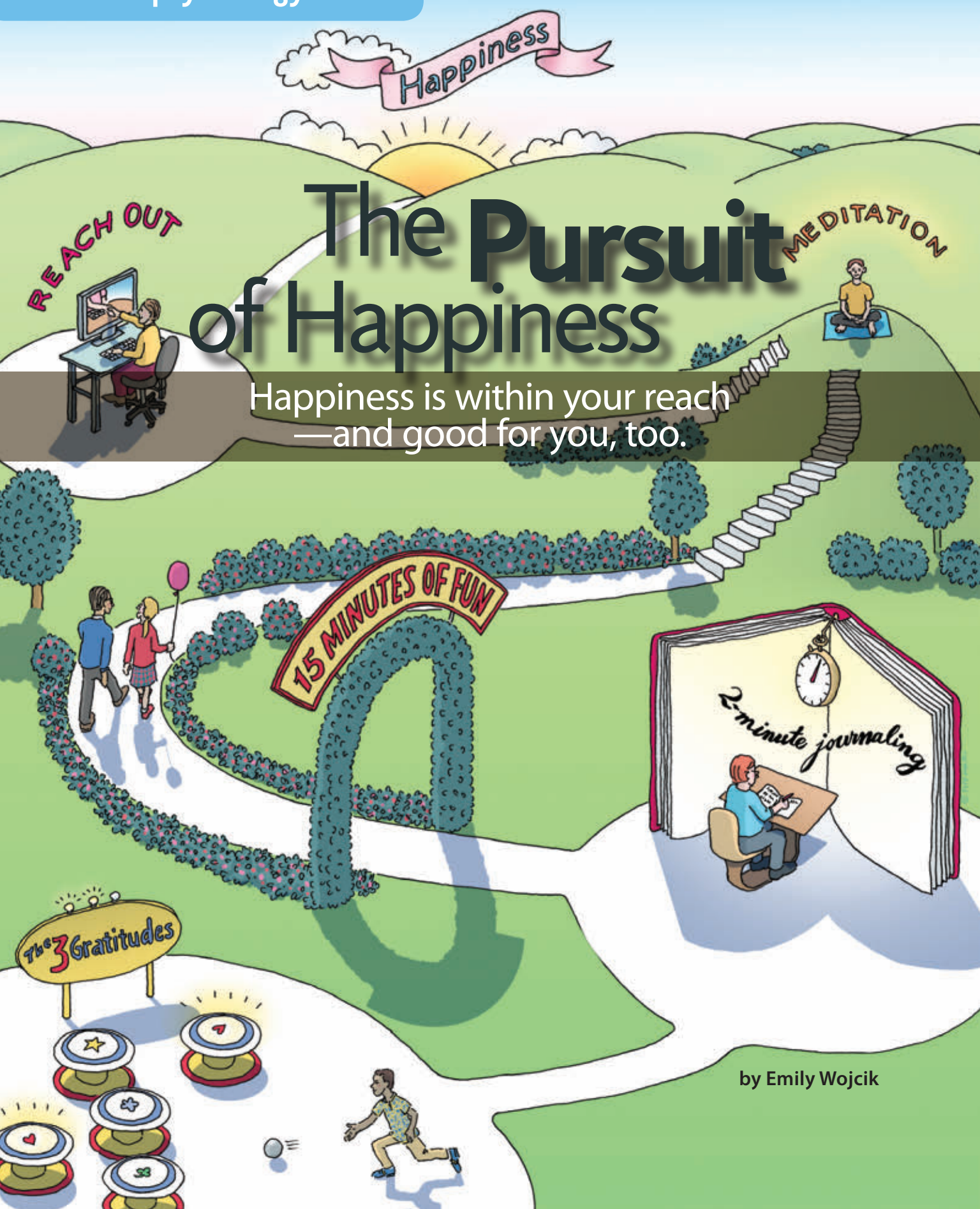
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# The Pursuit of Happiness

Happiness is within your reach  
—and good for you, too.



by Emily Wojcik

**W**hen Kristen Adams, an Emmy Award-winning television news producer, was diagnosed with multiple sclerosis in 2008, life began to feel like a series of things she couldn't do. "There's a tendency to do a lot of 'I can't's' when you're first diagnosed," she says. "There's a lot of fear about the future, because you have no idea what it holds."

Four years later, the Fairfield, Conn., mother of two has learned it's possible not only to survive an MS diagnosis, but to thrive. Adams is one of a growing number of people using positive psychology to feel better. The relatively new field cites research showing that happiness can improve physical health and well-being. "It underscores the power of your mind to reframe your circumstances, interpreting what's going on in positive ways," Adams says. But what, exactly, is "happiness"?

### **Nature vs. nurture**

By most accounts, happiness is a complicated combination of physical and environmental interactions. Just as people are born with specific physical characteristics, research by Dr. Yoram Barak, a professor of psychiatry at the Sackler Faculty of Medicine at Tel Aviv University, suggests that roughly 40 percent of our happiness may be genetically determined. His findings were presented at the 2008 World Congress on Treatment and Research in MS in Montreal and published in the April 2009 **Expert Review of Neurotherapeutics**.

"There is no single gene for happiness," Dr. Barak says. "We calculate that several hundreds of genes are involved in our happiness, which means that we all carry the happiness genes to some extent." If scientists can isolate these genes, he says, they might be able to make them more effective.

In the meantime, at least 60 percent of our capacity for happiness is within our control, says Dr. Barak—which is good news for everyone, including people with MS. "The science of positive psychology gives us psychotherapeutic interventions that help people living with chronic illnesses increase their happiness overall."

A 2012 analysis by Sonja Lyubomirsky, PhD, author of **The How of Happiness: A New Approach to Getting the Life You Want** (2008), and graduate researcher Kristin Layous, both of the University of California, Riverside, demonstrated that fulfilling people's basic psychological needs—autonomy, competence and social connection—contributes more to happiness than do seemingly more exciting events like a wedding or a raise. And most people have more control over meeting those needs than they think, according to the paper, which will be published as a chapter in the forthcoming book, **The Light and Dark Side of Positive Emotion** (2012). For some practical strategies, see "C'mon, Get Happy," pg. 29.

### **Positive approaches to living with MS**

"The natural reaction of many people is to think they've lost control over the things that matter to them when they're diagnosed with MS," says Rosalind Kalb, PhD, a clinical psychologist and vice president of the National MS Society's Professional Resource Center. "Positive psychology offers a whole new way to approach their experiences, and gives back that sense of control."

Dr. Kalb explains that positive psychology "isn't about putting on a happy face, being Pollyanna-ish or denying the negative feelings that people with a chronic illness may experience. It's about using some proven tools to enhance your own happiness, because that, in turn, will help you to be more

# THE **FIVE** HABITS OF HAPPINESS

“Over the past five years, I’ve researched happiness in 49 countries,” says Shawn Achor, author of **The Happiness Advantage**. “We found, throughout the world, that there are five habits that affect success outcomes and health.”

1. **The three gratitudes.** Every day, make a list of three new things that you are grateful for.
2. **Two-minute journaling.** Take two minutes to write about a positive experience, no matter how small.
3. **Fifteen minutes of fun.** Set aside 15 minutes each day for a fun, mindful activity, such as taking a walk with a loved one.
4. **Make time to meditate.** Practice meditation for two minutes each day. Focus on your breath. (Don’t worry if your mind wanders!)
5. **Reach out.** Write a two-minute positive email praising or thanking someone in your social circle.

successful in addressing the challenges you face with your MS and with life in general.”

In fact, practicing positive psychology can lead to better adherence to treatment programs, which may lead to better outcomes, says Dr. Barak, citing a study published in **Health Psychology** in 2008, which reported that for 127 people with MS, positive psychology therapies significantly improved depression and increased optimism, promoting increased resilience in managing MS symptoms. The end result: a greater sense of emotional **and** physical well-being.

Dr. Kalb warns, however, that the more serious problems that can accompany MS, such as major

depression, may require therapy or medication to control.

“I know positive psychology won’t take the place of my treatment plan,” says Adams. “But the things I do mentally to empower myself keep me active on my program, which helps my outlook on life and leads to a cascade of other good things.”

## Habits of happiness

Cultivating this positive outlook is easier than you might think, says Shawn Achor, author of **The Happiness Advantage** (2010). “We normally think, ‘If I felt better, I’d be happier,’ but it turns out that if you can raise your happiness level first, you can actually feel better and become more successful,” he says. “You then want to take better care of yourself and exercise more.”

Achor, a psychology researcher at Harvard University, and his team found that people demonstrated significantly improved levels of positivity after adopting several “habits” of happiness (see “The Five Habits of Happiness,” at left). While some of Lyubomirsky’s strategies may require overarching lifestyle changes, all of the habits Achor outlines are easy enough to perform every day for three weeks—the average time it takes most people to develop a habit. “We found that, if done each day for 21 days in a row, these habits rewire the brain for optimism and create the capacity for success that can make you healthier and happier,” says Achor.

The most effective habit, he says, is also the most selfless: writing a two-minute positive email every day, praising or thanking someone. “You reach out to 21 people in your social network, which also makes them feel better, and then they often give you more social support in return.” And good social networks matter: Achor’s team discovered a strong statistical correlation between feeling socially connected and happiness.



### A web of support

In light of this research, the Society and Genzyme, a Sanofi company, have collaborated to create Everyday Matters ([everydayMSmatters.org](http://everydayMSmatters.org)), an interactive program that tells the stories of everyday challenges faced by people across the nation, and uses positive psychology to help them address those challenges head-on. As part of this initiative, five individuals living with MS were selected to receive personal support from Achor and life coach Michelle Clos, who also lives with MS, in mapping out strategies to achieve a personal goal or overcome a challenge. Adams will produce stories about the participants, and the videos will be available on the Everyday Matters website through the end of

2012. The program will also offer free resources to help enhance the outlook and well-being of anyone living with or affected by MS.

For Adams, who had already begun following Achor's advice before joining the team, taking part in the initiative is just another step on her own path to happiness while living with MS. "If I tell their stories well, everyone who watches the series will be able to do it themselves. It's great to be the conduit for helping other people achieve a more positive outlook." ■

Emily Wojcik is a freelance writer and college instructor living in Northampton, Mass.

