

Summer 2015

# MSPerspectives™

Volume 8, Issue 1

Practical Insights on  
Multiple Sclerosis



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*“There shall be  
eternal summer  
in the grateful heart.”*

– CELIA THAXTER

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# NAVIGATING

## the Changing Health Care System

**T**he passage of the Patient Protection and Affordable Care Act (the ACA) in 2010 is creating major changes in the way health care is accessed, delivered, and insured in the United States. For instance, most Americans are required to purchase health care insurance or pay a penalty in the form of a tax (\$325 per adult in 2015, rising sharply to \$695 in 2016). All health care insurance policies are required to fully cover, without a co-pay, approved preventive health services such as annual doctor visits, basic blood tests, vaccines, mammograms to detect breast cancer, and colonoscopies to screen for colon cancer. All plans must provide comprehensive coverage, including for hospital and doctors' visits and prescription medications, but depending on the plan selected, you may have to pay a lot or a little for these services. For people with multiple sclerosis (MS), the best news is that you can't be turned down for health care coverage because of your medical history. In addition, people who can't afford coverage can get government assistance to purchase a plan, and parents can elect to keep their children on their health care plan until the kids turn 26 years old.

The workhorses of the ACA are the state-run health insurance exchange websites, which can be accessed through [healthcare.gov](http://healthcare.gov). Via these online health insurance

portals, you can compare available plans in your state, as well as apply for a plan and a government subsidy if you're eligible. If you need help deciding among the different



options and applying, you can call the federal government helpline at 800-318-2596 or be referred via the healthcare.gov website to a local, trained health care insurance “navigator” in your area.

You need to review your insurance options on a yearly basis, between November 1 and January 31, and either re-up with your current plan or select a new one. If you move, marry, adopt or have a baby, lose your health insurance, or experience other types of major life changes outside of the enrollment period, you may still be able to apply for and obtain a plan. Medicaid recipients can enroll at any time of the year.

## ***Working Through Health Insurance Issues***

As with most MS-related topics, the National MS Society has done a wonderful job of explaining the ins and outs of health insurance coverage and advocating for people with insurers and the government. *MS Perspectives™* interviewed Kimberly Calder, MPS, Director of Health Policy for the Society, to find out more about this complex, yet essential subject.

### **Question: How has the ACA changed access to health insurance and care for people with MS?**

**Ms. Calder:** The biggest change is that people with MS and other chronic diseases can't be denied insurance. Lifetime caps on benefits are also no longer allowed,

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# **FYI**

***Did you know that...***

- ***The Affordable Care Act has made it easier for people with MS to obtain health insurance because no one can be denied a plan because of their medical history.***
- ***All insurance policies must provide comprehensive and preventive care coverage.***
- ***Low-cost access to disease-modifying therapies (DMTs) and symptomatic treatments for MS remains an issue.***

# Choosing the Best MS Drug for You

The choice of the right disease-modifying therapy (DMT) for you at any particular time requires a complex calculation of risks and benefits, an assessment that is best made by you and your health care providers as a team. Unfortunately, when a decision is made to prescribe an MS drug, particularly one of the newer and/or more expensive drugs, health insurers may refuse to pay for it. "Patients are getting a lot of denials from insurance companies for new MS drugs, as well as for drugs that treat symptoms, such as Ampyra® (dalfampridine) to improve walking and Myrbetriq® (mirabegron) and Vesicare® (solifenacin) to manage bladder issues," says Barbara Green, MD, an *MS Perspectives*™ advisor and director of The MS Center of St. Louis. Both the American Academy of Neurology (AAN) and the International Organization of MS



Nurses (IOMSN) have released statements (see below) that acknowledge the need for curbing health care costs while encouraging insurers to cover all of the available DMTs and not restrict them solely on the basis of cost. The rationale for this stance is that when drugs that are truly needed are denied to patients, costs often escalate anyway due to increased hospitalizations, office visits, and other health care fees related to progression of the disease that might not have occurred otherwise.

