

The magazine of the National Multiple Sclerosis Society

# Momentum

SPRING 2013

Speaking the  
language of MS

~~~~~  
El idioma de  
la esclerosis  
múltiple

PAGES 17 AND 19  
EN INGLÉS Y  
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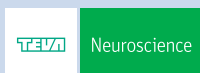
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## Readers report on MS and art

Nearly 200 people responded to our  
survey on art, and more than half  
(55%) said they regularly engage  
in some type of visual art, such as  
painting or photography. Many (45%)  
also like to write and another 46% play  
or create music. Most (88%) began  
their creative pursuits before they were  
diagnosed with MS, but many have  
found ways to continue engaging their  
passions. "I play flute," says one reader.  
"There are small plastic plugs that I  
use when my fingers are numb (about  
90% of the time) and I can't feel where  
the holes are to cover." Stay tuned for  
an article about art and MS in the  
Summer issue of **Momentum**.

### My creative pursuit helps me to:

Find an outlet for my emotions **79.7%**

Take my mind off my MS

**60.5%**

Feel more in control of my life

**52.0%**

Boost my self-esteem

**64.4%**

**I've been able to find adaptive tools or  
techniques that allow me to continue  
my art or craft despite my symptoms.**

Yes

**53.4%**

No

**46.6%**





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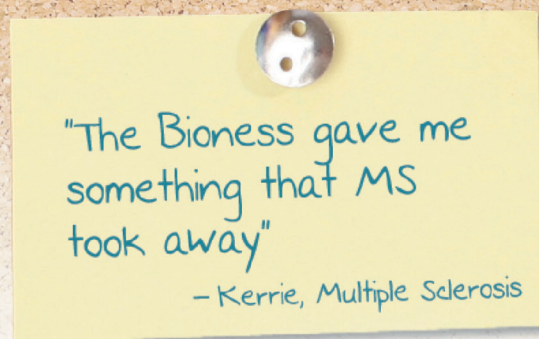
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# Momentum

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

Spring 2013  
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Three generations of an Hispanic family that lives with MS. From l to r: Julia, who was diagnosed with MS at age 12, her mother, Ana, and her grandmother, Divina.

Tres generaciones de una familia hispana que vive con esclerosis múltiple. De der. a izq.: Julia, quien recibió el diagnóstico de esclerosis a los 12 años, con su madre, Ana, y su abuela, Divina.

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**Momentum** explores how MS affects the Hispanic/Latino community.

by Elinor Nauen, with Gary Sullivan

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**Momentum** explora el efecto de la esclerosis múltiple en la comunidad hispana/latina.

por Elinor Nauen, con Gary Sullivan

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MS cuts across boundaries.

Increasingly, Walk MS teams do, too.

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## Monthly National eNEWS

Get the latest on MS research, advocacy efforts and more.

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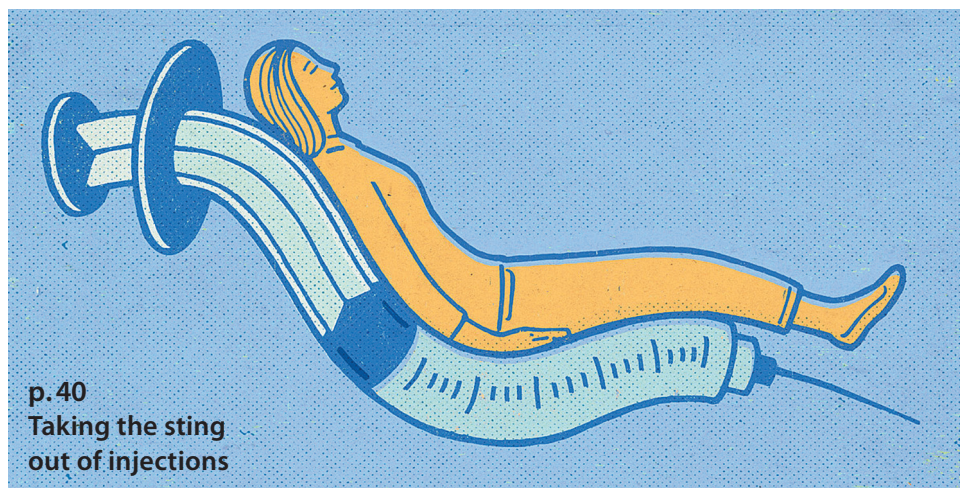


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In the news and on our website





## 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.

## Clarifying the doctor's role

In "Banking on a life with MS" (Fall 2012), the author describes the SSDI/SSI disability process as one that "involves your doctor presenting your case to the Social Security Administration." While the doctor(s) frequently plays a critical role in the disability claims process, SSDI/SSI cases are—for good reason—presented by attorneys (and occasionally non-attorney advocates). In 32 years of disability practice, I have never heard of an instance in which a physician "presents" a case to the government. On the other hand, I'm happy to

report that most of my clients' neurologists and family physicians have been good patient advocates.

David S. Bross, Esq.,  
New Jersey

## A misleading statistic

I am concerned about your use of the statistic in "Banking on a life with MS," which states that, on average, a person with MS leaves the work force 10 years after diagnosis. I do not see the value of creating a numerical average for this situation when so many conditions influence the need to leave the work force. I believe the statistic irresponsibly disregards such factors as age, severity of disease, field of work, household income or disability discrimination. I am a dedicated fan of **Momentum** and feel educated and empowered when I pore over its resources in each issue. But this statistic is not the kind of useful knowledge that we all depend on.

Christy, via email

## 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.

## Momentum wants to know

about your cognitive challenges  
[nationalMSSociety.org/cogchallenges](http://nationalMSSociety.org/cogchallenges)

Editor's note: While statistics never tell the full story, particularly for a disease like MS that is, by its nature, highly variable, they can be useful guideposts, and can help emphasize the importance of planning for the future—because there's no way for any individual to know how long he or she will be able to remain in the work force. For more detailed information about employment and finance issues, please visit [nationalMSSociety.org/employment](http://nationalMSSociety.org/employment) or call 1-800-344-4867.

## More caregivers with MS

Thank you to letter-writer Susan Alonso from Connecticut ("When the caregiver has MS," Fall 2012). I am 50 with relapsing-remitting MS. I have a family and my parents are four minutes away, but I am with them at least two times a day. They are both in their late 80s and one has Alzheimer's. I am their sole caregiver. I think it's actually making my cognition issues worse because I have to keep track of so much. I can only keep praying and having faith that God believes I can

do this. Because most of my symptoms are invisible, everyone thinks I will be fine. There needs to be some type of support for us caregivers with MS.

Anna Siegel, via email

### More support needed

The article, “MS activists on the frontline,” (Summer 2012) says, “The Lifespan Respite Care Program is a critical service that enables caregivers to receive support and often permits people with MS to live at home longer.” Apparently, that support was **not** enough to keep Kim and Gary Campbell (“A short guide to long-term care,” Fall 2012) from losing their house and cars when Kim needed full-time assistance because of her MS, and Gary had to quit his job. What did members of Congress say when MS activists told them that the Lifespan Respite Care Program did not provide enough support to help Kim and Gary Campbell?

Rose G., Illinois

Editor’s note: The Lifespan Respite Care Program, which supports family caregivers, has been severely underfunded by Congress since its inception. Despite this, state grantees have made great progress, including creating public awareness programs and online respite directories. The Society continues to advocate for annual funding for Lifespan Respite, so it can provide family

caregivers the support that they need. MS Activists most recently lobbied legislators for \$5 million for Lifespan Respite at the Society’s 2012 Public Policy Conference. While Congress has not finalized FY 2013 funding, the Senate Appropriations Committee approved \$4.99 million for Lifespan Respite. The Society will continue to advocate for this funding as the FY 2013 budget is finalized. To help us advance this critical cause, visit [nationalMSSociety.org/advocacy](http://nationalMSSociety.org/advocacy).

### Two tattoos

The article “A Deeper Tattoo” (Fall 2012) hit very close to home. I was diagnosed with MS five years ago at the age of 48. Two years ago I wanted to get a tattoo. I did a lot of research and came up with a cross, and my daughter Koren wanted to support me by getting the same one. We now have them on our lower necks. I chose the placement because MS can be in the spine and brain. By having the cross placed there, I am asking God to watch my back (and head).

Janet Pardiak, Michigan

## Coming this Summer: Disclosing Your MS

- The ifs, whens and hows of disclosure—on the job
- and in your life.



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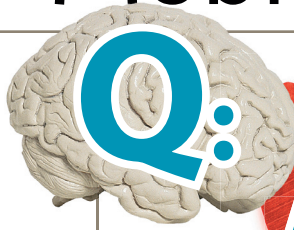
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# Mobility **ALERT**




## Taking steps A: toward better gait

by Laura Putre

**C**ecilie Fjeldstad, PhD, an exercise physiologist and senior researcher at Sisters of Mercy Health System in Oklahoma City, has been studying gait problems related to multiple sclerosis since 2006.


### **Q: How does MS affect a person's gait?**

 **A:** The neurological impairment that occurs in MS can affect multiple components of the nervous system, including both the sensory and motor systems as well as the cerebellar system, which regulates coordination. If all the components of the nervous system are not working together properly, a person may display spasticity, muscle weakness or vision disturbances, any of which can lead to impaired gait.

The most common gait problem in MS is foot drop. This weakness in the ankle occurs when the nerves don't properly tell the muscles to flex, and the person has trouble lifting one or both feet. Foot drop alone can alter the mechanism of gait and lead to knee and hip joint pain as well as increased risk for falls.


Spasticity, or an excess of muscle tone, can also significantly affect the ability to walk, even if you don't have muscle weakness.

### **Q: What kind of doctor should people with MS see for walking problems?**


 **A:** Usually a neurologist will address MS comprehensively. The neurologist may refer a person to other providers, such as a physiatrist (a physical medicine and rehabilitation doctor),

an orthopedic surgeon, a physical therapist or an exercise physiologist.

### **Q: How do you determine what course of treatment to take?**


 **A:** We have to figure out exactly why someone is having difficulty walking and whether that difficulty can be helped through medication or assistive devices like electronic stimulators.

### **Q: What do electronic stimulator devices do and how helpful are they?**

 **A:** Electronic stimulators, like the Bioness L300, for instance, have a gait sensor that attaches to the wearer's shoe and sends information to a cuff on the calf, telling it whether the heel is on the ground or in the air and what sort of surface is being walked on. A cuff that goes under the knee contains electrodes that deliver stimulation where it's needed. This can help with foot drop, and some of our patients use this system, along with a cane, for support when walking.

I don't know, percentage-wise, how effective it is, but we've worked with a number of people here who seem to be very happy with it.

### **Q: How helpful is exercising?**

 **A:** Increasing muscle strength through physical activity can be very beneficial. Usually with physical activity, we see an improvement in gait and an increase in balance. We also see an increase in quality of life and a decrease in depression. But anyone starting any kind of


physical activity should talk to a healthcare provider first about safety limitations.

People with MS often have trouble with heat, and some people avoid physical activity because it increases body temperature, and can exacerbate symptoms. When this happens, it's common to think the disease is getting worse. But actually it's just the symptoms, which go away once a person cools down.

I sometimes recommend aquatic exercises or resistance exercises with weights because they don't increase the body temperature as much as, say, running. People can also try activities that can increase balance, such as yoga or just stretching on a mat.

Biking can be a good idea because it doesn't increase body temperature as much as running does. Not only that, it's easier on your knees.


### **Are there any promising new medications for gait?**

 **A:** Ampyra, which was approved by the Food and Drug Administration (FDA) in 2010, is a pill you take twice daily that's been demonstrated to improve walking in people with MS. It seems to be quite effective, but some people do not respond as well as others. I know of cases where a person has been on it and then taken off it because it doesn't seem to be working. But sometimes when the person goes off the medicine, you really can tell the difference.


Baclofen or tizanidine can improve muscle tone and improve walking in some people with spasticity. Some people may consider having a baclofen pump surgically implanted to deliver medication straight to the spinal cord and reduce the amount of medication needed. The pump needs to be refilled every six months or possibly sooner, depending on the dose and rate of infusion. But it tends to result in fewer side effects than oral antispasticity medications, which can cause drowsiness or dizziness. This is because a person can receive the same beneficial effect at a far lower dose by pump than by mouth.

In some instances, Botox injections may be used to reduce or eliminate the spasticity of a specific muscle group in any limb. It can improve the functional use of the limb and reduce the risk of developing contractures (the permanent shortening or stiffening of muscles). However, doctors can't control the degree of weakness or paralysis the injection may induce. It also takes a week to see the benefit and the effects wear off after three to five months.

### **What kind of MS research have you been doing?**

 **A:** We have been doing quite a bit with a NeuroCom balance machine. It's a platform with sensors underneath that detect sway when a person is walking on it. Often, swaying is kind of hard to see if the person just walks up and down a hallway during an exam. But we're actually getting numerical data when we put someone on the platform. It not only detects the sway, but it also delivers information about stride length, step length, foot angle, step time (how fast you're walking) and swing time (how long your leg is in the air during a step).

### **Is there anything else people with gait problems should keep in mind?**

 **A:** It's important to get active early on in the disease process to minimize long-term disability. But to do that, a person needs to have sufficient muscle strength and balance. Work with your healthcare team to find the safest, most effective way for you to develop those assets—and get moving. ■

Laura Putre is a Cleveland-based writer whose work appears in health-related publications.