## C'MON, GET HAPPY

Sonja Lyubomirsky, PhD, has a website, [thehowofhappiness.com](http://thehowofhappiness.com), where visitors can take quizzes to assess their own happiness, learn the latest research on the subject and download a happiness app to stay on track. Her book, **The How of Happiness: A New Approach to Getting the Life You Want** (Penguin Books, 2008), outlines a dozen lifestyle strategies for boosting happiness. Get started with this handful, below.

**Cultivate optimism:** Imagine the best possible future for yourself, and write these ideas down in a journal.

**Avoid overthinking and social comparison:** Use strategies such as distraction to cut down on how often you dwell on your problems and compare yourself to others.

**Practice acts of kindness:** Doing good things for others, whether friends or strangers, either directly or anonymously, either spontaneously or planned, heightens our own happiness.

**Get involved in activities that truly engage you:** Increase the number of experiences at home and work in which you "lose" yourself, and which are challenging and absorbing.

**Replay and savor life's joys:** Pay close attention to life's momentary pleasures and wonders—and remind yourself of them through thinking, writing, drawing or sharing with another.

**Take care of your body and soul:** Engage in physical activity, and become involved in meditation, your religion, or even spiritually themed books or discussions.



# GILENYA for relapsing forms of multiple POSSI

## GILENYA. Proven to significantly reduce the

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

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

### Indication

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

### Important Safety Information

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 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.

sclerosis (MS). Discover your

# BILITIES

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

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.

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



\*GILENYA can result in a slow heart rate when first taken. Your first dose will be given in a 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 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.**

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## The balancing act: Managing balance problems

by Evelyn Leigh

**B**alance problems are among the most common symptoms reported by people with multiple sclerosis—second only to fatigue, according to a 2003 study of more than 650 people with MS. But just like MS itself, the ways in which balance problems show up vary from person to person.

“Balance is a complex phenomenon involving practically the entire brain,” explains Dr. Robert Baloh, professor of neurology and head and neck surgery at the David Geffen School of Medicine at UCLA, and a leading expert on neurological causes of imbalance and dizziness. “Just about any lesion in the brain or central nervous system can affect balance. Some of the most common causes are lesions in the spinal cord that affect sensorimotor function,” or the way your body uses input from its senses to propel movement.

“We see balance problems in all stages of the disease due to MS lesions and atrophy,” says Dr. Angeli Mayadev, a physical medicine and rehabilitation physician at the Multiple Sclerosis Center at Swedish Neuroscience Institute in Seattle. “We now know that

Maintaining balance is crucial to mobility. Staying active, adjusting activities to ability level—and adopting assistive devices when needed—can improve both stability and independence.

gray-matter atrophy can play a role in imbalance.” Gray-matter atrophy describes the shrinkage of brain cells that occurs in MS after the connections (in the white matter) are lost. Balance issues can also be a result of demyelination and loss of connection pathways, Dr. Mayadev explains.

For Mary Wideman-Williams, imbalance while walking was one of the first symptoms she noticed before being diagnosed in 2010. “I don’t know what it is like to have MS without balance issues. It was a very dramatic opening to my journey with MS,” says Wideman-Williams, 48, the chief operating officer of Seattle Center, home of the Space Needle.

### Complicating factors

Vertigo, a specific type of dizziness that causes a spinning sensation, often accompanies

imbalance in MS. “About 5 percent of patients experience vertigo as their initial symptom, and about 50 percent will have it at some time,” says Dr. Baloh. For people who don’t have MS, vertigo is often traced to structures of the inner ear, or vestibular system. However, for those who do have MS, “vertigo almost always results from lesions in the central nervous system,” Dr. Baloh says. “This type of vertigo is usually accompanied by other symptoms, such as double vision and imbalance,” so it’s unlikely to respond to treatments targeted to the vestibular system, he says.

Sensory disturbances can play a significant role in balance function as well. When Dr. Mayadev assesses her patients, she pays special attention to their visual and vestibular systems, as well as to their proprioception—their ability



to judge where their body is in space. If one of these systems is particularly weak, strengthening the others can help compensate.

Coexisting MS symptoms such as fatigue and spasticity can make balance problems even worse, as can sedating medications. “When I’m well rested, I tend to be able to march right along,” Wideman-Williams explains. “When I’m fatigued, my gait changes and I tend to stumble a bit. That’s how people in my life notice I’m fatigued.”

### Treatment methods

Because the factors leading to imbalance in MS vary so widely from person to person, no “one size fits all” approach to therapy exists. Your doctor and physical

therapist can help identify the causes of **your** impairment and determine the approaches most likely to help you fight back successfully.

No medication is approved specifically to treat MS-related imbalance, but a number of drugs have the potential to help, at least indirectly. For example, anti-spasticity drugs can lessen the chance that an erratic movement may further compromise balance.

The Food and Drug Administration recently approved dalfampridine (brand name Ampyra) to improve walking in MS. “The medication appears to work by improving transmission across demyelinating plaques,” says Dr. Baloh. “It’s not specific

for imbalance, but it has the potential to help by improving function.”

The potential benefits of any drug must be weighed against the risk of side effects. Dr. Baloh cautions against the indiscriminate use of anti-vertigo medications, such as meclizine, for people with MS. “It is purely a symptomatic treatment,” he says. “It does not get at the underlying cause and may even complicate balance problems by causing sedation.”

Similarly, vestibular rehabilitation—a treatment that uses specialized eye exercises, head movements and balance practices to improve balance—are probably useful for only a subset of people with MS. “Vestibular rehabilitation exercises help the brain adapt to impaired inner ear function,” says Dr. Baloh. “When the damage is central, as it is with MS, there’s less evidence that these exercises are going to be beneficial.” Still, a small

**Lisa Green, 48, diagnosed with MS in 1998, uses the Alter-G, an anti-gravity treadmill at Great Moves, a physical therapy clinic in Colorado Springs, Colo. The machine’s technology, along with its “zip-in” support, helps Green maintain her balance as she walks. “Gaining or maintaining strength in my legs helps my overall balance in other activities, too,” Green says.**



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study published in 2011 showed improvements in balance, fatigue and disability due to dizziness or imbalance after six weeks of vestibular rehab. More research is needed to confirm the benefits observed.

## Getting physical

Physical therapy can be an important part of the equation in treating imbalance.

The first step is to pinpoint the factors that increase imbalance in an individual, says Kim Kobata, physical therapist at the MS Center at Seattle's Swedish Neuroscience Institute.

*"Even if you use a wheelchair, specific strengthening exercises can help maintain or improve your sitting balance."*

"Is it due to decreased strength? Poor alignment? Decreased sensation? Reduced range of motion?" Kobata asks. "Once we've identified those factors, we develop an individualized exercise program to address specific areas," she says. For people with decreased range of motion or spasticity, stretching is particularly important. Other exercises may be geared toward reducing reliance on vision and strengthening other systems to help with balance, or strengthening the muscles

involved in maintaining an upright posture. "Even if you use a wheelchair, specific strengthening exercises can help maintain or improve your sitting balance," she says.

"We also make recommendations on assistive devices, and train people how to use them," says Kobata, who notes that the range of assistive devices available includes single-point and four-point canes; walkers, with and without wheels; crutches; ankle-foot orthotics; and manual and motorized wheelchairs. Kobata likes her patients to experiment with

various devices to see which ones may be most helpful in specific situations. "If someone is using a single-point cane, for instance, I may try them with Canadian (forearm) crutches to see if that feels more secure, or if the crutches might be beneficial on days when the person is not feeling as well."

Kobata adds, "We teach compensatory strategies when necessary, such as breaking down a task and practicing its parts." Wideman-Williams, who attends physical therapy sessions with Kobata, credits PT with

improving her confidence as well as her strength and balance. "The security of knowing what to do to help myself is a big deal for me." After a recent exacerbation, she noticed her balance was affected, "but physical therapy helped me bounce back right away."

## Staying active

It's now well established that exercise supports overall health and quality of life, and helps with MS-related symptoms, such as fatigue and depression. But what exercises are appropriate for those who have existing balance problems?

Kobata recommends incorporating four kinds of exercise: stretching, strengthening, cardiovascular activity and balance practices, all at a level safe and appropriate for the individual's experience and ability.

Dr. Mayadev emphasizes the importance of exercises that strengthen the core muscles most critical to better balance. "It's important to **strengthen** the deep muscles of the back, such as the back extensor muscles. This is especially important for someone who uses a wheelchair."

Dr. Mayadev recommends practicing **balance** exercises daily for maximum benefit, or at least five times a week. These may be as simple as standing

on one foot (holding on to a counter or chair for support) or closing eyes while standing and holding a stabilizing object. For additional balance exercises appropriate for home practice, visit [mstrust.org.uk/information/exercises/index\\_balance.jsp](http://mstrust.org.uk/information/exercises/index_balance.jsp).

Yoga and tai chi, practices that emphasize **breathing, stretching, relaxation** and **alignment**, may be good additions to an overall MS fitness and balance improvement program. Look for a teacher experienced in working with people with MS, particularly if you are new to these activities. Ask questions, and never push yourself beyond your comfort level, no matter what the rest of the class is doing. Chair yoga may offer an option for those who need extra support.

Appropriate **cardiovascular** options, critical for fighting fatigue and improving endurance for daily activities, can include aquatic exercises, recumbent stationary bikes, elliptical machines and treadmills—all commonly available at most gyms. Specialized fitness centers or rehabilitation clinics may also offer treadmills that support body weight—either with a harness or anti-gravity technology. (For information about anti-gravity treadmills, visit [alterg.com/product/anti-gravity-treadmills](http://alterg.com/product/anti-gravity-treadmills).)

For information about exercise and yoga classes in your area, call the National MS Society at 1-800-344-4867. Also visit [nationalMSSociety.org/exercise](http://nationalMSSociety.org/exercise) for more tips.

### Fear of falling

Walking, if you are able, is always good exercise, too. However, one of the more troublesome aspects of imbalance is an increased risk of a painful or embarrassing fall. “Studies have shown that about half of middle-aged and older people with MS have had at least one fall in the last six months,” says Nancy Law, executive vice president of Programs and Services at the Society. “A single fall can have life-changing consequences in terms of injury.”