The AAN and IOMSN statements can be accessed at the following urls:

- **AAN position statement:** [www.aan.com/uploadedFiles/Website\\_Library\\_Assets/Documents/6.Public\\_Policy/1.Stay\\_Informed/2.Position\\_Statements/DiseaseModTheraMS\\_PosStatement.pdf](http://www.aan.com/uploadedFiles/Website_Library_Assets/Documents/6.Public_Policy/1.Stay_Informed/2.Position_Statements/DiseaseModTheraMS_PosStatement.pdf)
- **IOMSN statement:** [www.iomsn.org/images/pdf/IOMSN\\_DMTAccess.pdf](http://www.iomsn.org/images/pdf/IOMSN_DMTAccess.pdf)





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although there are still individual caps on benefits in terms of how many visits are permitted for a particular issue.

Overall, I believe the ACA represents a mixed picture for people with MS and there's a lot of confusion among consumers and even doctors and nurses about how health insurance works, what it costs, and how it interacts with Medicare.

On the one hand, it's a relief for people with MS to know that they're not going to go without health insurance no matter what their status, and the benefits are richer. On the other hand, the coverage is more expensive. And people close to the income line who don't qualify for financial assistance may find insurance is more expensive than before the ACA became law.

### **Q: What are the key stumbling blocks in MS insurance coverage today?**

**Ms. Calder:** Access to prescription drugs is a big issue. We have a dozen disease-modifying therapies (DMTs) that are approved by the Food and Drug Administration for MS and these drugs are very expensive. [A recent report in *Neurology* estimated a cost of \$60,000 a year and more.] Many insurers will

only cover the drugs they can get the best price for in their negotiations with drug manufacturers, and they keep their formularies—the list of drugs they will pay for—small and limited.

Another issue is insurers making the decision about which drug is the best choice for a patient. It is easy for insurers to assume the DMTs are all the same, and so they may challenge a prescription drug they think is too costly or unnecessary. Patients also may have to pay more for drugs even if they are covered by their insurance plan. This is called cost-sharing. We hear from people with MS and their caregivers that cost-sharing can be 20% or 30% of the total cost, and that's a lot when you're talking about a drug that runs \$50,000-\$60,000 a year.

Another issue concerns utilization management techniques, practices that health insurers use to make sure they're only paying for drugs that are going to be used and are medically necessary. They often take the form of prior authorization requirements, particularly for refills on expensive drugs. This is a tool health insurers use after a drug has been prescribed but before they authorize payment for it, where they

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## Affordable Care Act Key Resources

The healthcare.gov website not only links you to the health insurance exchange in your state, but it is a rich resource of information about health care issues.

**Website:** [www.healthcare.gov](http://www.healthcare.gov)

**Telephone:** 800-318-2596

## MS Society Health Insurance Resources

The MS Society offers in-depth, MS-specific information on insurance issues; you can also call the Society to talk to a counselor about insurance issues or get a referral to a health exchange navigator in your state.

**Website:** [www.nationalmssociety.org](http://www.nationalmssociety.org)

**Telephone:** 800-344-4867

**For information on specific topics, visit these MS Society webpages:**

**Affordable Care Act:** <http://www.nationalmssociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance/Affordable-Care-Act>

**Job-based Health Insurance:** <http://www.nationalmssociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance/Job-Based-Health-Insurance>

**Individual Health Insurance:** <http://www.nationalmssociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance/Individual-Health-Insurance>

**Medicare:** <http://www.nationalmssociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance/Medicare>

**Medicaid and Other Public Health Insurance Programs:** <http://www.nationalmssociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance/Medicaid-and-Other-Public-Health-Insurance-Program>

**Health Insurance Appeals and Exception Requests:** <http://www.nationalmssociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance/Appeals>

**Resources for the Underinsured and the Uninsured:** <http://www.nationalmssociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance/Resources-for-the-uninsured-and-underinsured>





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insist on going back to the provider and confirming the drug is really needed.\*

Another technique insurers use to control costs is called the “Fail first policy” or “step edits.” This means the insurer may deny coverage of a certain drug, insisting instead that the patient try another, less-expensive drug on their formulary first. If that drug fails, then they will allow the patient to use the other drug.

