



SPRING 2013
INDIANA STATE CHAPTER

MS CONNECTION NEWSLETTER

RESEARCH

PROGRESS ON MS THERAPIES

BY MEGAN WEIGEL, CNP, ARNP-C, MSCN

In 1993, Betaseron was released to market as the first disease-modifying therapy for multiple sclerosis. With the approval of oral teriflunomide (brand name Aubagio®) by the FDA in October 2012, we now have nine disease-modifying therapies to treat relapsing forms of MS—and more on the horizon. The **MS Emerging Therapies Collaborative**, which includes the Society, provides downloadable information sheets at www.ms-coalition.org/emergingtherapies to facilitate communication between doctors and people with MS about newly approved treatments.

Research on potential treatments for progressive forms of MS is also underway and the **International Progressive MS Collaborative**, of which the Society is a member, plans to do all it can to speed the development of those treatments.

Here are the therapies to keep an eye on as we move forward into 2013.

BG-12 is an oral fumarate that has been used



THE MOST ENCOURAGING PART, IN ADDITION TO THE FACT THAT TREATMENTS FOR MS MAY BE GETTING MORE EFFECTIVE, IS THAT THE RESEARCH PIPELINE IS FULL.

in Europe for over a decade to treat psoriasis. Although its exact mechanism of action is not known, it is thought to inhibit immune cells active in MS and may even be protective against damage to the brain and spinal cord.

Two large phase III studies (the DEFINE trial and the CONFIRM trial, respectively) found that BG-12 significantly reduced relapses and disease activity as detected by MRI. The most common side effects were flushing of the skin and gastrointestinal upset. In 2012, Biogen Idec applied to the FDA for approval of BG-12 to treat relapsing MS, and the review process is now underway, with the FDA's decision expected within the year. *(continued)*

(continued from cover)

Alemtuzumab, a monoclonal antibody that depletes circulating immune (T and B) cells thought to be responsible for MS attacks, would be administered by IV infusion for five days and then for three days one year later.

Genzyme applied to the FDA for approval of alemtuzumab to treat relapsing MS, based on positive results from several clinical trials, including one that showed a 55% decrease in relapses compared to interferon beta 1a (Rebif); however, the FDA asked the company to resubmit its application, so a timeline has not yet been established. While this therapy is powerful against MS, there is concern regarding adverse events, such as immune thrombocytopenic purpura (ITP, a bleeding disorder), and autoimmune thyroid disorders.

Laquinimod is a once-daily oral immune modulator that proved in phase III studies to statistically decrease relapse rates though not as robustly as investigators *(continued on next page)*



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hoped. This drug is about to be tested in another phase III study in 1,800 people with relapsing-remitting MS.

Daclizumab and **ocrelizumab** are two other monoclonal antibodies currently under study, with favorable results thus far. A highly concentrated liquid formulation of daclizumab is under study in relapsing-remitting MS. Experimental ocrelizumab, given intravenously, significantly reduced disease activity on MRI scans in a study of 218 people with relapsing-remitting MS. One person died due to brain edema; however, the relation of this death to the medication is unclear. Additional research, now going on in primary-progressive MS and relapsing-remitting MS, is needed to further determine ocrelizumab's safety and benefits.

Clinical trials of treatments for **progressive forms of MS** are currently underway: these include **natalizumab (Tysabri)**, **fingolimod (Gilenya)** and **ocrelizumab**.

MAKING CHOICES

When we consider treatment now, in particular the possibility of switching therapies, we weigh the safety and efficacy of our older, injectable disease-modifying agents against the seeming convenience and perhaps superior efficacy of newer agents. The sequencing of therapies is a new consideration, as well as the effects of medications like natalizumab and fingolimod on the immune system may be prolonged. Questions about new therapies may mean longer or more



frequent appointments with neurologists to discuss their risk-benefit ratios.

Additionally, people with MS may choose to see an MS specialist, or be referred to one by a general neurologist, for treatment recommendations.

However, the most encouraging part, in addition to the fact that treatments for MS may be getting more effective, of course, is that the research pipeline is full. Thanks to those who are committed to research funding, science is able to continue searching for the cure, and on that search, discover medications that will keep this disease as quiet as possible.

