In the past several update surveys, including the Spring 2013 Update, there have been questions about health information and how you get your health information. Well, NARCOMS isn’t the only group interested in this topic!

In a recent nationwide telephone survey reported by the Pew Research Center (www.pewresearch.org), of 3,014 US adults:*

- 81% report using the internet
- 59% said they’ve looked for health information online in the last year
- 35% say they have gone online to try and diagnose a condition

It seems that everyone has a cell phone these days. In the same survey:**

- 85% of U.S. adults own a cell phone
- Of those with a cell phone, 53% have a smartphone
- 17% of all cell phone users say they’ve used it to look for health information

When asked about their most recent serious health issue, people reported getting information or support:

- From a doctor or other healthcare professional – 70%
- From family or friends – 60%
- From others with the same health condition – 24%

**NARCOMS & HEALTH INFORMATION**

While the research about where NARCOMS participants get their health information is ongoing, look for some results to be presented in 2013 and reported in future issues of *NARCOMS Now*!

*From Health Online: http://pewinternet.org/Reports/2013/Health-online.aspx
**From Mobile Health 2012: http://pewinternet.org/Reports/2012/Mobile-Health.aspx
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20 Play: Find These Words: consent, decision, symptom, treatment…

21 Faces of NARCOMS: Still Flying High With MS
Hello,

Welcome to the Spring 2013 issue of NARCOMS Now.

We will be talking about medical decision-making and treatment in MS. As we mentioned in our Winter 2013 edition of NARCOMS Now, new disease-modifying therapies (DMTs) continue to emerge for MS. With the advent of more treatment options, decision-making for MS is becoming complicated. You may ask how clinicians caring for persons with MS think about treatment options and make recommendations?

Clinicians often think about treating MS with respect to four broad areas: treatment of acute relapses, use of DMTs, symptom management, and rehabilitation. The emphasis placed on each may vary over the course of the disease, or with the type of MS. Symptom management and rehabilitation may play a more prominent role later in the disease course, as problems such as impaired mobility, bowel, and bladder management become of greater concern.

Treatment decisions related to DMTs depend on several factors. First, what are the benefits of the therapies with respect to preventing relapses, preventing disability progression, and improving quality of life? Second, what are the risks of the therapies? Third, these benefits and risks need to be considered in the context of the individual patient. What are the chances of the therapy being effective for this person? This will depend on the patient’s past and present clinical status. Clinical factors such as disease course (relapsing remitting versus secondary progressive), number, and severity of prior relapses, severity of disability, and therapies that have been used in the past should be considered. Does the individual have any other health conditions that would increase the risks of therapy? For example, liver disease would increase the risk of liver injury from interferon-beta. Heart disease would increase the risk of heart-related complications from fingolimod.

The clinician will also gather information from the patient about his or her perspectives on treatment. What route of administration— injection, infusion, oral—does he or she prefer? How often is she willing to take a medication? What risks is the patient willing to take? How much benefit would have to be gained for the patient to take that risk? Thus the patient’s “risk tolerance” is a critical preference that the clinician must understand when discussing treatment options. NARCOMS-related research regarding treatment options and risk tolerance will be discussed further in the next edition of NARCOMS Now.

Sincerely,

Ruth Ann Marrie
NARCOMS INFORMATION CORNER

HAVE AN IDEA?

We would love to hear from you! Send us your questions, comments & suggestions.

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Your personal information is always confidential.

The NARCOMS Global MS Patient Registry facilitates multi-center research on multiple sclerosis, developing collaboration between MS centers of excellence throughout the world to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.

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*Choose* the survey you would like to view from the drop down menus and click the View Summary link. *Print like you would any document.*

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Reminder when Completing Paper Surveys:

Please use pen rather than pencil when filling out NARCOMS paper surveys. Responses are scanned to electronic files for data capture and pen is easier to read. Thanks!
Jerry Wolinsky, M.D., is one of the world’s pre-eminent experts in the study and treatment of Multiple Sclerosis (MS), but he didn’t start his career examining MS. Although this giant in the field fell into a lifelong study of MS, he arguably has made some of the bigger discoveries in the field over the course of his career. NARCOMS Now spoke with Wolinsky recently about his work and, in particular, his use of MRI, or magnetic resonance imaging, to diagnose, treat, and advance research in MS.