If you’re worried about falls, ask your physical therapist about using a cane or walker; both can help widen your base of support and increase your stability while walking. But your best first step to fall prevention is to simply stay alert to the increased risk that comes with balance problems. When in a public place or otherwise outside your comfort zone, Law advises, “Scan and plan. Don’t just charge ahead. Take the time to look ahead and figure out how to get from point A to point B.”

Law suggests contacting the

Society to learn more about its eight-week fall prevention program, Free From Falls. The program emphasizes lifestyle adaptations (such as fall-proofing the home) as well as specific balance, endurance and safety exercises. The program also offers a “Free From Falls” DVD and a fall-prevention brochure (“Minimizing Your Risk of Falls: A Guide for People With MS”). Call the Society at 1-800-344-4867.

No matter what you are doing, pay attention to your body and resist any temptation to push yourself too far. Be sure to get your doctor and physical therapist’s advice and approval before embarking on any kind of exercise program. Know your limits, too. If you find your balance problems worsen when you are fatigued, for example, finish crucial activities before you reach the point of exhaustion.

Staying active is key to challenging any balance problems. “You have to continue to stimulate your brain,” Dr. Baloh advises. “Continue to try to pursue normal activities within your capabilities, without overexerting yourself. Just keep trying, keep walking. The worst thing you can do is become sedentary.” ■

Evelyn Leigh is a medical writer and health advocate based in Boulder, Colo.



## Meditation—more than just ‘om’

by Nathan Solheim

When Diedra Roesijadi was diagnosed with multiple sclerosis in 2007, she knew her life was changing. She lost her 70-hour-a-week job as a corporate real estate agent. Her doctor told her to cut down on stimulants, including coffee—a bad thing for someone who lives in java-obsessed Seattle. And she had to give up her favorite sport, participating in triathlons, because her MS symptoms included debilitating leg cramps and spasticity.

She needed something to fill the void. So, Roesijadi enrolled in a yoga class, and by last year was learning how to teach yoga. During the training course, she was introduced to a style of meditation that incorporates slow movements and controlled breathing.

Despite its origins as a spiritual practice, meditation today is often used as a practical tool to calm the mind and relieve stress, using techniques that can include sitting still and concentrating on breathing, engaging in repetitive motions or even listening to music.

After practicing meditation and incorporating it into her daily life, Roesijadi began to notice an impact. “Last summer, I was meditating 45 minutes a day, and with almost

While meditation has been around for thousands of years, recent studies are showing that its focus on mindfulness can have positive impacts for people with MS.

no other changes to my lifestyle or treatment plan, I was almost able to completely calm my leg cramps,” Roesijadi says. “And I was getting to the point where I could keep still, not just in meditation, but also when I was sitting and lying down.”

Roesijadi is one of many people with MS who say that meditation helps relieve symptoms such as stress—which can lead to other health problems—as well as fatigue, anxiety, spasticity and depression. And used as a complement to standard MS treatments, meditation also has been shown to improve overall quality of life and well-being.

While more needs to be learned about the effects of meditation, there are many mindfulness and relaxation techniques to choose from, with relatively few negative consequences. This means more and more people are opening their minds to meditation, and the MS community is joining right in.

### A growing body of evidence

A recent Northwestern University clinical trial looked at a randomized group of 121 people with MS who received stress management therapy—which included relaxation techniques and meditation—for 16 sessions during a 24-week period. MRIs showed that the therapy reduced the incidence of two types of brain lesions in MS by more than 20 percent. However, the study, published in the July 11 issue of **Neurology**, also showed that the improvements didn’t last after the stress management therapy ended, reinforcing the notion that meditation should not be used **in place** of standard MS treatments, and that meditation is most helpful when used on an ongoing basis.

In a 2010 Swiss study of 150 people with MS, 74 received usual care while 76 were enrolled in eight weekly group-therapy sessions that included training in mindfulness-based meditation—a technique aimed at creating awareness and acceptance of moment-

to-moment experiences, with the goal of reducing reactions that may worsen any pain or emotional distress that occurs from health-related changes. The meditation participants reported significantly improved health-related quality of life, depression and fatigue.

Dr. Frederick Foley, director of neuropsychology and psychosocial research at the Multiple Sclerosis Comprehensive Care Center at Holy Name Hospital in Teaneck, N.J., developed an interest in meditation after his own 1987 study of cognitive behavior and relaxation therapy showed reduced anxiety and depression in people with MS, as well as increased coping mechanisms.

Over the years, Dr. Foley has recommended meditation to many of his patients. “This is not an alternative treatment,” Dr. Foley says. “This is a standard approach to reduce psychiatric symptoms. This is mainstream now.”

### Getting the reward

Laurie Mischley, ND, a naturopathic physician who works solely with patients who have neurological disorders, such as MS, at the Seattle Integrative Medicine clinic, has seen the research but would also like to see more work done to fully understand meditation’s impact.



“I had a patient tell me, ‘All I know is that when I meditate, I like myself so much better,’” Dr. Mischley says. “Clearly, that’s a good thing, but that’s hard information to know how to evaluate clinically. Does that go to quality of life? Does it go to depression? Does it go to anxiety? How do we chart that? We haven’t studied all of it.”

Rosalind Kalb, PhD, a clinical psychologist and vice president of the Professional Resource Center at the National MS Society, raises a similar point.

“Some people report that this kind of mindfulness or meditation activity makes them feel very good,” Dr. Kalb says. “One of the challenges is that if you do this for 30 minutes a day every day and you feel less fatigue, for example, it’s hard to know if you’re feeling less fatigue because you’re meditating or you’re building 30 minutes of rest into your life. We need more studies to answer these questions.”

Still, Dr. Mischley doesn’t hesitate to discuss meditation

with patients. As she sees it, meditation should be more widely accepted as a way to help people with MS because learning and practicing meditation costs little or nothing (some people may learn meditation in a class or consultation that incurs a fee). Also, meditation doesn’t interact with other medications and treatments.

“The disease isn’t going anywhere, so why wait before employing something that’s simple and inexpensive?” Dr. Mischley says. Of course, people with MS looking to explore meditation—or any other complementary therapy—should first discuss it with their healthcare providers.

### In the beginning

There are many forms of meditation. For some people, learning a basic form of mantra meditation (see “Many paths to meditation,” pg. 40)—commonly described as focusing your conscious awareness on a sound, word or phrase to eliminate distracting thoughts—is their best option. For others, meditation can be prayer, or focusing on their breath or footsteps. Others free their minds working in their gardens or listening to music.

The wide range of techniques gives people with MS any number of avenues to find something that works for them.

## Many paths to meditation

Many styles of meditation have developed over thousands of years. Experiment to find which style works best for you.

**Guided meditation** is sometimes referred to as guided imagery or visualization. In this kind of meditation, a person forms mental images of places and situations that relax them, sometimes with the help of a teacher or guide.

**Mantra meditation** involves repeating a word or phrase, silently or aloud, to ward off distracting or anxiety-provoking thoughts, and to achieve stillness. This may include a technique commonly known as transcendental meditation.

**Mindfulness meditation** means a person increases awareness and focuses on living in the moment. Practitioners center on what they experience during their sessions, sometimes by focusing attention on their breathing.

**Movement meditation** teaches a practitioner to focus on breathing while performing slow, fluid movements. Movement meditation can be as simple as walking, but may also include techniques from yoga, tai chi and qi gong.

Source: [MayoClinic.com](http://MayoClinic.com)

Finding the right method can be a task, but Dr. Foley says physicians can help recommend something that matches a person's symptoms. For instance, someone with cognitive impairments may be matched with a form of meditation that doesn't require concentrating for long periods of time. Other symptoms, such as anxiety, could respond to mindfulness-based forms of meditation.

Once a person with MS settles on a technique, it's important to start off with a good dose of patience. Most

people teaching meditation recommend starting with a few minutes a day and working up to 20 to 45 minutes a day.

Most positive results happen after several months of practice, so people should be prepared to stick with it even if they don't feel any effects right away.

"You can't just try it once and move on. It requires practice and training in order to get good enough at it to get the benefit," Dr. Kalb says.

Lynne Shinto, ND, associate professor of neurology at Oregon Health and Science

University in Portland, Ore., says there are benefits to learning meditation in a group setting, where participants can gain insight from others with similar symptoms and experience.

"Social interaction is hugely important in health," Dr. Shinto says. "Any way we can foster social interaction and support systems is a good thing. For meditation, there is a shared group experience that empowers the whole group. And once the courses are over, people know each other and call on each other to help each other out. It's a resource network."

The Society offers information on stress reduction and alternative therapies. For more information, call 1-800-344-4867.

Maureen Manley, a wellness coach who was diagnosed with MS in 2001, teaches meditation during her "Empowered Living" classes. Her practice of meditation has not only helped her with her physical symptoms, but has also changed the way she perceives her MS and helped her live a healthier life.

"For a while I was trying to fix the MS, but through the experience of meditation, I found out there was nothing to be fixed," Manley says. "I wasn't battling the MS. I wasn't pushing against it. It's not me against it, it's me **with** it." ■

Nathan Solheim is a freelance writer and editor in Denver.