To follow progress on potential MS therapies, sign up for MS eNEWS at nationalMSSociety.org/signup, or visit nationalMSSociety.org/research.

Megan Weigel is a Doctor of Nursing Practice and MS Certified Nurse who has been caring for people with MS for 12 years.

NEWLY DIAGNOSED IS IT HARDER TO WORK WITH MS?

JULIE STACHOWIAK, PHD

Many people with multiple sclerosis find it difficult to continue working, even in the early years of the disease. Tasks that seemed challenging before MS can become seemingly insurmountable afterward. The fluctuation of daily symptoms and unknown levels of future disability make mapping out a strategic career path a challenge, to say the least. We simply do not know what the future holds around our ability to perform a job.

I am lucky enough to be able to work from home. I am able to work more when I feel good, less when I feel bad, and take a quick nap if needed. There are days when I can work a full day, but there are many days when I do not feel productive at all — when even looking at the computer screen feels like torture.

I know that as each year has gone on, the problems that I have had in trying to work efficiently seem to get worse. However, recent research indicates that some people who are newly diagnosed or have had an episode of a clinically isolated syndrome may already need

MEMORY ISSUES MAY IMPACT EMPLOYMENT



to adjust their time at work.

Researchers in the Netherlands wanted to look at how MS-related cognitive dysfunction affected work in people who are recently diagnosed with MS. In the Cognition and Socio-Economics (COGNISEC) study, the researchers studied 45 people who had been diagnosed with MS or had a clinically isolated syndrome within the past two years and have been on disease-modifying therapy for less than six months or not at all.

WHAT THEY FOUND:

- People with higher levels of fatigue and disability all decreased their working hours within 12 months following diagnosis.
- Lower long-term memory scores correlated with a lower number of hours and days spent working during the week.
- People who scored lower on “focused attention” and “speed of memory” were

more likely to say they “wished to work less.”

- Scores on tests assessing depression (Beck Depression Inventory) did not correlate at all with quantity of working hours.

While its findings need to be replicated in larger studies, so far this research shows that cognitive dysfunction can negatively impact the capacity to work, even in the very early stages of MS.

WORKING A BALANCE

What does this mean? Let’s face it, even jobs that we love can lose some of their luster when we have to negotiate symptoms that add to our physical disability. While it is tempting to keep pushing ourselves to do more and overcome some of these challenges, it is important to remind ourselves that we may have very real cognitive symptoms related to our MS that are

impacting our abilities to work the same way we did in the past.

On the other hand, many people with MS continue working long after their diagnosis. Disease-modifying therapies, new technologies, better symptom management, legal employment protections and community resources can help you remain in the workforce — and education and preparation can be your most powerful tools for success.



Diagnosed with MS in 2003, Julie Stachowiak, PhD, is the author of *The Multiple Sclerosis Manifesto* and www.ms.about.com.

CALENDAR LOCAL EVENTS

WALK MS: INDIANA 2013

Various Dates & Locations - Walk MS connects people living with MS and those that care about them. It is a day unlike any other! Visit walkMSindiana.org or call 1-800-344-4867 to find a Walk MS location near you.

MIDWEST TELECONFERENCE SERIES

Second Monday of Each Month - The topics

for April - September have been announced! See the article on the back page for more information.

RECENT UPDATES IN MS RESEARCH

Thursday, June 13 - Join us for this free Research Update program in **Bloomington** to learn about what research has been conducted and the direction in which research is headed in hopes of discovering new treatments and ultimately a cure for multiple sclerosis. Featuring David Mattson, MD, PhD, of the IU School of Medicine. Registration will open soon. Watch your mail for more details!

WAYS TO GIVE

A PLACE FOR EVERYONE AT WALK MS

BY LAUREL BENNETT

When she was 93 years old, Rose Hill embarked upon her third Walk MS in honor of her son Michael, who lives with multiple sclerosis. She wanted to do something to help Michael, and so many others who are affected by the disease, live better lives.

To get in shape for the big day, Rose walked laps around her retirement home, determined to be ready for the four-mile Walk MS route. On the day of the event, Rose made it halfway before she started to feel tired. Her family asked if she wanted a ride to the end and her reply was, “No way!” Grandchildren, children and friends held onto her arms and together they trekked toward the finish line. The next year, at 94, Rose registered as co-captain for her team, A Rose for a Cure.