A little background: Wolinsky is the Bartels Family and Opal C. Rankin Professor of Neurology of The University of Texas Medical School at Houston, and Director of the Multiple Sclerosis Research Group and the Magnetic Resonance Imaging Analysis Center. Wolinsky received his doctorate degree from The University of Illinois in 1969. Residency training in clinical neurology, a fellowship in experimental neuropathology, and faculty appointment at The University of California San Francisco followed. While in San Francisco, his research interests concentrated on the pathogenesis of viral infections of the nervous system, and his clinical efforts began to focus on experimental therapeutics of infections of the central nervous system and multiple sclerosis. He joined the faculty of The Johns Hopkins University Schools of Medicine, and Hygiene and Public Health in 1978 before settling in Houston in 1983. Wolinsky currently is active in the design, implementation, conduct, and analysis of clinical trials of multiple sclerosis and conducts basic and applied research in quantitative MRI and magnetic resonance spectroscopic imaging in demyelinating diseases.

He has served on review and advisory committees of the National Institutes of Health, MS International Federation, Food and Drug Administration, numerous pharmaceutical houses and as interim Dean of the University of Texas Medical School at Houston. Dr. Wolinsky currently oversees the centralized image analysis programs for the NINDS sponsored CombiRx Trial and the sanofi clinical development studies of teriflunomide in MS. He is past chair of both the Research Programs Advisory Committee and National Clinical Advisory Committee of the National MS Society, and past President of Americas Committee for Treatment and Research in MS (ACTRIMS). He is on the editorial board of Multiple Sclerosis and Multiple Sclerosis and Related Diseases, and recognized in Best Doctors in America and America’s Top Doctors. He has authored nearly 300 publications dealing with issues of relevance to neurovirology and neuroimmunology, clinical trials, and the imaging of MS.
**NARCOMS Now: How did you first get involved in MS research?**

When I was doing my fellowship in San Francisco after residency, I thought the simplest way for me to understand the world was through my visual system, and therefore thought it’d be good to learn experimental pathology. I started on a viral infection in the brain. That whole concept fascinated and caught me, how viruses can change and cause different outcomes, how they can persist, and what the host’s responses are to viruses and other infections. Back then the assumption was that MS was a viral disorder waiting for the specific virus to be discovered; so in clinic I increasingly saw patients with MS, which became equally fascinating to me. My focus changed over the years, from the structural to molecular aspects of how viruses are put together and do what they do, to immune responses. This eventually led to how you could apply a very novel technique of magnetic resonance imagining (MRI) to study the pathogens of infections in animal models. In talking with what became a long term collaboration with Dr. Ponnada Narayana, in the early years of starting MS programs at UT I found MRI was an ideal technique to apply to MS. Now, almost all I do now is clinical imaging, trying to develop newer approaches, most in the service of how you understand the effects of novel [drug] agents in people with MS.

**We’re setting out to explain to our readers why MRI is such an important tool in diagnosing and treating MS. How long has MRI been used as such?**

The first MRIs of MS patients were done in the early 1980s, when the technology was just beginning to be applied clinically. From the first time anyone did an MRI with MS, this was the best window we’d ever had to looking at the disease processes for the individual—the excitement was overwhelming.

We learned a tremendous amount from the early advances and early studies to apply MRI as a tool in clinical trials, even when we didn’t know it would be useful. I had the good fortune to have been, in the early 1980s, the chair of the medical advisory board of the National Multiple Sclerosis Society, when a fellow by the name of Byron Waksman was scientific director. We came up with the notion to set aside a small amount of money to entice a few MS centers to add MRI onto their studies as an outcome measure to see how it would work.

Patients often say, “I hate my injections,” or, “I don’t take it as frequently as I should.” So maybe I’ll say, we should do an MRI to see how you are responding, tolerating. It depends on how the patient’s doing.