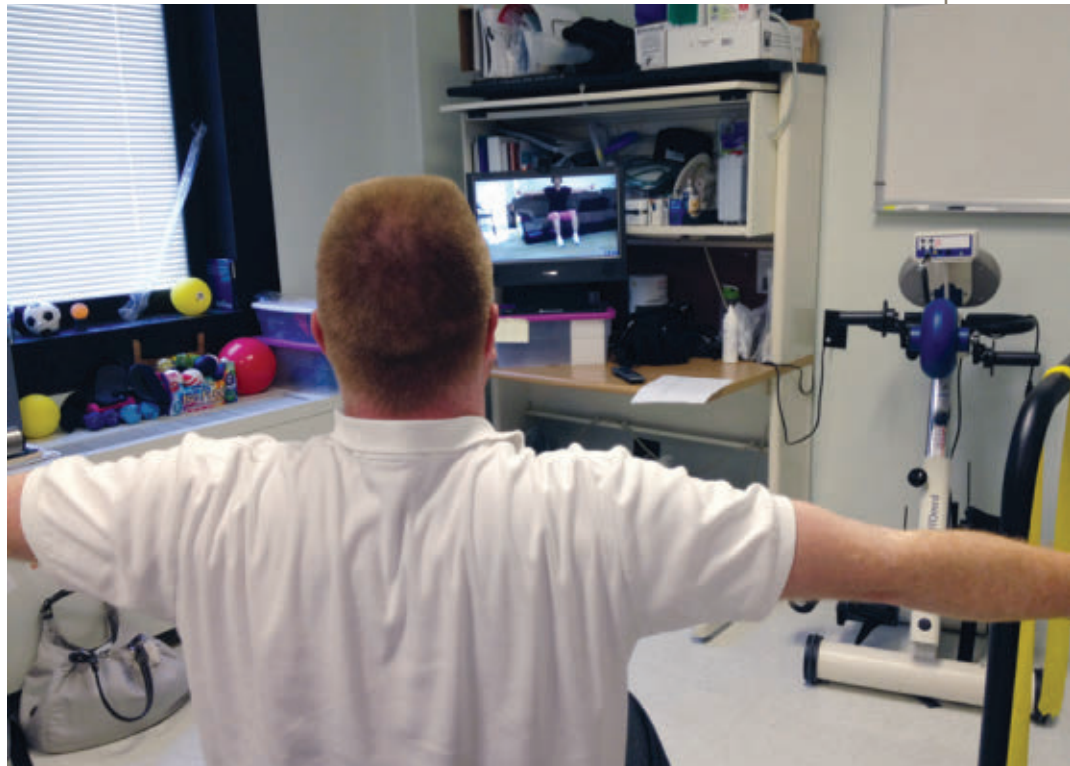
# Telemedicine reaches out

by Stephanie Watson

Michele Wilson, diagnosed with multiple sclerosis in 1991, had such severe numbness, tingling and pain in her left leg that the 47-year-old spent most nights tossing and turning. “Sometimes I’d only get an hour or two of sleep,” she says.

Her neurologist, Paul Hoffman, MD, examined her, testing for ankle clonus (repetitive muscle contractions), watching as she walked and checking her leg for numbness. He recommended pain relievers and physical therapy, which Wilson says have helped tremendously.

But what sounds like a standard office visit was anything but typical. Wilson was at her primary-care doctor’s office in Beverly Hills, Fla., while Dr. Hoffman communicated via monitor and camera from Gainesville, Fla., more than 50 miles away. The virtual visit saved Wilson a long and uncomfortable drive. “When I’m sitting for that long, when I get out, I can barely walk,” she says. “My legs are so stiff.” She’s happy not to travel if she doesn’t have to—and telemedicine offers an alternative.



## An advancing field

Treating patients remotely via videoconferencing and other electronic technology is at the heart of a growing field known as **telemedicine**. While it’s been around since the 1950s, recent technological advancements have made it more affordable and accessible. One study, published in April 2012 in **Multiple Sclerosis Journal**, found that the ease and convenience of telemedicine reduced medical costs and increased patient satisfaction.

Telemedicine’s major advantage is that it can allow

## A veteran with MS participates in a personalized exercise session through televideo.

people with MS to better access top-quality care. “There are a lot of issues for people with MS being able to get to the right doctors, particularly in rural areas,” says Lisa Skutnik, executive vice president of Clinical Programs at the National MS Society. Travel costs, lack of transportation and insurance that doesn’t fully cover out-of-area care all can affect access. “Consequently, some people with MS may only

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see a neurologist once a year or not at all,” Skutnik says.

## Delivering care

Dr. Hoffman is the director of the Veterans Rural Health Resource Center, Eastern Region, which is a division of the U.S. Department of Veterans Affairs, Office of Rural Health. Three years ago, with just five patients, he started the telemedicine program in north Florida that Wilson participated in. Today, the program includes 50 patients at 10 sites across the U.S.

The program uses monitors—each about the size of a computer screen—connected via high-speed Internet. “The lines go from the hub site, where the specialty clinic is, to a community-based outpatient facility—the closest medical office these patients can get to,” Dr. Hoffman says. A trained nurse or physical therapist assists the person with MS in the office, while a neurologist at the specialty clinic directs the exam.

Barbara Giesser, MD, clinical professor of neurology at the David Geffen School of Medicine at UCLA, is also piloting a telemedicine program. “With very few exceptions, we will be able to do all the parts of the neurologic exam,” she says. “I can see the patient speak and

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**Real-time, two-way video could deliver telehealth services directly to people in their homes.**

ask questions, and with a little assistance from someone who is with the patient, I can do the salient parts of the exam. I will make recommendations, and the doctor who is seeing the patient locally will be able to implement my recommendations.”

The next phase of Dr. Hoffman’s VA program is to determine what other types of MS care, beyond a follow-up exam, doctors can provide remotely. “Can we treat acute flare-ups? Can we treat infections?” he asks. “Can we treat wound and bedsore issues? And can we do rehabilitation? Those are some of the questions we will be considering.”

## Telemedicine challenges

Despite telemedicine’s promise, important questions remain about its widespread use. For example: How will doctors

be compensated? Health insurers must determine how much reimbursement the nurse or physical therapist who is working with the patient will receive, and how much will go to the doctor who is working remotely.

The insurance issues don’t end there. “Health insurance companies do not

recognize telemedicine visits as an actual encounter, so there is a reimbursement problem,” says Dr. Gabriel Pardo, director of the Oklahoma Medical Research Foundation’s Multiple Sclerosis Center of Excellence, also where a pilot telemedicine project is being tested. However, Medicare may cover telemedicine services if a person lives in what is considered a “healthcare shortage area.” It may also be possible to negotiate reimbursement from private health plans in some cases.

One more big issue is licensing healthcare providers. “Under the current law, in order to practice medicine in a given state, you need to be licensed in that state,” explains Ted Thompson, the Society’s vice president of Federal Government Relations. Will a doctor who is licensed in California, for example, be allowed to treat patients via telemedicine in Arizona?

One possible solution is to create a national licensure standard, which would enable doctors to treat patients in any state. Another idea calls for prohibiting denial of insurance reimbursement based on a patient's location. "There are a number of efforts on the legislative and regulatory ends to make this easier," Skutnik says. Find out how you can get involved at [nationalMSSociety.org/advocacy](http://nationalMSSociety.org/advocacy).

#### Future of the field

Despite these issues, telemedicine holds tremendous promise in treating people with MS. "I

### Telemedicine can help deliver quality care to people with MS who live in hard-to-reach areas.

think that there will be a number of places where telemedicine will be used for ongoing MS care," Skutnik says. "It's been on everyone's radar screen for the last three or four years."

Telemedicine programs may eventually expand to assess patients at home—both to monitor their health and to help them adapt their homes

to better accommodate their physical needs. "It potentially has a lot of applications that will simplify the process and save money through the system as a whole," Dr. Pardo says.

For now, the doctors exploring the uses of telemedicine say they intend to continue. "We're dipping our toe in the telemedicine waters, but hopefully they will expand and grow and flourish," Dr. Giesser says. "Access to care is one of the most important things we do, and this is a great step forward." ■

Stephanie Watson is a freelance health writer based in Atlanta.



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***— Kristie Salerno Kent,  
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AMPYRA® (dalfampridine) is indicated as a treatment to improve walking in patients with multiple sclerosis (MS). This was demonstrated by an increase in walking speed.

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Do not take AMPYRA if you have ever had a seizure or have certain types of kidney problems. The risk of having a seizure is higher in patients with certain types of kidney problems. AMPYRA should not be taken with other forms of 4-aminopyridine (4-AP, fampridine), since the active ingredient is the same. AMPYRA may cause serious side effects, including kidney or bladder infections. The most common side effects of AMPYRA include urinary tract infection, trouble sleeping, dizziness, headache, nausea, weakness, back pain, and problems with balance. The majority of side effects reported in the clinical trials were mild and transient. Take AMPYRA exactly as your doctor tells you to take it. Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you miss a dose of AMPYRA, do not

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**For more information, please see the complete Medication Guide on the next 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.**



## **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 do I take AMPYRA?”

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

### **What is AMPYRA?**

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

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

### **Who should not take AMPYRA?**

**Do not take AMPYRA if you:**

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

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

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

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

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

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

### **How should I take AMPYRA?**

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



**What are the possible side effects of AMPYRA?****AMPYRA may cause serious side effects, including:**

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

The most common side effects of AMPYRA include:

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

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

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

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

**How should I store AMPYRA?**

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

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

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

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

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

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

**What are the ingredients in AMPYRA?**

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

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

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Issued 07/2012

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U.S. Patent Nos.: US 5,540,938 and US 5,370,879

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T H E R A P E U T I C S

## Robin McGraw leads by example

by Gary Sullivan

Ten years ago, Robin McGraw knew several people living with multiple sclerosis, although he knew little about the disease. As a paramedic fluent in French, McGraw was hired in 2002 by the Tyler Hamilton Foundation to act as the medical director for its first MS Global ride, which wound its way through France, Germany and Switzerland.

"I was there to assess and treat anyone who had an accident or injury," he recalls. "Five riders had MS, and over the two-week ride, I got to know them a bit—and what living with this chronic disease was like for them. When I got back to the States, I told the Foundation that I wanted to donate my time rather than be paid for it."

Three weeks later, McGraw accompanied his wife to her high school reunion. "I was sitting on a couch having a beer with two women whose husbands had been in my wife's class," he says. "They were best friends and I was telling them about the ride I'd just been on when one of them, her eyes welling up, turned to her friend and said, 'I have MS.' They'd been very close for a decade, but only during this conversation did she feel comfortable revealing a long-held secret to her friend."



PHOTO COURTESY OF GREATER NEW ENGLAND CHAPTER

country. "It was my first board meeting," McGraw recalls, "and the expectation is for new members to listen and learn. But when I heard about this project, I couldn't keep myself silent." McGraw's enthusiasm proved to be contagious.