## **Additional resources**

The National MS Society's **Free from Falls** program includes a DVD and booklet that may be useful in reducing falls and improving gait. To order, call 1-800-344-4867 and select option 1.




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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.



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# 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.

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



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

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

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

GILENYA may cause serious side effects, including:

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

**You should stay in a medical facility for at least 6 hours after you take your first dose of GILENYA.**

After you take your first dose of GILENYA:

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

Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA.

Call your doctor or go to the nearest emergency room right away if you have any symptoms of slow heart rate.

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

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

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

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

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

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

**What is GILENYA?**

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

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

**Who should not take GILENYA?**

Do not take GILENYA if you:

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

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

**What should I tell my doctor before taking GILENYA?**

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

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

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

For more information, you can call the GILENYA Pregnancy Registry at 1-877-598-7237 or visit [www.gilenyapregnancyregistry.com](http://www.gilenyapregnancyregistry.com).

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

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

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

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

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

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

### How should I take GILENYA?

- Your first dose of GILENYA will be given in a medical facility where you will be watched for at least 6 hours after your first dose of GILENYA. See **“What is the most important information I should know about GILENYA?”**
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- If you start GILENYA again after stopping for 2 weeks or more, you will start taking GILENYA again in your doctor's office or clinic.

### What are possible side effects of GILENYA?

GILENYA can cause serious side effects.

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

Serious side effects include:

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

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

The most common side effects of GILENYA include:

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

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

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

### How do I store GILENYA?

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

### General information about GILENYA

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

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

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

### What are the ingredients in GILENYA?

**Active ingredient:** fingolimod

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

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

GILENYA is a trademark of Novartis AG.

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## Settlement reached in Medicare lawsuit

In October, a proposed settlement was reached in a nationwide lawsuit that challenged the Centers for Medicare & Medicaid Services' (CMS) practice of denying Medicare coverage to people unable to show improvement after certain skilled care services.

The so-called "Improvement Standard" particularly affected people with chronic diseases such as multiple sclerosis, for whom skilled services such as home health care and therapy are often necessary—and expensive. The National MS Society joined other organizations such as

the Parkinson's Action Network and Paralyzed Veterans of America as a plaintiff in the class-action suit.

As of press time, the settlement was awaiting approval by Chief Judge Christina Reiss of the U.S. District Court in Vermont. Once approved, it will effectively end use of the Improvement Standard. Medicare coverage standards will instead be based on people's need for skilled care, regardless of whether they show improvement. The change, which applies to Medicare and

to private Medicare Advantage plans, vastly benefits people with MS and their families, helping place needed services back in their reach.

"This is a very significant step in a long process that is leading us toward a just settlement for Medicare beneficiaries living with MS and other chronic illnesses," said Cyndi Zagieboylo, president and CEO of the Society. "They will now continue to receive important needed healthcare services as a result."

To follow the settlement's progress, visit **[www.MSActivist.org](http://www.MSActivist.org)**. ■



### Save the date: MS Awareness Week, March 11–17

Mark your calendars to move us closer to a world free of MS.  
The Society's year-round awareness campaign kicks off March 11.  
Call 1-800-344-4867 or visit **[MSConnection.org](http://MSConnection.org)**  
for ideas on ways to join the movement.

COURTESY OF THE SOUTH CENTRAL CHAPTER

# Speaking the language of MS

Multiple sclerosis doesn't discriminate. **Momentum** explores how MS affects the Hispanic/Latino community.

by Elinor Nauen, with Gary Sullivan



DAVID GODIUS. BACKGROUND: IHOR\_SEAMLESS/VEER



**T**reating multiple sclerosis, as far as Dr. Alicia M. Conill is concerned, is about much more than just taking medication.

“Illness is not simply a biological process,” she says. “How you view things socially, culturally and societally plays a role in how you deal with the disease.”

Dr. Conill, a retired primary care physician and member of the National MS Society’s Hispanic/Latino Advisory Council, was diagnosed with MS in 1987 when she was 30. Born in Havana, Cuba, she is quick to point out that there is no single Hispanic/Latino culture. “We come from many different areas of the world,” she emphasizes. “But a basic sense of family, tradition and loyalty threads through our different branches.”

Indeed, “The terms ‘Hispanic’ and ‘Latino’ are social constructs, with little biological basis,” says clinical psychologist Ron Durán, PhD, who is an associate dean at Alliant International University, and also a member of the Society’s Hispanic/Latino Advisory Council. “We’re black, Caribbean, mestizo, Native, white. What it comes down to is self-identity and key shared values.” Those shared values deeply affect the experience of living with the disease.

### Not a ‘Viking disease’

For a long time, healthcare professionals assumed that MS was uncommon in the Hispanic/Latino population. When Jessica De La Peña was diagnosed at age 27, “One doctor actually asked me, ‘Why do you have a Viking disease?’”



Ana Franco and her daughter Julia Laureano, who was diagnosed with MS at age 12 and is legally blind, take a stroll with Julia’s guide dog, Dogo.

“In our community, you don’t hear the words ‘multiple sclerosis,’” De La Peña, a teacher in Porterville, Calif., who is now 41, says. “I sometimes think my grandmother has it, based on her symptoms. It makes me wonder how many other Hispanic people are out there who might not know why they have their symptoms.”

A 1978 survey in **Neurology** that examined MS-related deaths in California found that people with Spanish-sounding last names had lower MS mortality compared with the others in the

# El idioma de la esclerosis múltiple

La esclerosis múltiple no discrimina.  
**Momentum** explora las formas en que afecta a la comunidad hispana/latina.

por Elinor Nauen, con Gary Sullivan

**E**l tratamiento de la esclerosis múltiple conlleva mucho más que tomar medicamentos, opina la Dra. Alicia M. Conill. “La enfermedad no es simplemente un proceso biológico”, afirma. “Tu forma de ver las cosas en términos sociales, culturales y como sociedad influye en la manera en que le haces frente a la enfermedad”.

La Dra. Conill, ex médica de cabecera y miembro del Consejo Asesor sobre Asuntos Hispanos/Latinos de la Sociedad Nacional contra la Esclerosis Múltiple (National MS Society), recibió el diagnóstico de esclerosis múltiple en 1987 cuando tenía 30 años. Oriunda de La Habana, Cuba, señala rápidamente que no existe una sola cultura hispana/latina. “Provenimos de muchas diferentes regiones del mundo”, recalca. “Pero un espíritu básico de familia, tradiciones y lealtad es común en todas las diversas ramas”.

En efecto, “los términos ‘hispano’ y ‘latino’ son productos sociales, con poco fundamento biológico”, afirma el psicólogo clínico Ron Durán, PhD, quien es decano adjunto de la Alliant International University y también miembro del Consejo Asesor

sobre Asuntos Hispanos/Latinos de la Sociedad. “Somos negros, caribeños, mestizos, autóctonos, blancos. Se trata de una identidad personal y los valores fundamentales que compartimos”. Esos valores comunes afectan profundamente la experiencia de vivir con una enfermedad.

## No es una ‘enfermedad de vikingos’

Durante mucho tiempo, los profesionales de salud daban por hecho que la esclerosis múltiple era poco común entre los hispanos/latinos. Cuando se la diagnosticaron a Jessica de la Peña a los 27 años, “Un médico incluso me preguntó, ‘¿Por qué tienes una enfermedad de vikingos?’”

“En nuestra comunidad, no se oyen las palabras ‘esclerosis múltiple’”, afirma de la Peña, maestra de 41 años de edad de Porterville, California. “A veces pienso que mi abuela la tiene, debido a sus síntomas. Esto hace que me pregunte cuántos otros hispanos por allí quizá no sepan por qué tienen los síntomas que tienen”.

Una encuesta realizada en 1978 y publicada en **Neurology** que examinó las muertes relacionadas con la esclerosis múltiple en California descubrió



study. Dr. Lilyana Amezcua believes the survey “might have led to less attention being paid to this population in terms of potential MS diagnosis.”

Dr. Amezcua, an assistant professor of clinical neurology at the University of Southern California’s (USC) MS Comprehensive Care Center in Los Angeles, says she hears a lot of “Why me?” from people. “They mean, ‘Why me when all the data about prevalence isn’t about me?’”

But recent studies conducted by Dr. Amezcua and others are showing an increase in the number of people throughout Latin America who have MS—a figure that is rising faster than the growth rate of the region’s total population.

### Can ancestry define the disease?

A small pilot study published in **Ethnicity & Disease** in 2010 found racial and ethnic differences in MS disease characteristics and treatments between Hispanics/Latinos, African-Americans and non-Hispanic Caucasians. For example, a larger proportion of Latinos reported normal function for mobility and for bladder and bowel function. According to a separate survey of 99 Hispanics/Latinos who were enrolled in the North American Research Committee on MS (NARCOMS) patient registry, more Hispanic people reported experiencing fatigue, cognitive symptoms, mental health problems and pain than did non-Hispanic people with MS.

Dr. Amezcua is delving further into differences within the Hispanic/Latino population itself. “For instance,” she says, “we’re looking at disease characteristics in relation to ancestral gene markers,” she says. “Some Hispanics have up to 90 percent European or Caucasian ancestry.”

So far her team has found that individuals with less European ancestry seem to be at increased risk of disability. “This could suggest that the variation in disease characteristics, including treatment response, may be linked to an individual’s background. This is critically important in order to understand treatment failures and differences in disease progression.”

### Culturally competent care

Latinos/Hispanics face a number of potential roadblocks to quality care. These may include language barriers for Spanish speakers, cultural differences that can lead to serious misunderstandings and, for undocumented immigrants, a fear of being deported if they seek medical help, as well as reduced access to programs that provide low-cost MRIs or drugs.

“This is an underinsured population even if they are documented,” says Moyra Rondon, the Society’s senior director of Counseling Programs and Hispanic Outreach for the New York City-Southern New York area. In fact, Latinos/Hispanics have the highest uninsured rates of any racial or ethnic group within the United States,

## A FAMILY OUTING

**T**he Society hosts an annual Day for Hispanic Families living with MS in the New York City area. In 2011, the 147 attendees could choose from a variety of bilingual activities: presentations on Finding the Family’s Strength and on MS pain and its treatment; performances by a Latino comedian and band; and a lunch of traditional Latino food. Kids could participate in interactive learning about MS symptoms plus face painting, arts and crafts and a Zumba dance class. People also were able to pick up bilingual literature about MS, and link to crisis services and support groups. Call the Society at 1-800-344-4867 to learn about programs in your area.

que las personas con apellidos de origen español tenían una tasa más baja de mortalidad debida a la esclerosis múltiple que otros participantes. La Dra. Lilyana Amezcua considera que la encuesta “puede ser el motivo por el que se le presta menos atención a este grupo en términos de diagnóstico potencial de esclerosis múltiple”.

La Dra. Amezcua, profesora adjunta de neurología clínica del Centro de Atención Integral de la Esclerosis Múltiple (MS Comprehensive Care Center) en Los Ángeles de la Universidad del Sur de California (USC), señala que con frecuencia oye a la gente decir “¿Por qué yo?”. “Lo que quieren decir es, ‘¿Por qué yo cuando todos los datos sobre prevalencia no se refieren a mí?’”

Pero investigaciones recientes realizadas por la Dra. Amezcua y otros indican un incremento en el número de personas en toda Latinoamérica con esclerosis múltiple, cifra que aumenta más rápido que la tasa de incremento de la población en general de la región.

### ¿La ascendencia es determinante con la enfermedad?

Un limitado estudio piloto publicado en **Ethnicity & Disease** en el 2010 descubrió diferencias raciales y étnicas en las características y tratamientos de la esclerosis múltiple entre hispanos/latinos, afroamericanos y personas no hispanas de raza blanca. Por ejemplo, una mayor proporción de latinos reportó funciones móviles, intestinales y urinarias normales. Según una encuesta distinta de 99 hispanos/latinos que se inscribieron en el registro de pacientes del Comité Norteamericano de Investigación sobre la Esclerosis Múltiple (North American Research Committee on MS o NARCOMS), más hispanos indicaron sentir fatiga, síntomas cognitivos, problemas de salud mental y dolor que personas no hispanas con esclerosis múltiple.

La Dra. Amezcua investiga más a fondo diferencias específicas entre los hispanos/latinos. “Por ejemplo”, dice, “estamos examinando las características de la enfermedad con relación



Evelyn Velázquez y una amiga disfrutaron del Día para las Familias Hispánicas que Viven con Esclerosis Múltiple del 2012 en Nueva York.



according to the U.S. Office of Minority Health.

Providing culturally appropriate MS care is another challenge because many healthcare providers don't always fully comprehend this population's values, beliefs, priorities and social processes, says Dr. Durán. According to Dr. Durán, key traditional values among Latinos include family, respect for authority, religious faith and good interpersonal relations.

By far the most central is family.

### **Treating the Latino family**

"The Latino family is a big part of treatment, and we need to educate all of them," Dr. Amezcua emphasizes. "They come to appointments and programs. We need community volunteers to talk with them about the disease, to provide social support and to transform medical information into lay language." (See "A family outing," page 20.)