**Q. What are some tips for dealing with health insurance companies—say, if you want to try one of the newer MS drugs and the insurance company refuses to pay for it?**

**Ms. Calder:** The law guarantees you the right to appeal any decision that your health care insurance plan makes that you are not happy with, so I urge people to use their right to appeal. The National MS Society can help you with that—we’ve outlined tips for working through the appeals process on our website ([www.nationalmssociety.org/Resources-](http://www.nationalmssociety.org/Resources-)

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\*Note from MS Perspectives’™ Tracy Walker, FNP-C: “Prior authorization requests can range from a relatively simple 1-page form to more complicated letters of medical necessity. Regardless of the requirement, understand that it takes additional time and personnel for your health care providers to process these requests, which can ultimately delay or disrupt your ongoing treatment.”

Support/Insurance-and-Financial-Information/Health-Insurance/Appeals), as well as posted template appeal letters for all of the DMTs that you can customize to your particular situation.

One thing you should do is make sure you use the right terminology in your appeals. For instance, if your health care plan doesn’t have a drug you’ve been prescribed on its formulary, ask for “an exception to the formulary.” Make deadlines, write the appropriate letters, and include documentation that supports your case. Keep good records of your interactions with your insurer and follow up—be politely persistent. If your appeal is denied, state that you want an “external review” of the appeal, where the determination has to be made by an independent reviewer outside of the insurance company.





# Get Your News!

Highlights from the Annual

Meeting of the American

Academy of Neurology

The treatment landscape for multiple sclerosis (MS) has progressed in a remarkable way over the past few decades, and breakthroughs continue today as new and emerging treatments for both relapsing and progressive forms of MS are studied in clinical trials. *MS Perspectives*<sup>™</sup> advisor Aliza Ben-Zacharia, DrNP, recently attended the 2015 annual meeting of the American Academy of Neurology (AAN) in Washington, DC, and we asked her to share new findings from the meeting. Here is her report.

## ***New Therapies to Treat MS***

Results of trials of promising new disease-modifying therapies (DMTs) were a highlight of the conference. These include biotin, phenytoin, and anti-LINGO.

**Biotin.** This vitamin (B7) activates an enzyme that may be involved in the synthesis of myelin (the fatty sheath surrounding nerve fibers that is damaged in MS). Therefore, biotin supplements may help to slow, stop, or even reverse the progression of disability associated with destruction of myelin. A French study of 103 patients with primary-progressive or secondary-progressive MS who were treated with 300 mg of biotin daily compared

with 51 subjects who received a placebo was presented at the meeting. After 12 months, the researchers found that biotin improved disability in 13% of those treated as measured by their clinical symptoms and how quickly they were able to walk 25 feet; there was no improvement among the subjects who received a placebo.

**Phenytoin (Dilantin®).** Researchers are looking for drugs that are neuroprotective—meaning they can protect the brain and spinal cord from the damage caused by MS. At the AAN meeting, a British study was presented where the epilepsy drug phenytoin was tested in 42 patients with acute optic neuritis (a common eye condition related to MS) to see if it could protect the nerves in the eyes. Subjects who received phenytoin for 3 months had 30% less damage to the optic nerves than those who received a placebo. Further research will be needed to see if phenytoin can be used in combination with current DMTs for MS or as a way to help protect the central nervous system during an exacerbation.

**Anti-LINGO.** Results of the first clinical trial of a new infusible agent called anti-LINGO in a group of





82 people who were experiencing optic neuritis were also presented at the meeting. Anti-LINGO fosters oligodendrocytes, which are the brain cells that are responsible for myelin production, so it is hoped it will promote myelination and repair damaged nerve fibers (axons). Compared with

a placebo, anti-LINGO did, indeed, significantly improve recovery of optic nerve conduction latency, a sign of myelin repair, although it did not improve the vision in these patients. Another study of this agent is currently in progress to test anti-LINGO in people with relapsing MS.