Now up and running at the Chelsea Jewish Nursing Home's Leonard Florence Center for Living in Chelsea, Mass., the Sonya Slifka House accommodates 10 people living with MS. Each resident has

*"I don't believe there are that many missing pieces in the MS puzzle. I want it eradicated."*

"It was a cathartic moment for us all and I realized I was meant to be involved," says McGraw.

McGraw soon connected with the Society through its office in Boston and began raising funds for MS research and programs benefiting people living with the disease through Bike MS events. He was invited to serve on the Greater New England Chapter's board, where he became an advocate for the creation of the Sonya Slifka House, the first urban Green House in the

a private, accessible bedroom and bathroom, and is served home-cooked meals made on site in the kitchen. They're also able to socialize with guests as they wish, taking advantage of a private meeting space, the patio or the living room and fireplace, as well as all that Boston has to offer. Through advanced interactive technology and a dramatically different administrative structure, the residents have the ability to control much that happens in their lives.



**Left to right: Josh, Robin and David McGraw**

### **NOW means NOW**

Two years ago, McGraw's niece, the daughter of his older brother Josh, was diagnosed with MS in her late 20s. McGraw was able to help guide his family through the initial steps of her diagnosis and treatment. Later that year, while at an MS research conference in New York City, McGraw and his sister-in-law, Sacha, went on a lab tour at New York University that opened their eyes.

"To actually see myelin—the fatty sheath that protects the nerve endings that are destroyed by MS attacks—being created in a petri dish and to watch the effects as it regenerated in lab mice with damaged myelin, was inspiring." McGraw believes it is only a matter of time before researchers will be able to restore the function lost to MS, to stop the disease in its tracks and to put an end to MS forever.

"My brothers and I were taught at a very young age that there is no other way to lead

than by example," McGraw says. "The research has come such a long way and my niece is counting on all of us to join together to finally lick this thing." Last year, McGraw made a \$50,000 gift to the NOW (No Opportunity Wasted) campaign; this year, he and his brothers, Josh and David, through the Donald C. McGraw Foundation,

committed \$1 million to the campaign.

"The reason the campaign is called No Opportunity Wasted is because this has to be done now," McGraw, who is currently a member of the Greater New England Chapter Board of Trustees and the NOW Cabinet, emphasizes. "I don't believe there are that many missing pieces in the MS puzzle. I don't want my niece to have to manage this disease anymore. I want it eradicated. And from everything I've seen and everyone I've talked to, I believe it will be eradicated in our lifetime." ■

Gary Sullivan is content project manager for the Society.

## **Give what you can—NOW**

We have reached the point when individual efforts can be made exponentially stronger through support and collaboration. Stand together with Robin, Josh and David McGraw to raise \$250 million to fuel MS research.

We will focus on all the most promising opportunities. One path unexplored is one too many left behind. We will stop the progression of MS and restore everything people have lost. Anything less is not far enough. And NOW, we will end MS forever, so that everyone is safe in the future.

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Visit **[nationalMSSociety.org/now](http://nationalMSSociety.org/now)** or call 1-800-344-4867 to take the first step and give what you can.



## Answering the call

by Jaclyn Muff

**W**e were celebrating the highly anticipated arrival of my soon-to-be-born nephew when I answered the phone call that would redefine my life.

Earlier that summer, as the Midwest temperatures soared, my level of fatigue did too, prompting my first visit to a neurologist. When the neurologist called back with my test results, my sister was busily unwrapping a blue crocheted baby blanket. While she was gleaming at the thought of swaddling a new delicate life with its softness, I was feeling as though my life was ending, as I heard the words: **lesions, positive spinal tap, multiple sclerosis.**

I was not a stranger to the disease, or else I would have attributed my fatigue to my busy lifestyle. MS had sent my once-healthy dad to a nursing home during what should have been his prime years. He passed away due to complications from the disease just four weeks shy of my 10th birthday. Now here I was, only nine years later, learning that I, too, might suffer in the same ways he did.

Before the phone call, I was excited about my future: I was looking forward to the birth of my nephew, returning to Westminster College in Fulton, Mo., to begin my sophomore

year, and being one step closer to medical school—a plan I'd nurtured since childhood. After the phone call, I only wanted to go home and mourn in my mom's arms, which I did for days. My dreams of becoming a physician turned into nightmares shortly after my diagnosis. Just weeks before, I had been determined and unstoppable. Now I felt limited and unmotivated.

The advice filtering in from every direction was that I should choose an easier career. No one wanted to watch me struggle with the mounds of studying, the long hours during residency or the stress of a physician's life. Even though I had thrived on late-night studying for a heavy load of academic classes during high school and my freshman year of college, I feared that the same stress now would pose a risk for an exacerbation. Not to my surprise, the day I decided to hang up my dream of wearing a stethoscope, the only response I heard from friends and family was, "It's probably for the best."

Three years and one exacerbation later, I graduated college with a 4.0 GPA and an acceptance into Saint Louis University, where I planned to earn my Master of Public Health (MPH) degree. During those last moments of my senior year at Westminster College, I heard the wise words of Mattie J.T. Stepanek, a young boy who lived with a rare neuromuscular



PHOTO COURTESY OF JACLYN MUFF

## I almost lost my first battle with MS: the right to make my dreams come true.

disease. He said: "Choose to inhale. Do not breathe simply to exist." It was in that moment that I realized I had made the wrong decision, and in that moment I realized I had almost lost my first battle with MS: the right to make my dreams come true. From that moment forward, I decided I wanted to live my life in pursuit of my dreams and not in the shadow of my diagnosis.

During this next year, not only am I finishing my MPH,

but I am also applying to medical schools. I will have important decisions to make, from whether to disclose my diagnosis in my application to determining whether a cooler climate (to minimize my heat-induced fatigue) should play a role in my school selection process.

Though it is a journey I have waited to begin since I was a little girl, I still struggle with doubts over whether I am making the correct decision for myself and my future. I often

find myself wishing my dad were still with me so I would have someone who understands my challenges and could confirm that I am doing the right thing. In those moments, though, I try to remember my dad's determination after he was diagnosed with MS. When I think of that, I cannot imagine him advocating a passive future for his daughter. Now I am at a fork in the road again, but this time, I am choosing the path I have long dreamed of. ■

Jaclyn Muff is a graduate student in St. Louis. She was diagnosed with MS in 2008.

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## Health coverage: What's next

by Marcella Durand

**M**any provisions of the Affordable Care Act will kick in Jan. 1, 2014, but others take effect earlier. This means you should expect some changes in your health insurance plan as you enroll or re-enroll this fall. Here are a few to look for.

### Making coverage understandable

For people who are covered through an employer's plan, the most noticeable change affecting open enrollment is the new Summary of Benefits and Coverage.

The summary, which went into effect Sept. 23, provides standardized information about what a particular plan covers and how it will work, making it simpler to compare plans and understand coverage options better. "Whatever choices you are making will be much clearer," says Kimberly Calder, the Society's director of Federal Health Affairs and Insurance Policy.

The summary includes a glossary (see "Defining the terms," pg. 53), a chart illustrating what the plan covers and excludes, plus coverage examples of common medical conditions. Perhaps most important, the summary provides

all this in understandable language with no fine print.

### Red flags

Even though the summary goes a long way toward helping people understand their coverage better, Kris Erickson, senior health insurance manager for the Society, recommends that people with multiple sclerosis be very careful as they enroll or re-enroll. "Make sure you take the time to review your options," she cautions.

Watch out for:

- Caps on prescription drug coverage
- No coverage of injectable medicine
- Co-insurance instead of copayments

"Instead of people paying \$30 at a pharmacy as a copayment, they may be required to pay 20 to 30 percent of a medication instead, if the plan stipulates

co-insurance," says Erickson. "This happens with medications in specialty tiers, such as disease-modifying therapies, a lot." Therefore, if you have the choice, consider choosing **direct co-pay**. Also examine the plan's **formulary**, which lists which drugs are covered and for how much.

### Getting credit

The Summary of Benefits is now included in all private individual and group plans. However, employers aren't **required** to offer health insurance. While larger employers have received tax advantages for some time for offering health coverage, and have generally been more likely to offer health insurance, there are some options if yours doesn't.

"If your employer is a small business, ask them about the **small-business tax credit**," Erickson recommends. "As





a result of the ACA, small-business employers can now receive substantial tax rebates for supplying health insurance to employees.” Businesses that employ fewer than 25 employees can receive a credit of up to 35 percent of the overall cost of providing health insurance (for certain plans). In 2014, that number will increase to 50 percent. For nonprofit organizations, the credit is less, but still substantial—25 percent now, and 35 percent in 2014. Your employer can learn more at [healthcare.gov/using-insurance/employers/small-business/index.html](http://healthcare.gov/using-insurance/employers/small-business/index.html).

If you are coming out of an employer plan, “COBRA is an option,” says Erickson. And if COBRA is coming to an end, she recommends calling your state’s division of insurance to see if an extension or subsidy for COBRA premiums is available.

### Pre-existing condition coverage

In 2014, discrimination against pre-existing conditions—such as MS—by health insurance companies will be officially prohibited. However, it’s still 2012 and that prohibition currently applies only to children up to age 19. Until it goes into effect for everyone, people with MS who have been denied coverage can explore the Pre-Existing Condition Insurance Plan, or PCIP. For information, go to [healthcare.gov](http://healthcare.gov) and search for “PCIP.” Then click on

## Defining the terms

As the ACA takes effect, you will begin to see some of the following standardized terms used in health insurance plans.

**Co-insurance:** The percentage of allowed charges for covered services that you’re required to pay. For example, health insurance may cover 80 percent of charges for a covered hospitalization, leaving you responsible for the other 20 percent.

**Copayment:** A flat dollar amount you must pay for a covered program.

**Deductible:** The amount you must pay for covered care before your health insurance begins to pay.

**Formulary:** A list of drugs your insurance plan covers. A formulary may include how much you pay for each drug. (If the plan uses “tiers,” the formulary may list which drugs are in which tiers.)

**Out-of-pocket limit:** The maximum amount you will have to pay for covered services in a year. Generally, this includes the deductible, co-insurance and copayments. This definition may vary from plan to plan.