"When I was first diagnosed, I wanted my friend and my mother to accompany me, but I was

allowed only one other person," Dr. Conill recalls. "If members of a Hispanic family find themselves in a space that's not welcoming, if there's no translator, they may decide not to come back. If they already feel like they're on the fringes, they're likely to become alienated and give up on care altogether."

### **The double-edged sword of family**

Society Ambassador and Queens, N.Y., resident Ana Franco says she often faces a lack of comprehension about the disease in the Latino world. Her daughter, Julia Laureano, who is now 21, was diagnosed with MS when she was 12.

"In the Dominican Republic they don't really understand what's wrong with Julia," she explains. "They don't know what MS is—no idea. Sometimes family members will tell her, 'You're so fat!' (she has gained weight due to steroid treatments) or 'You're so clumsy!' It's exhausting to explain every single time to the same people."

Many people deal with what Dr. Durán calls the double-edged sword of family involvement. "Aunts



At the 2012 Day for Hispanic Families Living with MS in New York, Lichiana Amigo, left, adds a bit of heart to the cheeks of a child of someone affected by MS.

a marcadores genéticos ancestrales”, afirmó. “Algunos hispanos tienen hasta 90 por ciento de ascendencia europea o caucásica”.

Hasta ahora, su equipo ha notado que aparentemente las personas con menor grado de ascendencia europea tienden a tener mayor riesgo de discapacidades. “Esto parece indicar que las variaciones en las características de la enfermedad, incluida la respuesta al tratamiento, podrían estar vinculadas a la ascendencia de la persona. Esto es sumamente importante para comprender el fracaso de ciertos tratamientos y las diferencias en el avance de la enfermedad”.

### Atención médica con un entendimiento de la cultura

Los latinos/hispanos enfrentan una serie de obstáculos para recibir atención médica de calidad. Estos pueden incluir la barrera de idioma para los hispanohablantes, diferencias culturales que pueden llevar a malentendidos y, en el caso de los inmigrantes indocumentados, el temor de ser deportados si buscan ayuda médica, como también menor acceso a programas que ofrecen pruebas de resonancia magnética o medicamentos a precios módicos.

“Se trata de un grupo con un nivel insuficiente de seguro médico, incluso en el caso de los documentados”, afirmó Moyra Rondon, directora principal en la Sociedad de los programas de asesoría y extensión a los hispanos en el área metropolitana de Nueva York y el sur del estado de Nueva York. De hecho, la tasa de latinos/hispanos carentes de seguro es más alta que la de cualquier otro grupo racial o étnico de Estados Unidos, según la Oficina de Salud de las Minorías de Estados Unidos.

También es difícil atender la esclerosis múltiple de manera apropiada a la cultura porque muchos proveedores de servicios de salud no entienden plenamente los valores, convicciones, prioridades

## UN PASEO FAMILIAR

La sociedad ofrece un evento anual de un día para las familias hispanas que viven con esclerosis múltiple en la zona metropolitana de Nueva York. En el 2011, 147 participantes tuvieron la oportunidad de escoger entre una serie de actividades bilingües: presentaciones sobre cómo encontrar la fuerza familiar y sobre el dolor resultante de la esclerosis múltiple y su tratamiento; la actuación de un cómico y grupo musical latino, y un almuerzo con comida tradicional latina. Los niños tuvieron la oportunidad de participar en actividades interactivas para aprender sobre los síntomas de la esclerosis múltiple, además de pintarse el rostro, hacer manualidades y tomar una clase de Zumba. Las personas también pudieron recibir información bilingüe sobre la esclerosis múltiple y conectarse con servicios para situaciones de crisis y grupos de apoyo.

y procesos sociales de este grupo, dijo el Dr. Durán. Son valores tradicionales fundamentales para los latinos, afirma, la familia, el respeto a la autoridad, la fe religiosa y las buenas relaciones interpersonales.

Lo más importante, de lejos, es la familia.

### El tratamiento de la familia latina

“La familia latina es un aspecto importante del tratamiento, y es necesario que informemos a todos sus miembros”, enfatizó la Dra. Amezcua. “Vienen a las citas y los programas. Necesitamos voluntarios de la comunidad para que hablen con ellos sobre la enfermedad, brinden apoyo social y pongan la información médica en términos comprensibles”. (Ver “Un paseo familiar”, arriba.)



and uncles are often as important to us as parents,” he says, describing the importance of extended family, “and first cousins might be seen as siblings. When it’s needed, there are a lot of people who can be supportive. But when family members don’t understand your symptoms, they think it’s your will, not your condition. If major caregivers believe that, it can be really awful.”

Another form of social support gone wrong, Durán explains, is when caregivers unintentionally disempower a person by sending invalidating messages, like “Let me do this for you; you’re a sick person and you cannot possibly take care of yourself.” Families need to understand the variability and unpredictability of symptoms, he says.

“The fact is, while there are wonderful programs and a number of therapy choices, this population doesn’t consistently take advantage of them,” Dr. Amezcua says. “MS has not been on their or their families’ radar, so its implications are likely misunderstood.” Having culturally sensitive, readily available Spanish or bilingual materials is essential. (See “En español,” at right.)

“In other conditions, such as diabetes, cancer and cardiovascular disease, we have learned that family involvement can be an important element in treatment success,” she says. “The family studies we’re doing now in MS could help close gaps in care.”

### The role of ‘respeto’

When he was first diagnosed in 2003, Leopoldo Perez, now 36, of Los Angeles, felt very lost. “I didn’t know where to find help,” he recalls. “There were services to help with job rehabilitation, school, where to get medical supplies and other devices that would make my life easier—but none of this was clearly explained. And being from a Mexican family, we were taught to never question authority.”

## EN ESPAÑOL

The Society currently offers 14 brochures in Spanish, including information on the basic facts of MS, disease-modifying medications, fatigue, depression, cognition and bladder problems, as well as guides for children, caregivers, employees and employers. The Society’s Spanish-language webpage ([mueveteMS.org](http://mueveteMS.org)) includes information and videos on diagnosis, treatment, symptoms and more. (Spanish-speakers can call the Society at 1-800-344-4867 and press option 3 to reach a Spanish-speaking MS Navigator.)

**Café con Leche** is a Society program offering free monthly professionally led telephone support groups for anyone affected by MS who speaks Spanish and wants to connect with others. To learn more or to register, call 1-800-344-4867.

Dr. Maria Reyes-Velarde, a physician who lives with MS, has written a book, **Con Los Pies en la Tierra**, and maintains an MS blog at [hablemosdeem.com](http://hablemosdeem.com).

The Society’s quarterly **Conexión Latina** offers education and resources in both Spanish and English. Readers can learn about programs that assist members of the community to live their best lives with MS. Call 1-800-344-4867 for the latest issue.

Dr. Durán says that it’s important to many Latinos/Hispanics to be polite and pleasant to authority figures no matter how much stress they are feeling. What is called “respeto,” or respect, is a significant value for many Latinos/Hispanics. “And who is more of an authority than a doctor?” he asks. Respeto suggests a formal kind of respect (say “yes, sir,” don’t argue), but it does not necessarily translate into cooperation with a service provider or a treatment plan. Hispanics/Latinos may or may not follow a doctor’s advice,



Ana Franco ayuda a su hija, Julia, con sus tareas escolares. Julia vive con esclerosis múltiple y es legalmente ciega.

“Inicialmente, cuando recibí el diagnóstico, quería que mi amiga y mi madre me acompañen, pero solo se permitía a una persona adicional”, recordó la Dra. Conill. “Si los miembros de la familia hispana se ven en un lugar que no es acogedor, si no hay intérprete, es posible que decidan no volver. Si ya se están sintiendo marginados, es probable que se distancien y abandonen el tratamiento del todo”.

### La familia como arma de doble filo

Según Ana Franco, embajadora de la Sociedad y residente de Queens, Nueva York, a menudo nota una falta de entendimiento de la enfermedad en el mundo latino. Su hija, Julia Laureano de 21 años, recibió el diagnóstico de esclerosis múltiple cuando tenía 12.

“En la República Dominicana realmente no comprenden qué le pasa a Julia”, explicó. “No saben lo que es la esclerosis múltiple; no tienen idea. A veces los familiares le dicen, ‘¡Qué gorda estás!’ (ha aumentado de peso debido al tratamiento con esteroides) o ‘¡Qué torpe eres!’ Es agotador explicárselo varias veces a la misma gente”.

Muchas personas enfrentan lo que el Dr. Durán describe como el arma de doble filo de la participación familiar. “Los tíos a menudo son igualmente importantes para nosotros que los padres”, dijo sobre la función de los parientes, “y posiblemente se trate como hermanos a los primos hermanos. Cuando es necesario, hay muchas personas que pueden prestar apoyo. Pero si los familiares no comprenden tus síntomas y piensan que es cuestión de voluntad, no de enfermedad; si los principales encargados de cuidarte creen eso, puede ser atroz”.

Otro tipo de apoyo social que puede ser contraproducente, explicó el Dr. Durán, es cuando quienes cuidan a la persona enferma le envían, sin querer, mensajes que le quitan control y la oportunidad de valerse por sí mismas, como “Déjame hacerlo por ti; estás enferma y no hay forma de que te cuides sola”. Los familiares deben comprender que los síntomas varían y son imprevisibles, señaló.

“La realidad es que a pesar de que existen programas fabulosos y muchas opciones de tratamiento, este grupo no los aprovecha sistemáticamente”, indicó la Dra. Amezcua. “La esclerosis múltiple no ha estado presente en su familia, por lo que es probable que no entiendan sus consecuencias”. Es esencial tener a la mano materiales en español y en inglés, escritos teniendo en cuenta la cultura. (Ver “En español”, pág. 28.)

“Con otras enfermedades, como la diabetes, el cáncer y las afecciones cardiovasculares, hemos aprendido que la participación de la familia puede ser un importante elemento para el éxito del tratamiento”, indicó. “Los estudios familiares que estamos realizando sobre la esclerosis múltiple podrían ayudar a cerrar las brechas en la atención”.

### El papel del respeto

Inmediatamente después de su diagnóstico, en el 2003, Leopoldo Pérez, residente de Los Ángeles



but they are less likely to question it. That's a big problem, Dr. Durán explains, especially when the doctor thinks that nodding means a person is simply agreeing.

"We have to learn to talk back, question and do things that may be antithetical to our basic values," he says. "Latino people have to learn a different way of communicating when working with the medical system. For example, we teach Latinos that in the U.S., physicians expect you to ask questions—it's not seen as disrespectful."

Another approach is to work with healthcare partners who better understand you. Perez, whose parents moved to Los Angeles from Mexico, says he found it very helpful to have a Spanish-speaking neurologist. "I feel like there's cultural empathy, which makes me more at ease. I feel like I'm able to disclose more about my situation and struggles."

### Illness as stigma

Hispanic/Latino people tend to value religious faith, which can help some people cope with living with a chronic disease. But it can have negative repercussions, Dr. Durán says. "Certain religious attitudes may lead some people to feel as though they should quietly bear their suffering, or that they're cursed. If they feel that God is punishing them, there's little they can, or even should, do about their situation."

Religion is not the only source of illness-related stigma, Dr. Amezcua emphasizes. "There's a huge stigma in the community attached to MS symptoms, such as fatigue," she says. "A lot of my patients tell me that their families write them off as being lazy."

Depression is another MS symptom with stigma attached. "The Latin world doesn't always appreciate that depression is a real biological disease and symptom of MS," says Dr. Conill.

"There's more stigma associated with emotional than even physical disease. So people aren't getting relief for their secondary conditions."

Leopoldo Perez says he hid the fact that he was going to see a psychiatrist. "I felt it would be met with resistance from family and friends, who would say, 'You're fine, you're young, nothing is wrong.'"

### Learning more, moving forward

A combination of studies currently being conducted on Latinos/Hispanics with MS, and increased MS awareness in the Hispanic/Latino population, will not only help us understand how the disease manifests itself in these communities, but could bring about quicker diagnoses and improved therapies for everyone.

To contribute to this growing body of knowledge, Latinos/Hispanics can participate in the Hispanic MS Registry, a project maintained by the MS Comprehensive Care Center at USC. Call 323-442-6817, email [mscare@usc.edu](mailto:mscare@usc.edu) or go to [keck.usc.edu/mscenter](http://keck.usc.edu/mscenter).

Meanwhile, Dr. Conill emphasizes a proactive approach to taking care of oneself. "There's no shame in needing or asking for or receiving help," she says, "and it's really important to get the best support possible." An MS Navigator can help anyone get started. Call 1-800-344-4867 (for a Spanish-speaking MS Navigator, choose option 3). ■

Elinor Nauen is a New York-based writer and editor who covers health, sports, science and other topics. Gary Sullivan is the content project manager for the Society.

Daily routine:  
Julia helps her  
mother, Ana,  
prepare meals  
and clean up in  
the kitchen.

de 36 años de edad, se sintió perdido. “No sabía dónde buscar ayuda”, recordó. “Había servicios de ayuda para la rehabilitación laboral, estudios, lugares para obtener suministros médicos y otros dispositivos para facilitarte la vida, pero no se explicaba ninguno claramente. Y como mi familia es mexicana, se me enseñó a nunca cuestionar la autoridad”.