## NEWS FROM THE MEDICAL LITERATURE

**M**any studies are constantly being published about multiple sclerosis (MS) risk factors, symptoms, tests, and treatments. *MS Perspectives™* asked advisor Barbara Bishop, MS, ANP-C, MSCN, CNRN, to give us some recent highlights from the medical literature.

### **A high salt intake may not just be taboo in cardiovascular disease.**

Recent research, conducted mostly in animals, suggests that dietary salt may increase inflammation in the central nervous system in autoimmune diseases such as MS. In addition, an increased rate of symptoms and activity on magnetic resonance imaging (MRI) testing have been linked to higher sodium intake.

### **Ginkgo biloba doesn't improve thinking ability.**

A 12-week clinical trial that compared the herb ginkgo biloba, long touted to improve brain function, to a placebo in 121 people with MS showed no positive effects on cognition (thinking, memory, concentration).

### **Adding vitamin D to interferon beta-1b may reduce MRI activity.**

A deficiency of vitamin D has been linked to the development of MS. Now, a 1-year study conducted in Tasmania suggests that vitamin-D supplements can reduce MS disease activity as measured on MRI. In addition, this research indicates that subjects who were taking interferon beta-1b disease-modifying therapy (DMT) had higher levels of vitamin D in their systems than those taking other DMTs. This suggests this drug, in particular, raises vitamin-D levels.



## ***Current and New Methods of Following Disease Progression***

Current tests and tools to measure disease activity and progression in MS are limited, and results of clinical tests such as the Expanded Disability Status Scale (EDSS) don't always match radiologic tests such as currently used forms of magnetic resonance imaging (MRI). Therefore, there is a need for better tests and techniques.

**MRI as a marker of disease progression.** A few studies presented at the AAN meeting underscored the importance of new, more powerful MRI techniques as tools for following disease activity in MS. For instance, researchers have seen significantly improved MRI activity using new techniques to track the effects of the infusible drug alemtuzumab (Lemtrada™), an anti-CD52

antibody recently approved by the Food and Drug Administration for relapsing MS. In the CARE-MS I trial, researchers evaluated the effect of alemtuzumab versus subcutaneous interferon beta-1a (Rebif®) in people with relapsing-remitting MS who had never received a DMT before. After 2 years, 78% of the people receiving alemtuzumab hadn't had a relapse compared to 59% of those who received the other drug. The researchers continued to examine how the subjects fared after the 2-year trial ended: At 3 years, 72% of those receiving alemtuzumab had no new MRI activity, and at 4 years, 70% had no new MRI activity.

The CARE-MS II, another 2-year trial, had similar results in patients with relapsing-remitting MS who had had relapses while on other DMTs. Most patients who received alemtuzumab were free of any MRI activity at year 3 (68%) and year 4 (70%) after the trial.

The sophisticated MRI techniques used in these trials are moving to center stage in MS research and may soon be used in clinical practice, too. (Although the effectiveness of alemtuzumab is high, it should be noted that this medication presents a few major safety concerns and is not appropriate for all patients.)

**A topographical tool to better understand each patient's disease course.** An innovative tool called the





Topographical Model of MS developed by Stephen Krieger, MD, looks at the disease course in a new, individualized way for each patient in the context of the broad range of experience clinicians have with the different forms of the disease. Using 3-D animation, it maps the locations in the nervous system where MS has caused damage and is producing

symptoms. It also incorporates the frequency and severity of an individual's relapses, how well he or she recovers, and how fast or slow the disease is progressing. This new tool, developed at the Mount Sinai Medical Center, is still in the testing stage, but shows promise for use in both research and in clinical settings to help guide treatment.