“Pre-Existing Condition Insurance Plan” for a clickable map of the United States. Click on your state for information about premiums, out-of-pocket costs and how to apply.

### Medicare

This year, people using Medicare won’t see many changes, although they will continue to receive the benefits added to Medicare since the ACA was enacted, including certain screening tests and vaccines, and major discounts on drugs they need while in the Medicare coverage gap, otherwise known as the “donut hole.” However, Erickson points out, “In 2012

and beyond, ACA provisions address the providers’ side, such as linking payments to quality outcomes.”

This year’s open enrollment period for Medicare began Oct. 15 and continues until Dec. 7. To compare drug and health plans, visit [medicare.gov](http://medicare.gov).

### Learn more

To learn more about provisions of the ACA and what they mean for your healthcare coverage, visit [nationalMSsociety.org/ACAFAQs](http://nationalMSsociety.org/ACAFAQs). Or call an MS Navigator® at 1-800-344-4867. ■

Marcella Durand is on the editorial staff for **Momentum**.

# Major Challenges

## When, why and how to hire in-home help

by Kelly Nieuwejaar

**F**or some people living with multiple sclerosis, deciding when and if to hire help at home isn't always easy. But there are things to think about that might help you and your loved ones make that decision. First, you deserve quality hands-on care, and help managing your symptoms when you need it. You also deserve a safe environment and greater accessibility. And, perhaps most important, you need to preserve your time and energy to pursue interests and activities that

give value to your life.

If your needs are no longer being met, for whatever reason, then the time may be right to look into help at home. "Give it a chance. Make it part of being good to yourself," says Marie Cooper, diagnosed with MS at age 50. "Save yourself for something you enjoy."

### The first step

Up front, it's important to evaluate your needs to understand what kind of

home care you will require. Some people need help with activities of daily living, such as dressing and bathing, or light housekeeping, while others might require ongoing skilled nursing services.

For ideas on how to self-assess, start with the Society booklet "Maximizing Independence: A Guide to Planning for Changing MS Care Needs," at **[nationalMSSociety.org/changingneeds](http://nationalMSSociety.org/changingneeds)**.

Healthcare providers or social service professionals can provide more formal assessments. "One's physician or neurologist is usually aware of their patient's needs and can provide input on the kinds of services he or she might require," says Dorothy Northrop, MSW, ACSW, vice president of Research and Clinical Operations for the Society. "Independent, community-based care managers can also go into a home and do an assessment of need, not only in terms



of direct care needs, but in terms of eligibility for a range of services and interventions. This professional expertise is particularly helpful if someone doesn't know where to start and is coping with a broad range of issues," says Northrop. Managers would then recommend a variety of interventions and supports that could improve the situation, such as an occupational therapy evaluation, adaptive equipment or a medical consultation. Call an MS Navigator® at 1-800-344-4867 for referrals.

### Next step planning

Planning for the cost of in-home help is the next—and for some the most challenging—step. Medicare, Medicaid, private health insurance and Society programs are key avenues to explore for financial assistance.

**Medicare.** "You have to meet certain criteria to be covered," says Kris Erickson, senior health insurance manager at the Society's Information Resource Center. Specifically, someone has to be largely restricted to home, under a physician's care, and require medically necessary skilled nursing or therapy services.

If you qualify, you'll receive a set number of hours per week of fully covered home healthcare.

**"Nurses and physical therapists can be very helpful connecting you to what you need. So make the connection."**

Care must be provided through a Medicare-certified home health agency for reimbursement, and assistance with activities of daily living is not covered. (The "Medicare and Home Health Care" booklet, available at **Medicare.gov**, defines what is and isn't covered.)

Find a certified home health care agency using Medicare's Home Health Compare tool at **Medicare.gov/HomeHealthCompare/search.aspx**. For added peace of mind, check to see if the agency is accredited by organizations such as The Joint Commission (**jointcommission.org**) or the National Association for Home Care & Hospice (**NAHC.org**). Some states also require that agencies comply with licensure regulations, making them subject to regular reviews. Past reviews are available upon request from your state's health department.

**Medicaid.** States are mandated to provide home health assistance through Medicaid to individuals who receive

federally assisted income maintenance payments, such as Social Security Insurance, and to those who are "categorically needy," which includes individuals with disabilities whose

incomes are too high to qualify for mandatory coverage, but are below federal poverty levels.

Many states offer additional assistance under Home and Community-Based Waivers. In many cases, it helps to be persistent, as Marie Cooper discovered. A few months ago, she went to her county's social services office in New Jersey, but was told that she didn't qualify for any programs. So Cooper got to work. "I wrote an email to my county's assemblyman and things moved quickly from there," she says. "I'm now on Medicaid and I found out that I also qualified for a county waiver program called Global Options. Today I receive 18 hours a week of home health aide care. I also qualify for a day program and take advantage of a wonderful meal-assistance program."

"Medicaid programs can come under various names depending on the state. In California, it's called Medi-Cal and in Tennessee, it's TennCare," says Erickson. "Depending on state regulations, you may be able to qualify for up to 24 hours of in-home care per day."



## Options at home

Learn more about in-home care:

- Read the Society's brochure "The Basic Facts: Hiring Help at Home" at **[nationalMSSociety.org/hiringhelp](http://nationalMSSociety.org/hiringhelp)**.
- Call an MS Navigator® at 1-800-344-4867 for referrals and more.
- Find out about respite care services at **[respitelocator.org](http://respitelocator.org)**, and long-term care options, including cost calculators and estimated costs by state, at **[longtermcare.gov](http://longtermcare.gov)**.
- If you or your loved one is a veteran, visit the Veterans Administration's A-Z Health Topic Finder at **[va.gov/health/topics/](http://va.gov/health/topics/)**. Click on H, then "Home Health Care."

To find out more about your state's program, visit **[Medicaid.gov](http://Medicaid.gov)**.

### Private coverage

Coverage and financial assistance through private health insurance

companies varies from policy to policy. "Some have great coverage and some have no coverage at all," Erickson says. "Call your insurance provider to find out what it offers."

### Hiring on your own

If you're not using Medicare or Medicaid, you can either hire privately, or use an agency. Agencies take on the administrative burden of hiring and billing, including background checks. Hiring privately can be less expensive and offer greater control, but you are responsible for ensuring that your hire's background is clean and that he or she has the skills in place to best serve you.

Susan Skoney, diagnosed with MS in 1999, considers her home health aide, Lori, whom she pays out of pocket, to be a part of her family. "Lori is my right hand," she says. "I need her to do a lot for me physically, from helping me get in and out of the shower, to doing my laundry and taking me to my physical therapy appointments." Skoney says her previous aide, now employed as a physician's assistant, helped her find Lori. "She contacted her aunt, who was a nurse at a local hospital, who put us in touch with another nurse who knew a network of private home care providers. Nurses and physical therapists can be very helpful

connecting you to what you need. So make the connection," she says.

Skoney's advice is to find someone with whom you're compatible, and to be honest. "You're with this person for hours every day. Some days I have a hard time brushing my teeth. You have to tell them exactly what you need to make it work. If you aren't hitting it off with the person, don't be shy about changing. They have to be able to focus on you."

The National Family Caregivers Association (**[nfcacares.org](http://nfcacares.org)**) is a good place to start learning about hiring independently. The site addresses liability issues and concerns, tax and legal implications, the importance of checking personal references and conducting background checks, and much more.

Making the decision to hire help at home isn't always a simple one, but as Sir Francis Bacon once said, "Knowledge is power." In this case, the more information you can uncover, the more in control you'll become—control that can lead to a positive experience for both you and your loved ones. ■

Kelly Nieuwejaar is senior writer and communications manager for Kemp Goldberg Partners in southern Maine, where she lives with her husband, Khoren, diagnosed with MS in 2001.

**Research Now** is a special feature of **Momentum**, produced by the Society's Research Programs Department.

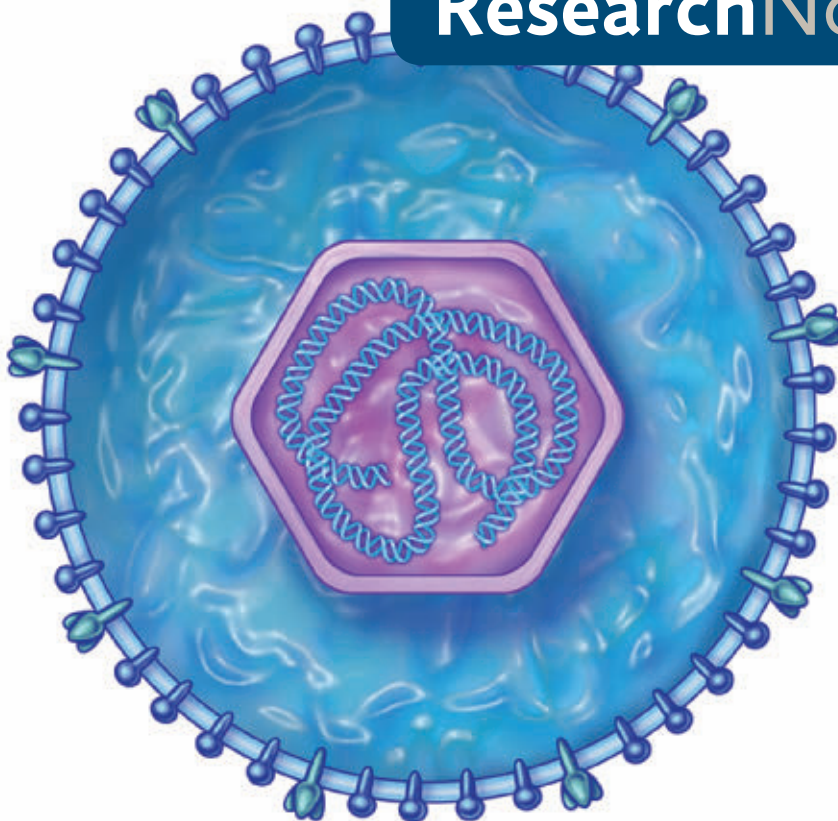
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Information

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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.