El Dr. Durán dice que para muchos latinos/hispanos, es importante ser corteses y amables con quienes desempeñan papeles de autoridad, independientemente del grado de estrés que sientan. Lo que se denomina “respeto” es un valor importante para muchos latinos/hispanos. “¿Y quién tiene más autoridad que un médico?” preguntó. Ese concepto de respeto implica cierta formalidad (decir “sí, señor”, no discutir), pero no necesariamente se materializa como cooperación con el proveedor de servicios de salud ni el plan de tratamiento. Los hispanos/latinos pueden seguir o no los consejos del médico, pero son menos propensos a cuestionarlo. Eso es un gran problema, explicó el Dr. Durán, particularmente

cuando el médico cree que si una persona asiente con la cabeza, realmente está indicando que está de acuerdo.

“Es necesario que aprendamos a responder, cuestionar y hacer cosas que parecen contradecir nuestros valores básicos”, dijo. “Los latinos deben aprender una manera diferente de comunicarse dentro del sistema médico. Por ejemplo, les enseñamos a los latinos que los médicos estadounidenses esperan que les hagan preguntas; no lo consideran irrespetuoso”.

Otra estrategia es escoger profesionales de salud que los comprendan mejor. Pérez, cuyos padres se mudaron de México a Los Ángeles, dijo que para él es útil tener un neurólogo que habla español. “Siento que hay empatía cultural, lo que hace que me sienta más cómodo. Pienso que puedo divulgar más sobre mi situación y dificultades”.

### El estigma de la enfermedad

Los hispanos/latinos tienden a valorar la religiosidad, lo que puede ayudar a algunas personas a sobrellevar una enfermedad crónica.

Pero también puede tener repercusiones negativas, afirmó el Dr. Durán. “Ciertas actitudes religiosas pueden hacer que algunas personas piensen que deben aguantar el sufrimiento en silencio o que son víctimas de una maldición. Si creen que Dios las está castigando, hay poco que pueden hacer o, incluso, deben hacer con respecto a su situación”.

La religión no es la única fuente de estigmas relacionados con la enfermedad, destacó la Dra. Amezcua. “Existe un enorme estigma en la comunidad relacionado con los síntomas de la esclerosis múltiple, como la fatiga”, afirmó. “Muchos de mis pacientes me dicen que sus familiares los consideran holgazanes”.





## EN ESPAÑOL

La Sociedad actualmente ofrece 14 folletos en español, que incluyen información básica sobre la esclerosis múltiple, medicamentos modificadores de la enfermedad, fatiga, depresión, problemas cognitivos y urinarios, como también guías para niños, cuidadores, empleados y empleadores. La página de Internet de la Sociedad también está en español, ([mueveteMS.org](http://mueveteMS.org)) e incluye información y videos acerca del diagnóstico, tratamiento, síntomas y más. (Los hispanohablantes pueden llamar a la Sociedad al 1-800-344-4867 y escoger la opción 3 para hablar con un MS Navigator en español.)

**Café con Leche** es un programa gratuito de la Sociedad que ofrece grupos de apoyo que se reúnen mensualmente por teléfono bajo la dirección de un profesional para todos los hispanohablantes afectados por la esclerosis múltiple y que quieren comunicarse con otros. Para averiguar más o inscribirse, llame al 1-800-344-4867.

La Dra. María Reyes-Velarde, médica que vive con esclerosis múltiple, ha escrito un libro, **Con los pies en la tierra**, y tiene un blog sobre la enfermedad en [hablemosdeem.com](http://hablemosdeem.com).

La publicación trimestral de la Sociedad **Conexión Latina** ofrece educación y recursos tanto en inglés como español. Los lectores pueden averiguar acerca de programas que ayudan a los miembros de la comunidad a llevar la mejor vida posible con la esclerosis múltiple. Llame al 1-800-344-4867 para recibir el número más reciente.

La depresión es otro síntoma de la esclerosis múltiple que conlleva un estigma. “El mundo latino no siempre comprende que la depresión es una verdadera enfermedad biológica y un síntoma de la esclerosis múltiple”, dijo la Dra. Conill. “El estigma es incluso mayor con las enfermedades emocionales que con las físicas. Por lo tanto, no se están aliviando los trastornos secundarios de las personas”.

Leopoldo Pérez dijo que ocultó el hecho que estaba yendo al psiquiatra. “Pensé que enfrentaría la resistencia de familiares y amigos, que dirían, ‘Estás bien, eres joven, no te pasa nada’”.

### Informarse más, seguir adelante

Una serie de estudios en curso acerca de latinos/hispanos con esclerosis múltiple y un mayor conocimiento de la enfermedad entre hispanos/latinos no solo nos ayudarán a entender las formas en que se manifiesta en estas comunidades, sino que podrían resultar en diagnósticos más oportunos y mejores tratamientos para todos.

Para contribuir a este conjunto de conocimientos en aumento, los latinos/hispanos pueden participar en el Registro Hispano de Esclerosis Múltiple (Hispanic MS Registry), un proyecto del MS Comprehensive Care Center en USC. Llame al 323-442-6817, envíe un mensaje electrónico a [mscare@usc.edu](mailto:mscare@usc.edu) o visite [keck.usc.edu/mscenter](http://keck.usc.edu/mscenter).

Mientras tanto, la Dra. Conill destaca la importancia de actuar con iniciativa respecto al cuidado propio. “Necesitar, pedir o recibir ayuda no debe avergonzar a nadie”, indicó, “y es realmente importante recibir el mejor apoyo posible”. Un MS Navigator® puede serle útil para comenzar. Llame al 1-800-344-4867 (para conseguir un MS Navigator que hable español, escoja la opción 3). ■

Elinor Nauen, escritora y editora que reside en Nueva York, se especializa en temas de salud, deportes y ciencias, entre otros. Gary Sullivan es el administrador de proyectos de contenido de la Sociedad.

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

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

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

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

AMPYRA can cause seizures.

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

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

### What is AMPYRA?

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

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

### Who should not take AMPYRA?

**Do not take AMPYRA if you:**

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

### 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
- Serious allergic reactions, including anaphylactic reactions

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.

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## Ken Regan—meeting people with MS where they live

by Vicky Uhland

**A**fter Ken Regan, vice president of Ardsley, N.Y.-based Regan Development, was diagnosed with multiple sclerosis in 1993, he turned to the National MS Society for help. “I was so pleased with the support and information they gave me at a difficult time in my life that I wanted to give back,” he says. So Regan, whose company specializes in building affordable and special-needs housing, asked Society staff members what they needed. “They told me that every day,

A developer with a heart—and MS—builds accessible apartments to meet an untapped need.

they get calls from people who are not appropriately housed because of their MS—perhaps they live in a second-floor walkup, or their apartment is too expensive—issues like that,” he explains.

With Society staff, Regan helped form a task force of people with experience in accessible housing and MS

to discuss how the Society could do more to meet the residential needs of people with MS. As a result of those discussions, Regan wrote “Developing Housing for the MS Community,” a step-by-step handbook that local builders can use as a guide for financing and constructing accessible housing. In addition, Regan’s company built the first of what he hopes will be many apartment complexes designed specifically for people with MS.

### A ‘commons’ cause

Kershaw Commons in Freehold Township, N.J., opened in 2011 and consists of 30 fully accessible rental apartments with helpful features such as automatic door openers, slide-out shelving in the kitchens and linen closets, accessible light and thermostat controls, and transfer showers.

On site, the Society offers MS-related educational lectures, as well as social programming and support services. In addition, residents are able to access nursing and therapy



Ken Regan visits with Samantha Hicks at Kershaw Commons.

PHOTOS BY MAUREEN KRENZ



professionals specially certified in caring for people with MS, thanks to an arrangement with the Visiting Nurse Association of Central Jersey.

Regan also worked with local county agencies to provide rental-assistance vouchers that ensure that even if residents' employment status changes, they will never pay more than 30 percent of their income on rent and utilities.

Today, Kershaw Commons is so popular that more than 230 people are on a waiting list for apartments. "Some of our residents are in their 20s or 30s, and before they found us, they

thought they would have to live in a nursing home their whole lives," Regan says.

## A labor of love

Regan hasn't stopped with Kershaw Commons. One



**Kershaw Commons in Freehold Township, N.J., was the first of several accessible housing developments that Ken Regan's company developed for people with MS.**

46-unit rental apartment building with six units dedicated exclusively for people with MS is set to open in Bayonne, N.J., this spring. A 28-unit building with 10 apartments for people with MS is under construction in Montvale, N.J., and similar projects are in the planning stages in Connecticut, Pennsylvania and Massachusetts. Regan's company also added several fully accessible units for people living with MS to apartment complexes it built in Fishkill and New Windsor, N.Y. In addition, the Society recently hired a housing development consultant to help chapters team up with other developers like Regan to create accessible living opportunities for their members.

"What it really comes down to is how do we assist people with MS so their overall quality of life improves?" Regan said. "It's exciting to have the opportunity to contribute to this. It's really a labor of love for me." ■

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

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# Widening the Circle of Walk MS

by Patricia Wadsley

Soon after Indianapolis resident Phyllis Pigford-Mason was told she had multiple sclerosis in 2010, she joined an exercise class for people with MS.

“I walked into a roomful of women of all ages and abilities, and they welcomed me with open arms,” she remembers. “It made me realize the disease doesn’t discriminate.”

Phyllis had visited the Society the same day and

MS cuts across boundaries. Increasingly, Walk MS teams do too.

was touched by all the help staff members offered. They suggested Phyllis form a team, so she started with three people from her exercise class and one Society volunteer. “I knew I wanted the team to be diverse,” she says. “I wanted my team to reflect the world around me.”

MS cuts across boundaries, affecting people of every age, ethnic background, income level and religion. These days, Walk MS is widening its circle, as well.



People with MS make up nearly half of FROG through MSI, the team Phyllis Pigford-Mason (far left, second row) started.

JEFF WAGGONER, COURTESY INDIANA STATE CHAPTER



### Going outside the 'comfort zone'

Phyllis was determined to keep growing her team, FROG through MS! (Fully Rely On God through Multiple Sclerosis!). Yet, when one of the women in her exercise class told Phyllis about a support group, she balked.

"I hated the idea of support groups," Phyllis remembers. "I just wanted to learn about new treatments and how to raise awareness. But the 16-year-old daughter of one of the women in my exercise class convinced me to go. It wasn't what I expected at all. Now I go regularly to support groups for support—and to find new team members."

Once Phyllis stepped out of her "comfort zone" to recruit team members, she found almost limitless possibilities. "I've met people who are interested in joining my team in the supermarket, in the museum I volunteer for, and in the most unlikely places. Since I was in the Army, I get my medical care at the VA Medical Center, so I've recruited veterans from there. I keep putting myself out there and taking chances. Now, my team is 40 people strong—16 of whom have MS."

### A common cause

Nowadays at Walk MS events, even severe mobility issues can't keep people away. All of the Society's Walk MS sites are fully accessible. And people can participate online by creating their own fundraising event or walking virtually with a team.

"People have such a great time," Phyllis says. "It's like a carnival. And part of my job is to let my team know how inclusive it is.



They can walk, they can use scooters, walkers, or any mobility aid to help them keep going. I let everybody know there are no hard-and-fast rules or requirements. It's our day and we are united by a common cause."

In Detroit, Marilena David-Martin experienced that unity firsthand. When her husband Alessandro was diagnosed five years ago at age 24, Marilena and the couple's friends and family formed a close-knit circle of support around him. "I guess you can call us a modern family," she says. "My heritage is Mexican and Puerto Rican. My husband is Polish-Italian. One of my best girlfriends is black and her husband is white. And my friend Tara is a Chaldean."

Two years later, that close-knit circle formed Team Alessandro, with Marilena as captain. Marilena regularly sends out emails telling donors and walkers how much money has been raised and about Alessandro's treatments. She also rewards walkers with gift certificates. The team, which now numbers 25, has added members from unexpected places.



COURTESY GREATER ILLINOIS CHAPTER (2)

Above: Beverly Johnson, center, says that her team, Bev's Crew, starts their walk in downtown Chicago in an area that "everyone" uses.

Left: Beverly, at right, is committed to raising awareness of the disease among African-Americans.

# THEN AND NOW: WALK MS

Twenty-five years ago, disease-modifying treatments for multiple sclerosis did not exist, MRI scans had just been recognized as a way to monitor disease activity and the very first Walk MS event took place in Minnesota.

That day in 1988, people who wanted to join the movement walked from downtown Minneapolis to the state capitol in St. Paul. They raised \$216,000 toward research and service programs for people with MS. And they began something that grew exponentially through the new millennium and beyond. Today, Walk MS events raise \$50 million a year to help people with MS move forward with their lives and end MS forever, with more than 330,000 people participating in events held in every single state. Keep the movement growing. Visit [walkMS.org](http://walkMS.org) today.



COURTESY OF THE MINNESOTA CHAPTER

“Some people just overhear us discussing our preparations and want to pitch in,” says Marilena. “We may be diverse, but we all have something in common that I never expected—besides wanting to end MS!” she says, laughing. “We’re all super-competitive and we each want to come in with the most money. This year we raised \$12,000 and next year we want to raise even more.”

## ‘The disease strikes all’

As many Walk MS team captains know, creating a successful team often means finding a way to keep it growing and crossing social boundaries to do so. As with any challenge, there can be bumps in the road.