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"From the first time anyone did an MRI with MS, this was the best window we’d ever had to looking at the disease processes for the individual—the excitement was overwhelming."  
—Jerry Wolinsky, M.D
how the clinician thinks they’re doing, are they apparent disease-activity free. Some define this as no relapses, nor accumulated disability, and no new MRI activity. But no new MRI activity is hard to come by, even in people who are pretty well treated.

**What makes MRI such an effective tool when diagnosing, monitoring, and treating MS?**

The MRI is very sensitive to changes in the mobility of water molecules—their freedom of motion in confined or non-confined areas. Because the lesions of MS tend to disrupt myelin, this leads to very dramatic changes in how free the water molecules in and around cells and tissues are to move. Even with the earliest, low field-strength magnets we could see things that look like what we were used to seeing only at the pathology table, as to how MS brains look. Now with higher field-strength magnets, looking at a really good quality MRI is almost like looking directly at brain tissue in an MS patient. The problem is, it doesn’t come with a label that says, “this is MS,” or “this is demyelination, or partial demyelination,” or “this is alteration of axons.”

It isn’t quite as precise as we would like it to be to be able to understand exactly what’s going on in a patient’s brain, but it’s the closest we can get to taking a person apart and looking at their brain. Depending on how long people can be in the magnet we can see almost the whole motion picture of the dynamics of the disease.

**In addition to magnet strength, how else have MRIs improved over the course of your career?**

We now use gadolinium as a contrast agent, which allows us to look at where the blood is leaking into the brain. What this enables us to do is see—in real time—these multiframe kind of studies to see how active the lesions are. Prior to this, pathologists didn’t know how variable the lesions could be from one to another, or how unusual the patterns could be. That’s helping us to characterize the disease, and controlling activity has translated into most of the drugs we currently use for MS.

**MRI has taken on an increasingly prominent role in how quickly we can diagnose the disease. For MS, because of MRI, we’ve been forced to rethink the diagnostic criteria rapidly in a way that hopefully will allow us to come up with a diagnosis more quickly and more accurately.**

**How often do patients typically get asked to do follow-up MRIs?**

It’s variable—depending on what the patient’s doing and what the clinician’s thinking about. Out of sheer curiosity, I’d be happy to have my patients do one every six weeks, but it’s just not practical. It’s expensive, and most patients don’t like to be “in that tube” that much. When we had just the first round of MS drugs, we didn’t have the option to look. But then we got to the issue of whether we should consider changing therapy very often every so often to see if we should switch from one drug that’s moderately effective to another one that’s moderately effective. Then we started looking a little more often because we understood that if we had more than “x” number of lesions in a certain time frame, maybe the drug wasn’t working, even if you or the patient thought they were doing well.
What do you see in the future of MS treatments?

I hope the next generation of MS drugs will be more directed at how to stop neurodegeneration, independent of the effects on acute lesion enhancements and formation—so, affecting things like atrophy (shrinkage of the brain). The drugs that have an effect on someone’s immediate daily life generally are the drugs that I would call symptomatic, like an antidepressant. We’re really talking about things that are harder to come to grips with and require longer studies, which are changing the natural history of the disease. We’ve got a pretty good handle on the inflammatory components, but not yet on the degenerative component of the disease—that’s the next big frontier.

“MRI has taken on an increasingly prominent role in how quickly we can diagnose the disease.”
—Jerry Wolinsky, M.D

Tell us about your involvement with Band Against MS—country artist Clay Walker’s nonprofit organization?

[Band Against MS is a not-for-profit, public charity committed to providing educational information for those living with Multiple Sclerosis, funding programs researching a cure for Multiple Sclerosis, and funding programs helping those living with the disease. Clay Walker started the organization in 2003.] At first, I only knew Clay as a patient—I didn’t know who he was as a musician. Some time later he came to me and said, “I really want to do something, I really want to find the cure for MS. Or at least I really want to feel like I’m doing something.” Out of that and other conversations came Band Against MS. Clay touches people a lot of ways and has done a very good job of trying to integrate with other organizations like the National MS Society and the Consortium of Multiple Sclerosis Centers, trying to be complementary—I admire his efforts.
Doctor-speak can sometimes be more confusing than your condition. Following are a few commonly used physicians’ phrases decoded to help you understand exactly what your provider means. (And don’t worry, there’s no quiz at the end.)