## Does a virus help trigger MS?

by Sara Bernstein

People have long wondered whether a virus might be responsible, at least in part, for causing multiple sclerosis. In 1958, people with MS asked their physicians to administer a rabies vaccine, in the hopes that it would neutralize a rabies virus that was believed to be involved in MS (**British Medical Journal 1958;1:7–9**). As we now know, that belief was mistaken. More

than 50 years later, we have a much better handle on what viruses—and other factors—may be involved in MS, and how they may trigger or contribute to the disease.

### Why look to a virus?

We know something in the environment triggers MS. For example, the identical twin of someone with MS, who shares

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virtually all the same genes, has only a one in four chance of developing the disease, suggesting that factors other than genetics are involved.

Another reason is that data from epidemiological studies (studies that analyze the geographical, socioeconomic, genetic and other factors that may contribute to who gets MS) suggest that exposure to an infectious agent may be involved in triggering the disease. And immune system proteins that are typically found in the spinal fluid of people with nervous system diseases that are known to be reactions to viruses are also found in the spinal fluid of 90 to 95 percent of people with MS.

That said, researchers have yet to pinpoint a single virus as the trigger for MS. Several viruses have been studied, but proving a cause-and-effect relationship between any virus and MS requires many research steps. One of these steps is to show that the virus is in the body before MS develops. We also need to show—and this is the most difficult step—that the virus actually **causes** the disease, and is not just happening alongside the disease.

Certainly, the virus that has come the longest way on this road is the Epstein-Barr virus.

**The case for Epstein-Barr**  
Epstein-Barr virus (EBV) is known to cause infectious

mononucleosis and other disorders. Most everyone has been exposed to EBV, though not everyone develops an illness from it. Key studies from Alberto Ascherio, MD, DrPH, and his team at the Harvard School of Public Health, have made EBV the front-runner for a virus involved in MS.

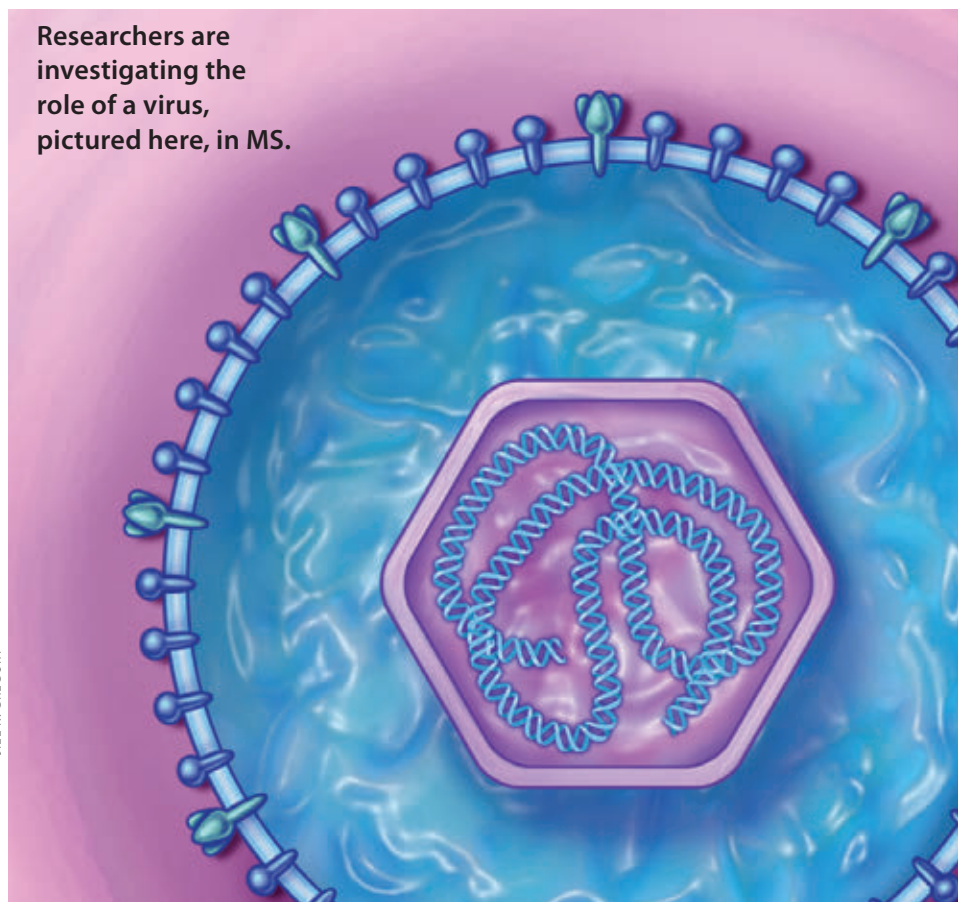
- Dr. Ascherio and colleagues examined stored blood serum samples that had been collected from several large groups of individuals who were then followed for the occurrence of MS. Antibodies (immune proteins that indicate a person has been exposed) to EBV were significantly higher in people who eventually developed MS than in control

samples of people who did not get the disease (*JAMA* 2001; 386:3083; *JAMA* 2005;293:2496; *Archives of Neurology* 2006;63:839).

- The group also identified 305 cases of definite or probable MS in electronic databases of the U.S. Army and Navy. For each case, they obtained up to three blood samples (the earliest and latest available, as well as a third interim sample) from each person, and compared MS development and EBV infection in each case with two people who did not have MS. MS risk increased significantly following EBV infection. They found evidence that EBV preceded MS—the first step toward

Researchers are investigating the role of a virus, pictured here, in MS.

JILL K. GREGORY





showing a causal relationship (**Annals of Neurology** 2010;6:324).

- The team also has investigated how EBV may interact with genes or other risk factors in the development of MS. They reported that people who had a specific immune-related gene **and** high levels of antibodies to EBV in the blood serum were nine times more likely to develop MS than those without that gene and with low levels of viral antibodies (**Neurology** 2008;70:1113–18). In another study population, they showed that current or previous smokers with the highest levels of EBV antibodies were 70 percent more likely to develop MS than those with neither risk factor (**Neurology** 2010; 74:1365).

These studies provide intriguing evidence that EBV plays some role in MS, although that role is still unclear.

Dr. Ascherio is now funded by the National MS Society and the National Institutes of Health to evaluate blood samples and data from more than 1,600 people who were followed since displaying early symptoms of possible MS. His team is evaluating the effects of vitamin D levels, EBV infection and cigarette smoking on whether these early symptoms eventually turn into MS and how rapidly they do so.

### HHV-6 and MS

Human herpes virus 6 (HHV-6) has also been tagged for possible involvement in MS, specifically with triggering exacerbations. Steve Simpson, PhD, and colleagues at the Universities of Tasmania and Melbourne examined HHV-6 antibody levels in blood serum samples taken from 145 people with MS, who were followed for three years.

The results, published earlier this year, show that HHV-6 antibodies were associated with a higher risk of relapse. Also, antibody levels were nearly three times higher in women with progressive MS. Although the findings need to be confirmed, the team suggests that tracking HHV-6 antibodies may help to predict the clinical course of MS (**Multiple Sclerosis** 2012;18:799).

### Taking virus research deeper

Advances in technology are helping MS researchers look for viral clues. John Kriesel, MD, and his colleagues at the University of Utah received a grant from the Society to use novel genetics technology to determine the presence of a virus that has not yet been associated with MS—the hepatitis G virus. “Subtractive sequencing” is a powerful new technology that allows researchers to detect millions of different RNA molecules in a single specimen. RNA, or ribonucleic acid, is

the chemical that delivers the instructions from a gene to a cell. In subtractive sequencing, investigators can subtract human RNA, leaving thousands of nonhuman, possibly disease-causing, RNAs.

Dr. Kriesel’s team applied subtractive sequencing to brain specimens taken from people who had MS during their lifetimes, and specimens from controls without MS. Although the hepatitis G virus was found in just one sample, the team concluded that this is a powerful new tool for revealing novel viruses that may not yet have been associated with MS (**PLoS ONE** 2012;7:331886).

Others are investigating the idea that perhaps it’s not a virus itself that causes MS, but some immune response triggered by viruses. Stephen Miller, PhD, at Northwestern University, led a team funded by the Society to investigate why some strains of mice infected with Theiler’s murine encephalomyelitis virus (TMEV) develop an MS-like disease, but others do not.

The results are intriguing. In mice bred to be susceptible to the disease, the immune response led them to produce “Tregs”—a type of immune cell usually known for **suppressing** the immune attack in MS. In these mice, however, Tregs actually interfered with the anti-virus response, lessening its effectiveness, while mice that lacked the Tregs could

fight off the virus (**Journal of Autoimmunity** 2011;36:142). The team is exploring its findings further, as they shed new light on how an immune attack may result from viral infection.

## Raising the bar

When researching viruses and other risk factors, it's important to study large numbers of people for a long time. Emmanuelle Waubant, PhD (University of California at San Francisco), is leading a nationwide study in which 640 children who have early MS or are at high risk for the disease are being followed for four years to determine how viruses and other environmental and genetic risk factors make children susceptible to developing MS. Their results will be compared with those from 1,280 children without MS. The five-year, \$3.2 million grant from the NIH is based on data collected by the Society's Network of Pediatric Centers of Excellence, which showed that in children, certain viruses were associated with MS risk (**Neurology** 2011;76:1989–1995).

These and other studies are getting us closer to determining what causes MS by identifying triggering factors, thereby increasing the possibility of preventing MS. Read more about what causes MS on our website: [nationalMSSociety.org/Causes](http://nationalMSSociety.org/Causes). ■

## In the news and on our website



### STOP Fast Forward partners to prevent MS disability

Fast Forward LLC, the Society's commercially focused drug development enterprise, is partnering with Merck Serono to support Axxam SpA, a company that is developing compounds to help prevent disability in MS. Early studies show that blocking CLIC1—a small protein in certain brain cells—may protect nerve cells from damage. Axxam SPA is developing a cutting-edge method of screening for molecules that can block CLIC1, which can then undergo further testing. This work could lay the groundwork for new ways to protect against nervous system damage in MS.