Just ask Beverly Johnson. Diagnosed in 1993, the Chicago native only started taking her MS seriously after an exacerbation nearly 10 years later, and formed a Walk MS team, Bev’s Crew. She started by recruiting her friends, and then continued to build her team by speaking at health fairs, churches and senior centers.

Part of her job as team captain was to hang up fliers to promote Walk MS. “Last year, I went to get the posters specifically to put up at a senior center. But when I took a look at them, something was wrong. There was not one senior or person of color represented.”

So Beverly, who is African-American, made her own posters featuring herself and her husband Johnny. Then she wrote to the president of her chapter.

“It was really hard to do that,” she says. “But I told him my concerns—that the posters didn’t represent my own experience. And he listened. This year, the posters will look different.”

Bev’s Crew is now one of the top teams in the Chicago area, and, to support the Society’s initiative to raise awareness of the disease in the African-American community, Beverly mentors newly diagnosed African-Americans.

“A lot of people—even doctors—think that ‘certain’ people don’t get MS,” Beverly says. “The first doctor I was seeing said I was too old to have it. Then she told me that black people rarely get it. Well, I have it and so do four older ladies of color in my church. Now I feel it is my job to go into the black population and tell them that the disease strikes all.”

To learn more about how to start—and build—**your** team, visit [walkMS.org](http://walkMS.org). ■

Patricia Wadsley is a freelance writer who contributes regularly to **Momentum**.



## For people with relapsing MS

# "STILL



### Indication

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

### Important Safety Information

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

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

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

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

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

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

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

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

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

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

*(Continued on the following pages.)*

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



ING"

Jane Y.  
Taking AVONEX  
*STILL GARDENING*

## AVONEX may help you stay active longer

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

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



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

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



## Important Safety Information (cont'd)

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

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

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

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

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

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

The most common side effects of AVONEX include:

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

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

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

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

# Brief Summary of Medication Guide

## AVONEX® (a-vuh-necks)

### (interferon beta-1a)

#### Injection for intramuscular use

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

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

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

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

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

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

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

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

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

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

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

#### What is AVONEX?

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

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

The way AVONEX works in MS is not known.

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

#### Who should not use AVONEX?

##### Do not take AVONEX if you:

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

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

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

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

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

#### Tell your healthcare provider about all the medicines

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

#### How should I use AVONEX?

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

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

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

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

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

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

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

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

The most common side effects of AVONEX include:

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

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

#### How should I store AVONEX?

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

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

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

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

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

#### What are the ingredients in AVONEX?

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

##### Inactive ingredients:

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

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

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

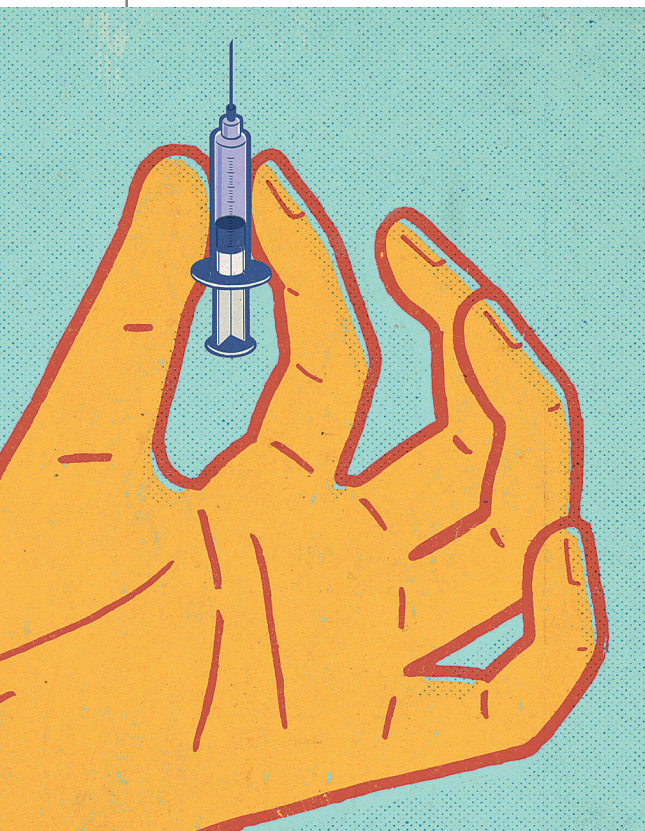
Revised 02/2012



## Taking the sting out of injections

by Emily Wojcik

**S**tacey Max remembers well the first time she couldn't face giving herself her weekly injection of Avonex, the disease-modifying therapy (DMT) that she takes to manage her multiple sclerosis.



injecting myself,” she says. “But that night I called my mother and my boyfriend, asking them to help me.”

For many people using injectable therapies, Max's story is familiar. Until very recently, DMTs were only available as injections—either an intramuscular shot, such as Avonex, or subcutaneous injections like Betaseron, Copaxone, Extavia or Rebif. Research has shown that DMTs help reduce the incidence of relapses and slow the progression of the disease, but adherence can be difficult for a variety of reasons.

### Not built to inject

Many people with MS call it “injection fatigue” or “needle fatigue,” while healthcare providers may call it “adherence resistance.” It can result from skepticism about a

medication's efficacy or from fear of pain involved with the injection itself.

“From the first injectables, we have faced this problem,” says Pat Kennedy, RN, CNP, MSCN, a nurse-educator and programs consultant for Can Do MS, which provides lifestyle

advice and support for people living with MS. “We're not built to do this. We don't wake up and say, ‘Oh, I **want** to inject myself today.’ ”

But there are ways to overcome the challenge. With the help of healthcare providers, people taking injectables can try a number of physical and mental management techniques.

### A purpose to the plan

Part of the problem is related to the way DMTs work. People with MS don't feel or see the immediate effects of their injections, which may make it difficult to stick with their dosing schedule.

For Christine Osborn, 30, a stay-at-home mom in Lawrenceburg, Ind., the connection can definitely be hard to make. Her mother took insulin for diabetes and “if she missed a dose, she saw the consequences immediately,” says Osborn. With Rebif, a subcutaneous injection that Osborn takes three times per week, missing a shot seems not to matter. “Honestly, I can't tell the difference when I take the meds. I don't know if that means they are keeping me healthy or if they don't have an effect.”

Kennedy says that doubts like Osborn's can be a signal that it's

“It was exactly a year after I started taking it,” says Max, 46, a real estate broker in New York City. “One night, I just couldn't do it. It suddenly seemed so violent.” Max was diagnosed in 1999 and had been on a DMT ever since. “I never had a problem with the idea of

time to revisit treatment goals with a doctor or nurse—and remember **why** you're taking the medication. "I like to remind people that there's a purpose to the plan," she says.

If a person with MS finds taking his or her medicine truly challenging, it's time for a frank discussion with a healthcare provider about treatment options. "When someone gets to that place," says Kennedy, "it isn't going to be long until they say, 'That's it, I've had it.'"

Carrie Sammarco, DNP, FNP-C, MSCN, a nurse practitioner and co-author of a forthcoming handbook for nurse practitioners working with people with MS, agrees. "It's wonderful to be able to prescribe someone a drug that may more effectively manage their MS, but if there's something about it that prevents a patient from taking it, it won't be the best therapy for that individual." Each treatment for MS comes with its own risks and benefits, but with five injectable DMTs, two infused therapies and two oral medications recently approved by the Food and Drug Administration (FDA), people with MS now have more choices than they did even five years ago.

### Starting with honesty

Dr. Sammarco often begins her consultations by asking people how many times they've skipped

an injection over a given period. "I give them permission to be honest," she says, because honesty is instrumental to developing a workable treatment plan.

Hilary Gladstein Basis, 32, a television producer in Los Angeles, had no problem with her Avonex injection for the first three years. "My nurse told me to just pick a spot, count to 3, and jab the needle in. And I was fine with it, at first," she says. Then

## Creative approaches help people with MS overcome injection fatigue.

suddenly, she wasn't. "I'd think, 'Oh goodness, I'm jamming a needle in my leg!' And I'd end up with 10 little pricks because I just couldn't get it in."

Basis ended up stopping Avonex for several months without telling anyone—a potentially dangerous move. "I just kept telling myself, 'Next week I'll be fine.' I didn't want to admit that I didn't want to do it anymore." When Basis finally called her doctor, he sent a nurse to teach her a new way of doing injections. "She told me to pinch my leg, so that my pain receptor was feeling the pinch, and to do the injection as slowly as I need to. I've been doing it that way for four years now with no problem."

### Pluses and minuses

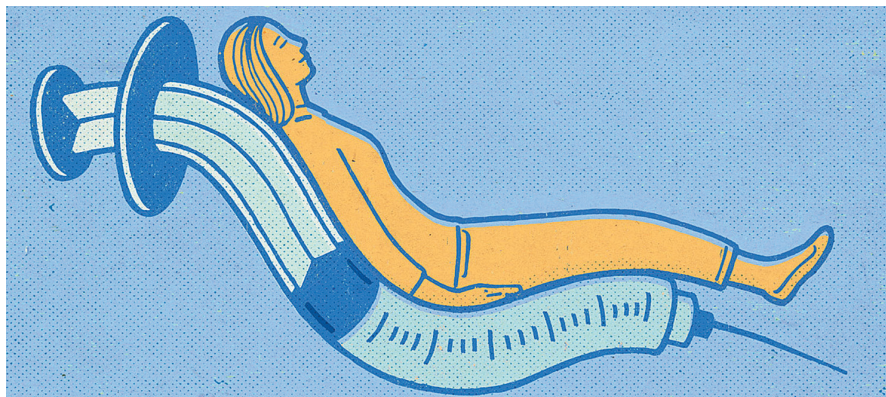
DMTs taken subcutaneously, or under the skin, must be taken frequently since the medication disperses throughout the body quickly. But they can cause soreness at the site of the injection and break down fatty tissue, resulting in dimpling and pain. Therefore, it's necessary to rotate injection sites in order to avoid hardening and oversensitivity.

Lenny Moschitto, 56, the owner of a New York City-based women's accessories manufacturing company, has used Betaseron every other day for the past 11 years and has reached his limit on certain areas of his body. "My stomach has gotten to the point where it can be painful to do an injection," he says. "I won't go near the right side of my abdomen because it has become lumpy and hard."

Still, Moschitto notes, he has not experienced an exacerbation and his MRIs have not shown a new lesion since he began the injections. "It seems to be working, which keeps me going with it."

For Avonex, which is injected directly into the muscle, site reactions are less of a problem than psychological and physical responses to the longer needle. The injections are needed less frequently, since the muscle dispenses the medication slowly. But, says Kennedy, "my patients have said to me that they look at that needle and feel as if they're





holding a telephone pole.” The new Avonex “pen,” an autoinjector that minimizes the visual and physical discomfort of the syringe, could potentially help, she says.

### Tips on technique

Dr. Sammarco encourages her patients to keep a log of their injections and watch for patterns, such as injections in one location—say, the arm—hurting more than other sites, such as the thigh. This can help people with MS plan their injections and prepare for side effects, she advises.

Such strategies may reveal ways to improve technique, too, says Kennedy. “Sometimes we get into bad habits, and make injections more difficult than they need to be.” After three hours talking through the problem on the phone with her mother and then-boyfriend (now her husband), Max realized that “I don’t need to stab it in. I can pick a spot, and push the needle up against the skin and just push it in.” Since then, she says, the injections have become easier to face.

Inadequate technique may be a particular problem if you have been giving yourself shots for a long time, says Dr. Sammarco.

“It’s easy to assume that people are fine with injections just because they’ve been doing them for years. But this might be the point where they’re getting fatigued,” she says. “They’ve been stable, relapse-free, and it’s easy to fall off a little.” A refresher course in injection technique with a healthcare provider can go a long way toward getting people back on track with their treatment.

### Sweeten the task

Overcoming needle fatigue can also be a matter of changing how someone approaches the injection itself. For many, developing a routine that provides comfort and relaxation around the injection can help. A warm bath, meditation, or a sweet treat taken before or after injecting oneself can lessen anxiety and even reduce pain.

Sherrie King, 64, a tax accountant from Raleigh, N.C., took Avonex without incident for eight years. Then one night, “I sat there for an hour or more, and I just couldn’t do it.” But King was determined to stay on her DMT. “I realized that nurses do this hundreds of times a day, so I thought, ‘What if it’s not me doing it, but just the hand of a nurse approaching the leg of

a patient?’ ” That visualization, she says, initially helped her get over her resistance.

Since then, a number of strategies have helped King continue on her treatment. She switched to the pen, which she says has made a huge difference in terms of ease and visual appeal. And she cultivates support from loved ones. After injections, “my husband would reward me with a dish of ice cream. You need any support system that gives you a boost.”