There is a place for everyone at Walk MS—anyone who wants to be inspired, get connected and do something about MS now.

Whatever your experience is with MS, we invite you to join us. Be a part of the Walk MS community. Start a team, join a team or volunteer. No matter how you participate—

ROSE HILL WITH HER TWO SONS, MICHAEL, AT LEFT, WHO LIVES WITH MS, AND LARRY



you don't even have to walk—each step brings us closer to a cure. Go to walkMSindiana.org or call 1-800-344-4867 to register and start fundraising today.

Laurel Bennett is a staff writer for Moore Ink.

THE FIRST STEP

Twenty-five years ago, people living with MS and those who cared about them decided to take their first steps—literally—toward joining the movement to end multiple sclerosis, walking from downtown Minneapolis to the state capitol in St. Paul in the first Walk MS event. They raised \$216,000 toward research and service programs for people with MS. The idea quickly spread, with Walk MS events taking place in more cities across the nation the very next year. Today, Walk MS events raise \$50 million a year, with more than 330,000 people participating nationwide.

LIVING WITH MS

GIVING CARE

BY TERRI KUCZYNSKI, M.DIV., CT

All of us give care throughout our lives, whether it is through holding a hand or helping with daily needs from transportation to bathing. We give care when we listen to another's sadness and when we fix a meal. We give care when we send a card or manage medication.

Giving care to a loved one with MS can be very rewarding and at the same time unbelievably challenging. In some ways being a caregiver is like using a battery-powered drill. At first the drill is fully charged and the task at hand seems to be manageable. As the charge dies down, the task becomes more difficult until the drill just can't continue. The only way to go on is to recharge the drill. If the caregiver does not recharge over time, even the smallest task becomes overwhelming.

SOME WAYS TO RECHARGE ARE TO:

- 01 Ask for help. Even simple things such as getting a gallon of milk for you or providing respite care so you can take a walk around the block can make a big difference.
- 02 Join a support group or an Internet chat room set up for carepartners.
- 03 Take care of your body with proper

nutrition, exercise and sleep.

- 04 Do something — call a friend, write a letter, read — that gives you a daily break from the caregiving role.
- 05 Stay connected within the community — don't become isolated.
- 06 Laugh. Watch funny movies or TV programs.

Just recently I visited a friend who was caring for her husband. We talked about the many difficulties of caregiving. She talked about her feelings of helplessness and shared that at times she felt a lot of anger, which in turn made her feel guilty. She went on to tell me that her husband's physical care could be overwhelming, but keeping track of all the day-to-day activities of life sometimes seemed crushing. She felt weary and alone in this role that she was so unprepared for. After we talked, I walked out of the room and, when I turned to say goodbye, I saw her struggling to help her husband transfer from the sofa to a wheelchair. I then witnessed the true meaning of giving care. In the middle of the transfer, I saw them share a loving embrace.

It was very brief, but very intentional. At that moment I could not tell who was caring for whom. I saw two people caring for each other. What a great way for both to recharge.

Terri Kuczynski, M.Div., CT, is a patient / family counselor at the Rex Cancer Center in Raleigh, N.C. Originally published in CARE eMagazine, Eastern North Carolina Chapter



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PROGRAMS & SERVICES

MIDWEST TELECONFERENCE SERIES

The Midwest Teleconference Series is a free educational program series that focuses on a different topic each month. At 8:00 p.m. EDT / 7:00 p.m. CDT, the second Monday of each month, a variety of experts speak on topics covering all aspects of life with multiple sclerosis. The topic schedule for April through September is as follows:

April 8, 2013 - Calm Before the Storm

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May 13, 2013 - It's Not Just in Your Head

June 10, 2013 - My Family Has MS

July 8, 2013 - WAKE UP!

August 12, 2013 - Probiotics and MS

September 9, 2013 - Complimentary and
Alternative Medicine for MS

For more information or to register for any of the upcoming topics, please call 1-800-344-4867 option 1 or visit nationalMSSociety.org/ini and click the Programs Calendar.