**What the Doctor Says: Acute**

**What it Means:** Symptoms occurring suddenly over a short period—over the course of days or weeks, not months.

**Versus: Chronic**

A longstanding problem, or one that comes and goes frequently over a long period of time. This term is often used to describe degenerative diseases, including MS.

**What the Doctor Says: Asymptomatic**

**What it Means:** You are without symptoms, even if a test indicates you have a condition.

**What the Doctor Says: Atypical**

**What it Means:** Your test results, symptoms, or conditions aren’t classic or completely normal—which doesn’t mean bad, it just means different. It could mean you need follow-up testing or monitoring.

**What the Doctor Says: Comorbidity**

**What it Means:** Two health conditions are present at the same time. This can also be referred to as coexisting or co-occurring; the two (or more) conditions do not have to be related, but the presence of one can affect the treatment of the other.

**What the Doctor Says: Contraindication**

**What it Means:** A reason not to use a specific drug or procedure, such as being pregnant—when the use of a certain drug to treat an illness could cause harm to the fetus, for example.

**What the Doctor Says: Diagnosis of Exclusion**

**What it Means:** All readily diagnosable conditions have been ruled out; this applies for conditions like MS that have no definitive test.

**What the Doctor Says: Iatrogenic**

**What it Means:** An adverse effect, or not what was supposed to happen. If you develop a skin infection, for example, after having a mole removed, the infection is iatrogenic.

**What the Doctor Says: Idiopathic**

**What it Means:** There is no known reason why you have the illness or condition you have—often used for problems with as-yet unidentified causes. HIV was once considered idiopathic.

**What the Doctor Says: Lesion**

**What it Means:** An abnormal change or spot in an organ or tissue, such as the brain.

**What the Doctor Says: Pathology**

**What it Means:** The precise study and diagnosis of disease through examination of organs, tissues, bodily fluids, and whole bodies (in autopsy). A pathology report would show the results of a biopsy after a suspicious Pap test, for example.
In our Winter 2013 issue, Dr. Robert Fox, Managing Director of NARCOMS, wrote in “MS Reflections” about Progressive MS as “the next frontier” in MS research. In February 2013, Fox and a diverse group of individuals from across the globe making up the International Progressive Multiple Sclerosis Collaborative (IPMSC) took part in the group’s first scientific conference in Milan, Italy.

The collaborative is made up of six MS foundations from the U.S., Canada, the United Kingdom, Italy, and the Netherlands, plus the Multiple Sclerosis International Federation, that are combining forces to address both primary and secondary progressive MS. Progress in research and treatment for the disease have, up to now, “been disappointing” when compared with advances in the relapsing form of MS, Fox says.

“The purpose of this scientific conference was to focus on progressive MS and on the challenges that are before us, with developing effective therapies for treating it,” says Fox. “The meeting was a chance to bring together the researchers involved in all the different aspects of MS,” he says.

Participants ranged from basic scientists who study brain and spinal cord tissue in labs, to geneticists, clinical trial researchers, those who conduct MRIs, clinicians who care for patients, and rehabilitation specialists who perform targeted therapies.

“There really hasn’t been a meeting to bring together these very disparate folks in one room to talk collectively about it,” says Fox.

Also represented were academic researchers, foundation representatives, and individuals representing corporations—including pharmaceutical companies. Importantly, individuals with MS and patient advocates attended the conference as well. The meeting began with a talk by a patient with progressive MS who charged the group at large with finding a treatment, quickly, for progressive MS. The group then discussed the collaborative’s five areas of focus, which are:

1. Experimental Models
2. Identification and Validation of Targets and Repurposing of existing therapeutic agents
3. Proof-of-Concept Clinical Trial Strategies (Phase II Trials)
4. Clinical Outcome Measures (Phase III Trials)
5. Symptom Management and Rehabilitation

“This meeting was less about presentations than it was a chance for the group to gather face-to-face to conceptualize the issues surrounding progressive MS in a way that we can move forward,” says Fox.