### Make the choice

Dr. Sammarco says change may be as simple as refocusing on **why** one takes DMTs. “Assessing your mindset is important: Are you taking these injections because you want to stay well, or are you giving yourself injections because you’re sick? That distinction is a huge factor,” she says. “It’s like taking vitamins, brushing your teeth, exercising. You do these things because you want to stay healthy, not because there’s something wrong with you. We have to think of this as one of the choices you make to have the lifestyle you want.” ■

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

## Getting the job when you have MS

by Stephanie Watson

**G**etting hired when you have multiple sclerosis is challenging—but not impossible. If you handle the interview process with confidence, and know how much to reveal to a prospective employer, you can vastly improve your odds of getting an offer.

### Can you handle the job?

Before you send out a resume or accept an appointment for an interview, think about whether the position is a good match. “I definitely think it’s important to do a self-assessment,” says Steve Nissen, the National MS Society’s senior director of Employment and Community Programs in the Washington, D.C., area. Make a list of symptoms you’re experiencing or have had in the past, “and strategize how to manage those symptoms moving forward,” Nissen advises.

Would you need accommodations to perform certain job functions? What would those accommodations be? Under the Americans with Disabilities Act (ADA), companies with more than 15 employees are required to make any “reasonable accommodations” that employees with disabling conditions need to fulfill their essential

job responsibilities. Those accommodations may include a flexible schedule, a parking space close to the building or ergonomic office equipment.

### To tell, or not to tell?

So you’ve decided the position is within your abilities—or can be made so with a few accommodations. You’ve sent out your resume (see sidebar, “The right resume,” pg. 45) and now the employer has asked you for an interview. What next? Do

Visit the Job Accommodation Network at **askjan.org**, or call 800-526-7234 for a wealth of information about the ADA. Find real-life examples of workplace accommodations at **askjan.org/media/mult.htm**.

you tell the interviewer about your MS, or not?

“You want to be evaluated based on your skills and abilities, so if your symptoms aren’t visible,

Applying for jobs can be nerve-wracking enough on its own. But MS makes it even more complicated. Use these ideas to turn the process to your advantage.



IMAGE SOURCE/GETTY IMAGES



it's not recommended that you disclose at the interview," says Barbara McKeon, the National MS Society's director of Employment Programs and Services in the New York City area. "You really want them to focus on you as a worker, not as a person with MS."

Lakshmi Roberta Roy decided not to disclose her MS when interviewing for a job in the mid-1990s. "I didn't feel like I needed to because I had no outward signs that I had MS," says the 46-year-old attorney from Delran, N.J. She decided to disclose her condition only **after** she had already established herself and her abilities at the law firm that had hired her. Legally, you're under no obligation to broach the subject and your interviewer may not ask about your disability. And ethically, it's well within your rights to decide

when and where you disclose.

If you decide, however, to disclose your MS and the employer rescinds its offer, then you may have a case for a discrimination charge through the U.S. Equal Employment Opportunity Commission (EEOC), Nissen says. Visit the EEOC at [eeoc.gov](http://eeoc.gov) or call 800-669-4000.

### When MS is visible

If you have discernable symptoms, the decision to disclose your MS can become more complicated. Mobility challenges may become an issue even before a job interview if the interview room or building is inaccessible. But if you stay focused on your abilities, not your disabilities, you may even turn potential negatives—such as your need for accommodations—into positives.

"You always want to stay focused on your strengths," says Kris Graham, employment manager at the Information Resource Center of the National MS Society. "You want to make sure the message you convey is about how the accommodation will assist you in doing a good job."

If you do decide to disclose your MS, Nissen suggests letting the hiring manager know only as much as you're comfortable telling. This may be no more than, "I've been diagnosed with a chronic condition." Describe symptoms in nonmedical terms (for example, "I often feel tired because of my condition") and then outline any accommodations you expect to need. Give the person time to absorb the information and ask questions.

While the hiring manager may not legally ask you questions about your disability, there can be a fine line between legal questions about whether you're able to perform essential job functions and illegal ones. "Can you type 65 words per minute?" would be an acceptable question for an administrative job. But "Why are you in a wheelchair?" would be unacceptable. Visit [nationalMSSociety.org/DiscloseWork](http://nationalMSSociety.org/DiscloseWork) for more information about the disclosure process; and be sure to read our feature on the ifs, whens and hows of disclosure both on the job and in your life in the Summer 2013 issue.



HUNTSTOCK/GETTY IMAGES

### Stay positive

Living with MS can take its toll on your professional self-esteem, especially if you've been out of the work force for a while. When Colleen Stover started looking for work after a few years out of the job market, she was worried her skills wouldn't be up to par. "I wasn't really putting myself out there," says the 53-year-old King of Prussia, Pa., resident. "I tended to go for jobs that weren't very demanding."

McKeon works with many people with MS whose confidence has been affected by their disease. "What I tell them is, 'You're still the same worker you were before you needed to use a cane,'" she says. "You need to focus on that and go in with confidence."

Remember, during the interview, a prospective employer isn't only evaluating you—you're also evaluating the company. Think about whether this job suits your skills and personality, and also whether it fits your MS.

Stover was eventually hired to work in the admissions office at The Sierra Group Academy, a company that teaches computer skills to people with disabilities. She says it was a perfect fit because the company made the accommodations she needs to get her job done—including equipping her computer with voice recognition

software. "I really do love it," Stover says. "It's very fulfilling." It may have taken awhile, but she found the right fit for her, and her life with MS. ■

Stephanie Watson is a freelance health writer based in Atlanta.



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## The right resume

To land a job interview, you'll first need to polish your resume. "With so many people looking for jobs, the employer is only going to look at your resume for a few seconds," says Barbara McKeon, the National MS Society's director of Employment Programs and Services in the New York City area. If there were times you were unable to work because of your MS, there are ways to reorganize your resume to focus on your skills instead. McKeon offers these possible solutions:

- Lead with a skills profile, and tailor it to the job. Say you're applying for a bank teller position, and you've been working as a server in a restaurant. At the top of your resume, write: "Customer service professional with X number of years

interacting with customers and strong money-handling experience."

- Structure your resume by function rather than by dates of employment. List experience types (such as project management, customer service or financial) first, where an employer is likely to notice them. Then, further down, list jobs chronologically.
- Highlight responsibilities you held during times you were unemployed. Maybe you volunteered, took a class online, or managed a household. "You want to show an employer that you're keeping your skills fresh, that you believe in staying productive," McKeon says.



## From military man to MS activist

by Stephanie Watson

When naval officers stand watch on a ship, they do just that—remain standing. “You don’t sit down because you want to set the example to your men and women that you’re in control, and you’re the lead,” says 28-year-old Donnie Horner of Jacksonville, Fla. But in the summer of 2009, while serving as an officer on the bridge of the USS Bonhomme Richard, Horner suddenly couldn’t

“You have a choice: You can stand on the sidelines, or you can play in the game—the game of beating multiple sclerosis.”

stand. His legs felt as if they had turned to rubber, overcome with vibrations he couldn’t control.

When the ship returned to the port in San Diego a few weeks later, Horner immediately flew home and saw a neurologist. “I was having a really hard time

walking. I was panicked,” he recalls. A series of tests revealed that Horner had multiple sclerosis.

It was devastating news to someone who had been instilled with a sense of duty from a very young age. His father, a former



MS activists took their passion to Capitol Hill in March 2011. From left to right: Derrick Lee, Multiple Sclerosis Foundation; Cathy Kerns, MS activist; Donnie Horner, MS activist; Carroll Franklin, president, Mid Florida Chapter; Jim O'Brien (former Society staff).

Army colonel, had taught Horner that to be a good citizen, he had to serve his country.

When Horner graduated from the U.S. Naval Academy in 2008, his future seemed certain. “When you come out of the Naval Academy, the world is your oyster, and you feel like there’s nothing that can stop you.”

A year later, his future looked far less promising. Horner’s life was about to take a markedly different turn from the military career he’d envisioned. “I knew I would have to retire,” he says.

### Out of the comfort zone

Horner took a positive approach, and began to set new career goals. He enrolled in the MBA program at Jacksonville University’s Davis College of Business.

Then, a friend invited him to a National MS Society Dinner of Champions event, where he met North Florida Chapter President Corrina Steiger. “Donnie was young, fresh-faced and infinitely accomplished, and he was living so openly and positively with MS,” Steiger recalls. She asked Horner if he wanted to get involved with MS advocacy efforts, and he agreed.

“Corrina insisted—in a supportive manner—that I could make a difference,” Horner says. “I was reluctant, at first, to become an advocate. I become embarrassed if I stumble in

public, or if my vision blurs when I’m reading from a speech, even though people tell me it’s OK, or that they don’t even notice. It isn’t easy, but I’ve had to step outside of my comfort zone.”

### To Capitol Hill and back

Horner was especially interested in the Congressionally Directed Medical Research Programs (CDMRP), a Department of Defense initiative that sponsors research into health conditions that affect significant numbers of current and former service men and women. The Society was successful in advocating for an MS program within the CDMRP in 2008, and since then has received more than \$20 million in funding.

After noticing Horner’s interest in legislative issues and public policy, Steiger invited him to join the chapter’s government relations committee. He was eloquent, passionate and committed to the cause—traits that got him noticed right away. “We took him straight to Washington, D.C.,” to attend the Society’s 2011 Public Policy Conference, where MS activists from around the country gather each year, garnering Congressional support for policy initiatives, says Jenna Paladino, statewide director of Public Policy for the Society in Florida. “I had no hesitation that he was going to take his passion to the highest level,” she says.



JOE SHYMANSKI

**Donnie Horner funnels his ambition into MS advocacy.**

The conference became a turning point for Horner. “I was taken aback by everything I learned and the impact we could make on Capitol Hill,” he says. “I came back from that trip feeling empowered.”

Horner brought his passion for MS advocacy back to D.C. in 2012, this time as a speaker to a crowd of about 375 advocates, donors, board members and legislators. He told the audience that when you live with MS, you have a choice: “You can stand on the sidelines, or you can play in the game—the game of beating MS.”

### Gaining momentum

The message resonated. As a former Naval officer with MS, “Donnie not only has a compelling story, but also a perspective that elected officials appreciate hearing,” says Ted Thompson, vice president of



Federal Government Relations for the Society. Horner was recently named to the Society's Federal Activism Council (FAC), which helps determine policy priorities for the organization.

Horner's moving things forward in his own life, too. He's vice president of business development for MainOcean Port Services in Jacksonville, a company he launched along with two former classmates from his MBA program. MainOcean provides concierge services to ships docking in Jacksonville and other local ports—anything from assistance with customs

paperwork to warehousing and crew transportation—and it enables Horner to use both his naval and business expertise.

Horner is realistic about his MS, but remains optimistic. "While each day poses its own challenges, I'm always hopeful for a better tomorrow."

And his goals for the future remain lofty. He wants to raise awareness and money for MS research, influence change at the congressional level through his work on the FAC, and expand his business. He also wants to run for Congress—"and win before my legs give out on me," he says.

"I see an opportunity to be the torch bearer for the next generation of American leadership." ■

Stephanie Watson is a freelance health writer based in Atlanta.

To watch a video of Donnie Horner talking about his perspective as a veteran with MS, go to **[nationalMSSociety.org/MSlearnonline](http://nationalMSSociety.org/MSlearnonline)**.



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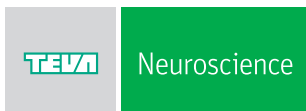
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## Handling the office bully

by Kelly Pate Dwyer

**B**ullying doesn't just happen at school. It's prevalent among adults, too. Childhood shoving and name calling evolve to more subtle and manipulative forms of aggression, intimidation and exclusion—behaviors that can profoundly impact a person's psychological and physical health.

What's more, people who live with chronic illnesses such as multiple sclerosis and who may have a visible disability are more likely targets.

"When you live with an illness with any kind of disabling symptom, you can easily find yourself in a situation where someone else is taking advantage of your sense of vulnerability," says Susan Swearer, MS, PhD, associate professor of psychology at the University of Nebraska. She has conducted large-scale studies of youth bullying, and sees similar patterns among adults.

### Understanding bullying

Perceptions vary on how to define and quantify adult bullying. Teasing, for instance, amounts to bullying in some contexts, but not others. Still, experts agree that bullying:

- happens where there is a power imbalance, such as between a boss and an employee.

Bullying at the workplace is, at its best, hurtful. At worst, it can put your livelihood at risk—and even your health.

- is repetitive.
- is deliberate and personal, whereas other types of conflict center around tasks or concepts.

Adult bullying can happen just about anywhere, but it can be particularly difficult to handle in the workplace, which is a hotbed for power inequities. And work is one place many people can't avoid a bully, says Nova Scotia-based organizational psychologist and human resources consultant Kevin Kelloway, MS, PhD.

Experts agree that bullies get a boost when they overpower their targets and when peers accept their behavior.

Bullying can involve a range of behaviors, from outright threats or disparaging comments to more subtle actions such as ignoring a person's ideas, repeatedly excluding someone from social activities, or spreading misinformation.

Bullies pick on people they perceive as weak in situations where they expect to get away with it.

As such, people who already feel victimized by their health

make attractive targets, says Rosalind Joffe, ACC, a Boston-based career coach and mediator who has MS and counsels clients with disabilities and chronic illnesses. "You may feel guilty that your illness or disability is inconvenient for other people, that you've let other people down."

If that weren't enough, says psychologist and bullying expert Peter Randall in his book, **Bullying in Adulthood: Assessing Bullies and their Victims** (Taylor & Francis, 2001), bullying victims often feel trapped in their situation, too, which can cause or exacerbate anxiety, depression and other health problems common with prolonged stress.