### Support Programs for MS Disease-modifying Therapies (DMTs)

**Aubagio® , Genzyme Corporation:**

[www.aubagio.com](http://www.aubagio.com), 855-MSONE2ONE (855-676-6326)

**Avonex® , Biogen Idec:**

<http://www.avonex.com/multiple-sclerosis-support.xml>, 800-456-2255

**Betaseron® , Bayer HealthCare:**

<http://www.betaseron.com>, 800-788-1467

**Copaxone® , Teva Neuroscience:**

<http://copaxone.com/AboutSharedSolutions.aspx>, 800-887-8100

**Extavia® , Novartis:**

<http://www.extavia.com/info/PatientSupport/Patient-support-program.jsp>, 888-NOW-NOVA (888-669-6682)

**Gilenya® , Novartis:**

<http://www.gilenya.com/c/go-program>, 800-GILENYA (800-445-3692)

**Lemtrada™ , Genzyme:**

[www.lemtrada.com](http://www.lemtrada.com), 855-MSONE2ONE (855-676-6326)

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**Tecfidera® , Biogen Idec:**

<http://www.tecfidera.com/support/ms-support-services.html>, 800-456-2255

**Tysabri® , Biogen Idec:**

<http://www.tysabri.com/ms-support-services.xml>, 800-456-2255

### MS News, Support, and Self-Help Groups

**MS Views & News**

[www.msviewsandnews.org](http://www.msviewsandnews.org)

**MS World**

[www.msworld.org](http://www.msworld.org)

**Multiple Sclerosis Association of America**

[www.msassociation.org](http://www.msassociation.org), 800-532-7667

**Multiple Sclerosis International Federation**

[www.msif.org](http://www.msif.org)

**Multiple Sclerosis Foundation**

[www.msfocus.org](http://www.msfocus.org), 888-MSFOCUS

**National Multiple Sclerosis Society**

[www.nationalmssociety.org](http://www.nationalmssociety.org), 800-344-4867

# Ask the Clinician

**Q.** How can I improve communication between the different members of my health care team?

**A.** The past several decades have seen tremendous changes in the world of health care. Through research and improved technology, we have a much greater understanding of the human body and the medical conditions that affect it. With that understanding have come new treatments and the age of specialized medicine. Specialized medicine has many benefits—especially for people who suffer from complicated conditions such as multiple sclerosis (MS). But along with the benefits come some additional challenges, communication and coordination of care being two of them.

Many of us remember the days when the answer to the question “Who is your doctor?” was *not* a list 3 pages long! Our family doctor was the one doctor who knew everything about us and our health, and when he or she referred us to a specialist it was usually

someone the doctor knew and interacted with on a regular basis. Unfortunately, those days are over, and much of the responsibility for keeping your health care providers informed falls to you, the patient.

But what about electronic medical records (EMRs), you ask? Aren't they supposed to improve communication between members of your health care team? Yes, that was one of the big arguments for the new laws requiring the implementation of EMRs. But the reality is that the technology is still evolving, and right now it can sometimes actually pose a barrier to communication. For instance, there are many forms of EMRs and different providers use different ones. They do not automatically communicate with one another, so in



Tracy Walker





order to see records from other medical providers, the same system of faxing or mailing paper copies is often still the norm.

So what can you do to help the members of your health care team communicate? Here are some tips to help you keep everyone informed.

**1. Keep your own records.** At each visit, ask your providers to give you a copy of their documentation and any tests that have been completed. Then put everything in a notebook or on a jump drive and take it with you when you go to see other providers. Your notebook/jump drive should include all of the doctors you see and their contact information, your diagnoses, a list of all the medications you take, and your pharmacy information.

**2. Keep it “short and sweet” at health care visits.** Many times we are so busy trying to share every little detail of our health that the main point gets lost in the shuffle. Prepare for your visits by making a

note of the one or two biggest problems you need to discuss at that visit, since it’s likely your provider will only have the time to address a couple of items.

**3. Find a good primary care provider (PCP) and see him or her regularly—not just when you are sick.** Specialists are good, but they don’t manage your overall health and wellness. Keep up with recommended preventive care visits and keep your PCP informed of what is going on with your health. And take your notebook/jump drive with you!

— Tracy Walker, FNP-C  
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