### STOP Gilenya prescription information revised

Prescription information for the oral MS therapy Gilenya (fingolimod, Novartis) has been revised to define who should avoid using it. The recommendation will be based on a person's pre-existing medical conditions, and updates recommended testing and heart monitoring that occurs when the first dose is given. The revision was made after independent safety reviews initiated by the agencies when deaths had been reported among

patients taking Gilenya. Read more at [nationalMSSociety.org/gilenya](http://nationalMSSociety.org/gilenya).



### STOP Misdiagnosing MS

A diagnosis of MS sometimes occurs in people who are later found to not have the disease. A team at Oregon Health and Science University evaluated survey results from 122 doctors specializing in MS to find out why and how often this happens. The results showed that 95 percent of the survey respondents had encountered at least one patient who had been misdiagnosed with MS. An editorial that accompanies the study's publication recommends that physicians perform thoughtful and complete assessments of symptoms and laboratory results when making a diagnosis, and that there should be a high level of confidence in the diagnosis before a person goes on long-term disease-modifying therapies. ■

Read more news  
and details of  
these stories at  
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# The science of MS and bone health

by Sara Bernstein

We've long known that multiple sclerosis takes its toll on the nervous and immune systems, and that decreased activity or corticosteroid treatments related to MS can reduce bone density, too. But now, new research shows that MS itself affects bone health.

## Study: Bone affected early

In 2011, a team from Oslo University Hospital measured bone density in 99 people newly diagnosed with MS, or with clinically isolated syndrome (CIS), a first episode of MS-like symptoms. They compared the results with those from 159 controls without MS and also administered a questionnaire concerning risk factors for osteoporosis (a disease that causes bones to thin).

More than half of the people with MS or CIS had low bone mass, compared with 37.1 percent of control participants, even after adjusting for other possible risk factors. (**Neurology** 2011;77:151). The authors conclude that these findings call for people with MS to think about protecting bone health

when they are first diagnosed with the disease.

## What causes early bone loss in MS?

To understand how early bone loss may happen in MS, we need to understand a little about how bones are formed. Two cells are primarily responsible for this process: osteoblasts, which help to build bone tissue, and osteoclasts, which remove it, to control the amount of bone that is formed.

Recent findings indicate that T cells—immune cells

involved in the attack on the brain and spinal cord in MS—stimulate proteins that increase osteoclasts, resulting in too much bone removal. High levels of these proteins have been found in people with MS, even in the early stages of the disease, indicating that T cells may be affecting bone as well (**Multiple Sclerosis** 2008;14:431).

On the other hand, cells that suppress the immune attack in MS may **improve** bone health. For example, Tregs—regulatory T cells that can “put down” attacking T cells in MS—actually prevented bone loss in animal models of arthritis (**Biochemical and Biophysical Research Communications** 2010;402:173).

People with MS should think about protecting bone health when they are first diagnosed.



## Taking care of your bones

Why is this research important? It shows us the urgency of taking care of your bones along with your MS. You can build healthier bones by avoiding things that cause bone loss (smoking, alcohol consumption) and embracing things that increase bone density, such as calcium and vitamin D intake and exercise (weight bearing, flexibility or resistance activities). Read more at [nationalMSSociety.org/osteoporosis](http://nationalMSSociety.org/osteoporosis). ■



### Society research: More than test tubes

by Timothy Coetzee, PhD

A few months ago I received a letter from a long-time supporter who asked, “Why is the Society funding research to assess the impact of out-of-pocket health-related costs on people with multiple sclerosis and their families?” He wondered why we would commit funds to a project that, while possibly important, wouldn’t lead to a cure for MS. He challenged us to explain why we don’t just pour all of our resources into laboratory research.

At the Society, we take a comprehensive approach to research, and focus most of our efforts and resources on innovative projects to stop progression, restore function and end MS forever. However—while we work to free the world of MS—we need to ensure that people who live with the disease now have access to high-quality treatment and care.

To advocate with insurers, agencies, legislators and others, we need verifiable statistics and data on the true impact of policies that may put people with MS at a disadvantage for accessing medical care and therapy. Even if we discover all of the answers tomorrow, we will still need to figure out how people can get affordable access to everything.

Our Health Care Delivery and Policy Research (HCDPR) program addresses these and other concerns. Led by the Society’s Vice President of Healthcare Delivery and Policy Outreach, Nicholas LaRocca,

PhD, this program invests \$1 million to \$2 million each year in research projects that help us understand how MS affects people in their daily lives. Some of the research questions we’ve addressed through this program include:

- How cost-effective are the FDA-approved MS disease-modifying therapies?
- What are the experiences

of people living with MS in nursing homes?

- How do we effectively measure quality of life for people with MS?

The HCDPR program was responsible for the design and launch of the Sonya Slifka Longitudinal MS Study—the

If we discover the cure tomorrow, we will still need to figure out how people can get access to it.

first study of its kind in MS—which tracked a large, diverse sample of people with MS to understand how the disease influences daily life, how effective treatments are, and how people with MS utilize healthcare. The information we gathered in this study fueled efforts to improve quality of life for people with MS and helped us advocate for changes in policies with state and federal governments.

We strive to balance our research portfolio so that we are serving the needs of everyone living with MS now, while also investing in the laboratory research that brings us closer to the day when MS is a thing of the past. ■



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



## In the pipeline for MS: Rehab by phone

### Why use telephone-delivered programs?

Rehabilitation programs can help people with multiple sclerosis achieve their highest potential—be it physical, psychological, social or vocational—using innovative techniques that can restore function. Such programs, of course, are most helpful if they're also accessible to people with impaired mobility or to those who live too far away from a treatment center. Telephone-delivered programs can often fill these gaps. (For more on accessing care remotely, see “Telemedicine reaches out, page 41).

### What does the research show so far?

Researchers at the MS Rehabilitation Research and Training Center at the University of Washington in Seattle reported on two studies of phone-based programs in 2008. In one study of 130 people with MS, participants showed significant improvements in fatigue, mental health and participation in health-promoting activities (e.g., physical activity, spiritual activity and stress management) after a single in-person motivational meeting followed

by five counseling sessions by phone (**Archives of Physical and Medical Rehabilitation** 2008;89:1849).

In another study, 101 people with MS participated in a single face-to-face session with a rehabilitation specialist, who taught them to implement a home exercise plan, and then participants had eight follow-up phone sessions. Participants in this group showed significant reductions in depression, which was the primary outcome measured by the investigators (**Abstract #P13, Consortium of MS Centers Annual Meeting**, 2008).

These studies suggest that phone-based programs can provide an accessible option for improving health and quality of life for people with MS.

### What are current studies in this area?

Now this team is conducting two trials of phone-based programs, both funded by the National Institutes on Disability and Rehabilitation Research. Both have completed enrollment and the investigators are analyzing the data.

**“Take Charge” Study:** This study is comparing the effects of two phone-delivered

programs targeting people's ability to independently manage pain, fatigue and depression. The team enrolled approximately 200 people nationwide with any type of MS. Participants were randomly assigned to one of two “self-management” approaches, both involving eight phone treatment sessions.

**“InMotion” Study:** This study was designed to determine whether two phone-coordinated exercise programs can improve depression. Investigators recruited 108 people nationwide with any type of MS or spinal cord injury. Participants were randomly assigned to one of two groups. In one group, a study counselor helped participants to develop a personalized exercise program, and provided follow-up phone counseling sessions. In the other group, participants received one phone session only, during which a counselor reviewed how to exercise safely and find exercises that suit individual needs.

The results of these studies may provide more evidence for the value of telephone-delivered rehabilitation interventions.

Read more about research to restore function in people with MS on our website at **[nationalMSSociety.org/research/restore](http://nationalMSSociety.org/research/restore)**. ■

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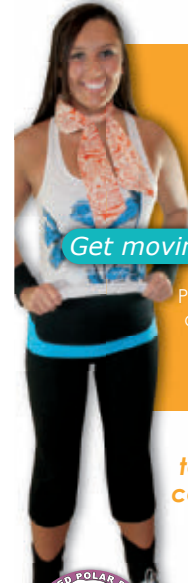
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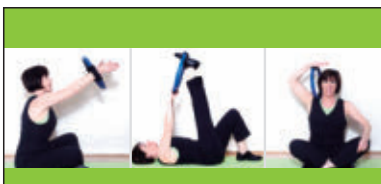
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## Keeping an even keel

**B**alance issues are among the most common symptoms in MS (see “The balancing act,” p. 34). There are lots of ways to lose your footing in life, though, and many of them don’t have anything to do with physically standing up.

For example, we know that simple, everyday activities, like showering or picking up the

bending exhaust you? Or could you save your energy for things that add value to your life—maybe taking a class or having a date night?

Balancing what you need with the needs of your family and friends can be difficult for everyone. People affected by MS commonly tell me that because basic activities do take more time, they feel obligated

connections outside of family as well. At the National MS Society, we strive to be a catalyst to connect people, not just with information, but with each other—in whatever way is most comfortable. Our newest online resource, **MSconnection.org**, enables engagement where you can create and deepen meaningful relationships with others. People who prefer to talk on the phone can call 1-866-673-7436, and start connecting with another person like them through our peer program, **MSFriends**. If you’d rather attend an educational program or participate in a social activity, we create those kinds of experiences as well. No matter what, you have a partner in managing MS—and in keeping your balance. ■



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If we have honest conversations with the people who are most important to us, they can help us achieve balance in our lives.

mail, take more energy when you have MS. Over the years, I’ve met many people who have given up doing things they enjoy so that they have enough energy to meet their perceived obligations—and in the process, they sometimes throw their lives off balance.

To get back on an even keel, people may need to change their view of what’s critically important in life. It was a lesson that was important for me to learn when I had children, and it can be even more challenging when you add MS into the mix. You may need to reconsider: Is it essential that your house be clean at all times if reaching and

to devote any “spare” time to loved ones and their needs, and this can cause stress or a sense of inadequacy. But I’ve learned that if you talk with your family about what’s important to them, you may discover that much of that stress is self-imposed—that they don’t care if dinner is ready at 6 p.m. sharp, and that they’d fully support you taking an hour after work for a nap or a yoga class, or whatever sustains **you**. If we have honest conversations with the people who are most important to us, they can help us achieve balance in our lives—and that, in turn, strengthens our connections to them.

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