### Targeting disabled people

That's what happened to Amy\*, who was diagnosed with MS in 2007. A Florida resident, Amy worked in medical coding and billing for several years. Currently, she is unemployed and studying for a new certification, in hopes it'll expand her job opportunities. Amy told her instructor about a learning disability, which



qualifies her for extended time when taking tests. However, her instructor now repeatedly questions her potential to succeed in future jobs, and she feels excluded by classmates. So, while she experiences fatigue, cognitive difficulties and sometimes uses a cane, she has decided not to disclose her MS to her instructor—because she fears further discrimination.

Situations like Amy's, where a person receives accommodations for a disability, may fuel resentment by peers, says Joffe. She notes, for example, that people who don't know about an MS diagnosis may mistake fatigue for laziness. Problems can also arise when a person shares his or her diagnosis: Colleagues may observe inconsistent

MS-related symptoms and decide a person is faking her illness.

That was the case with Karen\*, who worked for a small company and used a wheelchair only on days her symptoms flared. "My co-worker believed that you don't use a wheelchair unless you're paralyzed," she says. "That's when the bullying started." The coworker repeatedly attacked Karen's character and misled her on work tasks.

### **They've got your back**

"To be mistreated is difficult and injurious, and it's not always clear what to do," says David Rintell, Ed.D., a psychologist with Partners Multiple Sclerosis Center in Brookline, Mass. Having MS can make people feel isolated, and it's important not to become even more isolated in a bullying situation.

Building bonds with coworkers you trust helps to create allies, which in turn helps to deter bullies. Accept coworkers' invitations to coffee, lunch, or even hallway conversations. If fatigue isn't an issue, join coworkers for after-work get-togethers when you can.

Workplaces may have unexplored resources for dealing with bullying situations, as well. Employee assistance programs (EAPs) can connect you with a counselor, who can help you create coping strategies. If the organization has an employee



## Major Challenges

resource group (ERG) for people with disabilities, the group can lend support and give you the unofficial scoop on how your company handles complaints, says Mendham, N.J.-based consultant Nadine Vogel, MBA, who provides organizations with disability etiquette and awareness training. And if your workplace does not already have a disability ERG, you can ask your human resources department about forming one.

### Finding a resolution

Some experts recommend confrontation at the first sign

a coworker is mistreating you. “That could simply mean saying, ‘When you did this, I felt uncomfortable about it,’” says Alex Yaroslavsky, MILR, NCM, a mediator and conflict resolution expert based in New York. “That alone makes you less attractive to bullies.” Before you do this, however, evaluate how safe you feel around the bully. If you feel physically threatened, it is **not** recommended to confront him or her on your own.

Role play with a friend or family member before having the conversation—and cool down first. Acting

upset encourages bullying. If you still feel uncertain about how to handle the conversation, reach out to discuss the problem. Call an MS Navigator at 1-800-344-4867, or call the MSFriends program, where you can talk to a peer with MS, at 1-866-673-7436.

If a direct approach doesn’t work and one incident of treatment turns into a pattern of bullying, consider what outcome you desire and what you’re willing to do to get there, Joffe says. Start by reviewing your employer’s policies to see if and how bullying is addressed. Current laws do not specifically protect against adult bullying, in the workplace or elsewhere (see “The legal landscape,” pg. 53), but your workplace may still have some policies that you can turn to your advantage.

If you decide to pursue the matter with your employer’s human resources department, document in detail each episode of bullying, so that you can present specific information to a manager. Save any emails that display bullying behavior or language; write down the time, date and details of in-person incidents. If you haven’t disclosed your MS at work, consider the culture where you work and whether managers and coworkers would more likely react to the situation with compassion or



intolerance, Vogel suggests. “If your employer has a disability ERG and they celebrate Disability Awareness Month, you’re more inclined to be met with respect.” If not, you may want to proceed with caution. Visit [nationalMSSociety.org/DiscloseWork](http://nationalMSSociety.org/DiscloseWork) for more about disclosure at work.

### Exploring all options

If you take your complaint to a manager, introduce your documentation and avoid making an emotional case, Joffe suggests. “Explain how the bullying is getting in the way of your performance and ask specifically for what you’d like to see change.”

However, there may be instances when office politics favor the bully, Kelloway says. “I once consulted with a hospital where a surgeon was a well-known bully and he was the only surgeon there that did a certain type of transplant,” he says. “The hospital decided they couldn’t afford to lose him.”

In such situations, it may be time to make some decisions about how to move forward. Seeing a counselor can help you work through your feelings about the bullying, as well as identify strategies that can help you deal with the situation on a day-to-day basis. An MS Navigator can refer you to professionals in your area. And, if you ultimately decide that the situation is untenable, and that



you need to leave your job, an MS Navigator can refer you to employment resources. Visit [askjan.org/indiv/index.htm#job](http://askjan.org/indiv/index.htm#job) for links to job sites specifically for people with disabilities. ■

\*The names of individuals in this article have been changed to protect their identities.

Kelly Pate Dwyer is a freelance writer in Denver. She writes about workplace issues, business and health.

## The legal landscape

No federal law specifically protects adults from bullying, though several bills on the table address bullying in schools, and Rep. Mike Honda, D-Calif., launched the Congressional Anti-Bullying Caucus in June 2012 to spread awareness about bullying among people of all ages. He is considering proposing legislation, says his communications director, Michael Shank.

That said, some bullying behaviors are considered harassment, such as a coworker disparaging your character and spreading lies about you. And harassment based on disability **is** illegal. To prove harassment, you need to show yours is a “hostile work environment,” says employment attorney Elaine Fitch of Washington, D.C.–based Kalijarvi, Chuzi, Newman & Fitch, and that due to your MS you are “substantially impaired in a major life activity” or “regarded as having a disability or history of being disabled.”

However, harassment cases can be difficult to prove, Fitch says, and even if an attorney believes you have a strong case, weigh carefully whether fighting is worth the price—in terms of dollars, time and your health. Visit [eeoc.gov/laws/types/disability.cfm](http://eeoc.gov/laws/types/disability.cfm) to learn more, or call the Equal Employment Opportunity Commission at 800-669-4000.



# 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.

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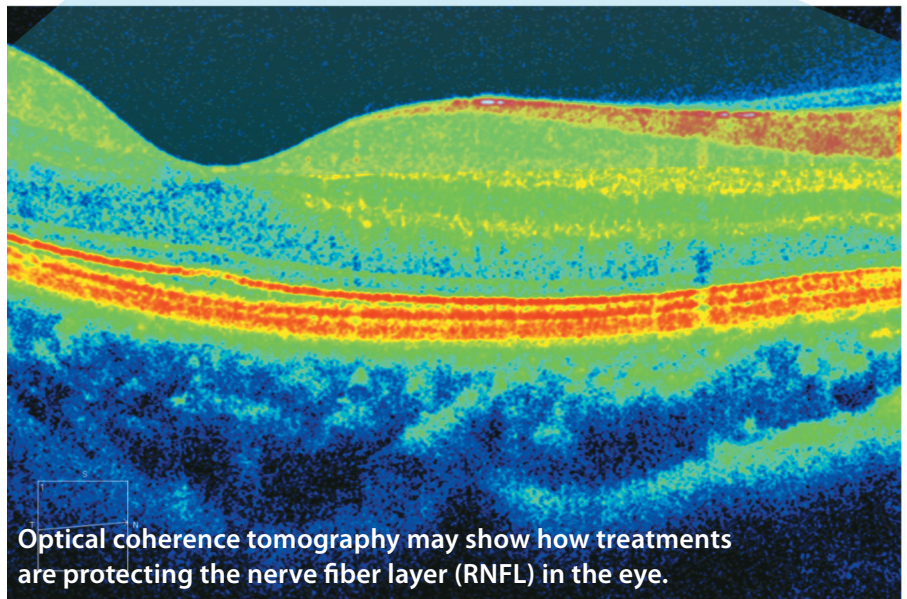
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## Protecting the nervous system from MS

by Sara Bernstein

**A**ntioxidants, green tea extract and drugs used in other diseases are topping the list of agents being studied for their ability to stop multiple sclerosis by preventing nervous system damage. This quest goes beyond trying to stop immune attacks and into the realm of armoring the brain and spinal cord so that they can stay healthy in the midst of potentially harmful

disease activity—to stop MS progression in its tracks.

The National MS Society is funding researchers around the world who are exploring these and other promising avenues to “neuroprotection” in people with MS right now.

#### Repurposing treatments

If we knew that therapies approved to protect the nervous

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system in other diseases also worked in MS, it could mean a speedier road to approval from the Food and Drug Administration (FDA). Dr. Raju Kapoor (National Hospital, London) is testing whether the epilepsy drug phenytoin can reduce or prevent nerve fiber injury in 90 people with optic neuritis, an eye disorder that's often the first sign of MS.

Optic neuritis involves inflammation of the optic nerve, causing a loss of vision that is usually temporary. Since damage is limited to one nerve, and can be measured relatively easily using an eye scan known as optical coherence tomography (OCT), this is an ideal group in which to test whether nerves are being protected.

Beyond OCT, Dr. Kapoor's team is also assessing the extent to which phenytoin improves recovery of visual function.

Dr. Kapoor's team is working within a newly formed clinical trials network in the United Kingdom that was created specifically to speed the development of neuroprotective strategies for MS. The trial, co-funded by the Society and the MS Society in the UK, is proceeding on schedule, and results are expected in 2014.

Dr. Emmanuelle Waubant (University of California, San Francisco) and her colleagues are testing whether an oral therapy, called riluzole, which has been approved to treat amyotrophic

lateral sclerosis (ALS, also known as Lou Gehrig's disease), can also protect nerve fibers from damage in MS. The team is conducting a small trial in 40 people recently diagnosed with MS. Participants are taking the approved immune-modulating therapy Avonex plus riluzole, or Avonex plus inactive placebo, for two years. Besides looking at safety, the team also is using MRI scanning to track disease activity and progression in the brain. Results are expected this year.

## MS researchers are exploring the uses of therapies approved for other diseases.

A successful result from both of these trials would likely lead to larger scale, more definitive trials.

### Assessing antioxidants

Other researchers are looking at novel strategies for neuroprotection, such as the use of antioxidants. "Free radicals" are normal byproducts of bodily processes that may cause tissue injury and even turn on immune attacks in MS. In particular, damage to nerve cells in MS is thought to be due to free radicals affecting mitochondria, the energy factories of nerve cells. Antioxidants are compounds that block or sweep up free radicals.

Dr. Vijayshree Yadav (Oregon Health & Science University) and her colleagues found that one antioxidant in particular—lipoic acid—reduced inflammation and prevented nerve fiber loss in mice with optic neuritis (**Journal of Neuroimmunology**, 2002; 131:104–14). Now they are conducting a clinical trial sponsored by the Society of oral lipoic acid involving 54 people who have optic neuritis to see whether this dietary supplement

can protect the optic nerve. They are using tests of vision and direct measurements of the loss of nerve fibers in the back of the eye (retina) to look for benefits.

Dr. Jesus Lovera (Louisiana State University, New Orleans) is investigating polyphenon E, an antioxidant isolated from green tea. Previous work (**Journal of Immunology** 2004;173:5794) indicates that a component of polyphenon E reduces the loss of nerve cells in mice with EAE (experimental autoimmune encephalomyelitis), a disease similar to MS. Now, Dr. Lovera and his colleagues are conducting a small clinical trial (48 people) to see whether oral polyphenon E alters the rate of nerve damage in people with

MS who are taking a disease-modifying therapy.

This research could show whether a well-tolerated antioxidant can slow or prevent the destruction of nerve cells.

### Under study in the lab

Even more novel strategies are under study in the laboratory, where safety and effectiveness must be determined before human trials can proceed. Dr. Kenneth Shindler, is studying how mice with EAE respond to resveratrol, a naturally occurring antioxidant found in grapes and other foods. Dr. Shindler's team has found that resveratrol prevents nerve cell damage in EAE. The compound did not affect inflammation, so the authors suggest that further studies might test whether combining resveratrol with anti-inflammatory medications used in MS would be beneficial (**Frontiers in Neurology**, 2012;3:84).

Dr. Rhonda Voskuhl (University of California, Los Angeles) has shown that the sex hormone estrogen may prevent nerve damage in MS models in the lab (**PNAS**, 2007; 104:14813). This is exciting because Dr. Voskuhl—a leader in research on gender differences in MS—is already conducting a clinical trial to see whether estriol (an estrogen hormone produced during late pregnancy) can reduce disease activity in women with MS.

The trial is funded in part by the Society, NIH and other generous donors.

Dr. Voskuhl is exploring the neuroprotective role of sex hormones in men with MS as well. In 2008, she administered testosterone to 10 men with MS, and found that participants experienced reductions in brain tissue loss, and increases in proteins that protect nerve cells (**Journal of Neuroinflammation**, 2008;5:32). In a more recent study, Dr. Voskuhl showed that testosterone, whether administered before or after disease induction, restored proper nerve impulse transmission in mice with EAE (**The Journal of Neuroscience** 2012;32:12312).

Understanding how gender hormones may confer protection against nerve damage will help lay the groundwork for their use as a neuroprotective treatment in people with MS.

### Measuring success

How do we know if neuroprotective treatments are working—without having to wait, possibly for years, to see a difference in disease course? Clinical trials of these strategies are relatively new, so measuring success is still a work in progress. Gavin Giovannoni, PhD (Barts and The London School of Medicine and Dentistry), is investigating one possible

assessment tool: levels of a protein called “neurofilament,” found in the fluid that bathes the brain and spinal cord (cerebrospinal fluid, or CSF). Neurofilament is released into the CSF in conditions that cause nerve damage, such as MS. Dr. Giovannoni, who was team leader in the Society's Nervous System Repair and Protection Initiative, funded by the Promise: 2010 campaign, is studying whether the level of neurofilament is a good indicator of nerve protection.

The Society is funding Dr. Giovannoni and his team to look at neurofilament levels in a small, ongoing study of people in the early stages of secondary-progressive MS who are taking oxcarbazepine (an epilepsy drug that has shown neuroprotective capabilities in EAE) in addition to approved MS treatments. The researchers are comparing neurofilament levels in those taking the study drug with those taking placebo. The results of this research could provide a new way to measure the success of experimental neuroprotective therapies.

Efforts like these are fostering hope that researchers will find ways not only to stop MS immune activity, but also find ways to shield the nervous system from ongoing harm and open up new treatment strategies to stop MS progression for people with MS. ■



## Aubagio: The road to approval and beyond

When Aubagio (the brand name of teriflunomide, manufactured by Genzyme, a Sanofi company) was approved by the U.S. Food and Drug Administration (FDA) last September to treat relapsing multiple sclerosis, it became only the second oral disease-modifying therapy approved for this disease—and its very development was a bit surprising.

### An unexpected finding

In the 1980s, the chemical company Hoechst AG was screening numerous compounds for use in agricultural pesticides. The company's researchers discovered that one of the pesticides actually had the ability to defend against inflammation, which occurs in MS. The compound eventually was developed into the drug leflunomide, which was approved to treat rheumatoid arthritis, another disease that involves immune attacks.

In 2004, Dr. Thomas Korn (Universität des Saarlandes, Homburg, Germany) and his colleagues found that leflunomide prevented the development of EAE (experimental autoimmune encephalomyelitis), a disease similar to MS, in mice bred to be susceptible to it (**Journal of Leukocyte Biology**,

2004;76: 950). A “metabolite” of leflunomide—a molecule produced when leflunomide is digested—suppressed inflammation as well, and became known as “teriflunomide.” Sanofi Aventis began testing it in people with MS, and its company Genzyme brought the therapy to the finish line.

### How does it work?

In MS, immune cells such as “T cells” and “B cells” are key players in the attack on the nervous system. Teriflunomide inhibits enzymes that help these cells to proliferate, so it can reduce the number of cells entering and attacking the brain and spinal cord.

### The clinical studies

Teriflunomide went through several stages of trials, and was approved based on safety and effectiveness data from two large studies. In one, called the TEMSO study, two different doses of teriflunomide reduced relapses and disease activity on MRI scans significantly more than placebo in 796 people with relapsing MS over two years (**The New England Journal of Medicine**, 2011;365:1293).

In the TOWER study, when compared with placebo, two dosing levels of teriflunomide

reduced relapses in 1,169 people with relapsing MS. The higher dose—14 mg—also slowed progression of disability.

In trials to date, Aubagio has been generally safe and well tolerated. The most common side effects include diarrhea, liver abnormalities, nausea, flu and hair thinning.

The prescribing information includes a boxed warning related to the potential for liver damage in people taking Aubagio, and a warning that Aubagio is not indicated for women who are pregnant or could become pregnant. Information is provided on how to clear Aubagio from the system if necessary.

### Further research

Research continues on teriflunomide, including one investigating its use in people at high risk for developing MS. Such studies will help to clarify teriflunomide's role in managing MS.

“We are greatly encouraged to see a new oral therapeutic option become available to people living with MS,” remarked Dr. Bruce A. Cohen, (Northwestern University), incoming chair of the Society's National Medical Advisory Committee. ■

## NARCOMS: Researchers need YOU

To really understand multiple sclerosis, you have to talk to people who have it. Researchers who are tackling difficult questions about the disease are no different—except they need to talk to thousands of people about it. In 1993, the Consortium of Multiple Sclerosis Centers (CMSC) recognized this need and created a registry called NARCOMS (the North American Research Committee on Multiple Sclerosis), to capture the experiences of people living with MS.

In the 20 years since NARCOMS' inception, more than 36,000 people have joined the registry. But more participants are needed right now to help it grow and become even more representative of people with MS. In 2012 alone, researchers used data from the registry participants to report on mobility impairment, walking speed, quality of life, disease progression, genetics, overactive bladder, vertigo and many other topics to help express the MS experience.

### NARCOMS studies risk tolerance

In just one example of the research that NARCOMS is facilitating, Dr. Robert Fox—the current managing director of NARCOMS and medical director at the Cleveland Clinic's

Mellen Center for Multiple Sclerosis—received funding from the National MS Society to look at people's views on the risks involved in newer MS therapies, such as the possibility of developing the brain disease PML from using Tysabri.

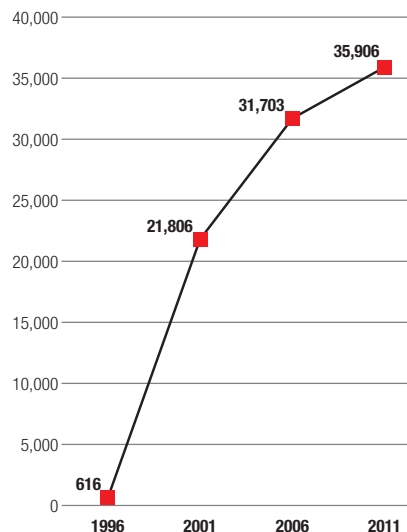
Dr. Fox and his colleagues administered a survey on the topic to 5,446 people from the NARCOMS registry and then repeated the survey one year later. Team members have found, not surprisingly, that people who are more severely disabled by MS are willing to take higher risks with therapies. Interestingly, tolerance to risk shifted over time, with more than one-fifth of respondents becoming less willing to tolerate risks over the one-year period. These results suggest that patients' acceptance of the risk of MS therapies is subject to change and may require ongoing discussions with healthcare providers.

This study and many others using data from NARCOMS are being used to improve our understanding of life with MS (Abstract #P986, ECTRIMS 2012).

### How do you sign up?

Anyone with a diagnosis of MS can participate in NARCOMS and contribute to research studies. Participants are asked

Total enrollment in NARCOMS from 1996 to 2011



to complete an enrollment questionnaire, and then update surveys twice a year. Surveys take about 45 minutes to complete and can be filled out online or in print.

NARCOMS conducts other studies beyond the biannual surveys, and provides recruitment assistance to other MS researchers, but participation in those is completely optional. Although NARCOMS builds collaborations with other investigators to further our understanding of MS, it does not sell or share personal information; what's more, all analyses are conducted with data that cannot personally identify any participant.

To enroll, call 800-253-7884 (toll free) from 8 a.m. to 5 p.m. Central Time, Monday through Friday, or visit the website at [narcoms.org](http://narcoms.org). ■



## Meetings of the mind keep research moving

by Timothy Coetzee, PhD

Last year the National MS Society invested more than \$45 million in a diverse portfolio of research projects, fellowships and strategic initiatives. A small but vital part of that investment consisted of financial support for scientific meetings focused on the topics of vitamin D in multiple sclerosis, clinical trials in pediatric MS, and creation of new tools for monitoring MS.

Why do we invest in scientific meetings? Some of the best ideas come from bringing smart people together in informal settings to shed light on problems. Simply put, the Society brings together the brightest scientific minds to collaborate on solutions for some of the biggest challenges in MS. Some successful examples of the return on this investment include:

- **Setting the standards for clinical trials of new MS therapies.** The FDA-approved disease-modifying treatments for MS were all evaluated using a clinical trial strategy that was developed following a meeting of key experts in 1982 in Grand Island, New York, which was convened by the Society

and the MS Society of Canada. This standardized approach has facilitated testing of new treatments for MS and enable speedier approval of the therapies by the U.S. Food and Drug Administration.

- **Improved diagnosis of MS.** Today, neurologists are able to more efficiently and accurately diagnose MS because of the McDonald Diagnostic Criteria, the result of the work of an international task force created by the Society in 2000. This tool, which has been updated at task force meetings twice since then, has taken some of the guesswork out of an MS diagnosis and is now a core tool in a neurologist's toolbox.

- **Increased focus on nervous system–repair research.** The MS research community is actively engaged in pursuing new treatments to promote nervous system repair. In 2002, the Society convened the scientific community at a meeting in Nice, France, that focused on this topic. This groundbreaking meeting led to the Society's

\$14 million Promise: 2010 Nervous System Repair and Protection Initiative and subsequent clinical trials of treatments to protect the nervous system from damage in MS.

- **Global collaboration on progressive MS.** Tackling progressive MS is a priority of the Society and our partners around the world. That's why we've joined with our colleagues in Canada, Italy, the Netherlands, the United Kingdom and the MS International Federation to form the International Progressive MS Collaborative. This global research collaboration is the direct result of a think tank on progressive MS convened in 2010 in Boston by the Society and Fast Forward.

Convening and connecting the scientific and medical community is how we break down barriers and accelerate research to STOP progression, RESTORE function and END MS forever. ■



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

## In the news and on our website

### **STOP Taking steps toward personalized medicine**

The disease course in multiple sclerosis—and the response to therapy—varies from person to person, and we currently have no reliable means to tell early on how active any individual's MS is likely to be.

However, a team led by Dr. Philip L. De Jager, a Harry Weaver Scholar of the National MS Society (Harvard's Brigham and Women's Hospital, Boston) has discovered that differences in active genes—detectable in blood samples—have the potential to be used to predict disease course and response to therapy. Further research is needed to verify and refine this approach before it becomes a tool that can benefit MS treatment decisions.

### **RESTORE Ginkgo fails to improve cognitive function**

Results of a placebo-controlled, 12-week clinical trial showed that Ginkgo biloba failed to improve cognitive function in people with MS. The study involved 121 people with all types of MS and some cognitive impairment. After 12 weeks, no differences were seen between those people taking ginkgo and those taking placebo in any of the outcome measures. The authors, led by Dr. Jesus Lovera

(Louisiana State University, New Orleans) and funded by the Department of Veterans Affairs, point out that this study only looked at the short-term use of ginkgo.

### **STOP** **RESTORE**

#### **Changing how MS progression is measured**

A Society task force is launching a far-ranging collaboration to analyze how MS progression is measured in clinical trials, and to develop a new method for measuring MS-related disability. This work addresses a glaring need for a way to quickly evaluate the ability of potential therapies to stop or reverse MS progression. The task force is collaborating with the Critical Path Institute, a nonprofit partnership with the U.S. Food and Drug Administration (FDA), to help advance this new tool. ■

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## Embracing diversity in the MS movement

**M**ultiple sclerosis doesn't discriminate. It affects people of every skin color, ethnicity, religion, sexual and gender identity, marital status, socioeconomic status—you name it. At the National MS Society, we know it's critically important that we have a diverse perspective, so we can most effectively overcome the challenges MS brings. We know, too, that we're not as diverse as we need or want to be. We must be more welcoming and more open; more sensitive to the wide range of experiences and needs of people affected by MS; and more effective in communicating with everyone. We are working hard to close that gap.

In this issue of **Momentum**, we explore the Hispanic/Latino experience of living with MS. Recently, African-American leaders have worked with us on being more relevant—altering the look of our brochures and changing our outreach methods to make the MS movement more inviting. And we've received funding from the Medtronic Foundation for videos that speak to the African-American community. But we know we have much more work to do to gain the trust and feel pertinent to people of any background who have MS or are affected

by MS. We know it goes far deeper than just having Spanish-language materials available or showing a person of color on a poster.

It's a challenge to become more diverse, and we need a complete effort to understand **how** to do that. We have a commitment, starting from our National Board of Directors, to welcome **all** people affected by MS, as part of our strategic response to MS, and have developed a diversity statement to affirm our commitment (go to **[nationalMSSociety.org/corevalues](http://nationalMSSociety.org/corevalues)** to read it). We've put together a dedicated team of volunteers, staff and people with MS to address questions of diversity and inclusion, and to create a specific, measurable action plan.

But we recognize that many of the answers must come from people who are not yet connected with the Society. I welcome input from **Momentum** readers about what feels supportive and engaging, and what doesn't. We want to hear your ideas. I invite you to share what you know, and help us connect with others. If you have an idea, skill or a talent that you can bring to the movement to make sure we're as relevant as possible, please reach out.

We intend to be the Society

for **everyone** affected by MS. Regardless of where you live, whether you are Hispanic/Latino, African-American, Asian-American, Native American, Caucasian, gay, straight, rich or poor—the common denominator is that you have MS, or care about someone who does.

People of different backgrounds may have different expectations or perspectives of the National MS Society and how it could serve them. We aim to understand what people everywhere need to move their lives forward. Share your ideas and feelings about how the Society can be more inclusive and welcoming for everyone affected by MS. I look forward to hearing from you!



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walk to  
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free of MS

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Walk MS connects people living with MS and those who care about them. This community event raises critical funds to support life-changing programs and cutting-edge research.



Susan, diagnosed in 1998

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