For more information on the IPMSC, visit: www.msif.org/en/research/international_pr.html. Look to future issues of NARCOMS Now for updates on the collaborative.
**Q:** Sometimes I read that parts of the survey are supported by a pharmaceutical company. What does that really mean?

**A:** It is very important to know that NARCOMS is a project of the Consortium of Multiple Sclerosis Centers (CMSC), a non-profit organization. The NARCOMS registry is not owned by or linked to any for-profit organization, such as pharmaceutical companies. NARCOMS was designed to expedite MS research by providing a useful resource for researchers. Examples of groups that use de-identified (i.e. data that cannot be used to identify you) NARCOMS data:

- **independent investigators:** physicians, laboratory researchers

- **academic research groups**

- **students:** for MS or PhD level projects, under faculty mentorship

- **government research groups:** NIH, CDC, FDA

- **non-profit groups:** CMSC, NMSS, MSAA

- **pharmaceutical companies:** for research purposes—never for marketing!

NARCOMS charges fees for these projects to cover the time and expense involved in questionnaire design, as well as data collection and analysis. NARCOMS is not-for-profit, so our fees simply cover the costs of operating NARCOMS. The collaborating researchers and sponsoring organizations do not own NARCOMS data. They are only granted limited data access for an agreed upon purpose, such as a publication. Moreover, NARCOMS reviews all manuscripts using NARCOMS data prior to publication to ensure appropriate use of the data.

When a data-collection project is funded by a group outside of NARCOMS, we will always let you know, and give you the option to skip those extra questions or decline to participate in that particular study.

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Visit [www.narcoms.org](http://www.narcoms.org) to find out how!

We enjoy hearing from you. If you have a question or comment, please email [narcomsnow@narcoms.org](mailto:narcomsnow@narcoms.org) or call toll free at **1-800-253-7884**.
Q: Your website says: “Additional support has been provided by unrestricted grants from the following pharmaceutical companies…” What does that mean?

A: Unrestricted grants are monies that have been given to NARCOMS to be used for any part of the program we determine is in need of additional funding. The money is not associated with a specific research project.

If a pharmaceutical company gives NARCOMS unrestricted money, they do NOT have any input or access to the data collected through NARCOMS. It is simply an in-kind gift to support the operating costs of maintaining the database, covering printing or mailing costs for the survey, enrollment packets, brochures and publication of NARCOMS Now.

Companies or organizations can give an unrestricted grant, for example to go specifically to publication of NARCOMS Now. But even in that case, the group will have no input in or influence over the content of the magazine. The money would only go toward the costs of publishing, printing, and mailing the magazine.

NARCOMS strives to present unbiased research results for the information you provide and varied content in NARCOMS Now. We are very proud of the resource that NARCOMS has become and remain grateful for your participation!

TAKE A WALK THIS SPRING!

Please consider taking part in your local National Multiple Sclerosis Society Walk MS event, and “Walk to Create a World Free of MS.” Team NARCOMS will be walking in our chapter’s walk in April but walks take place March—May, nationwide.

The walk is a great opportunity to meet others in your community who support MS efforts, and to raise some of your own funds for the cause. Starting your own team is easy, just visit their site at: www.walkms.org. Look for helpful tips and ideas for pre-walk fundraising ideas.
**SPRING 2013 UPDATE SURVEY**

**Spring 2013 Update Survey:** The survey will be mailed out in mid-April and will be available online from April 15 to June 28. If you receive the paper version of the update, please return it at your earliest convenience, by the end of May.

**New Survey Questions:** In this survey you will find new questions about communication with your healthcare provider, and your thoughts and experiences living with MS. How people feel about their disease and whether they talk about it with others may be related to their disease progression, but there has not been much research done in this area. By asking these questions, we hope to help develop more effective social interventions.

**Patient-Provider Communication**

These questions will ask you about talking to your health care providers over the last 12 months (1 year). This includes your doctors, neurologists, physical therapists, etc. You will also be asked about talking to your health professionals about information you found on the internet.

**Thoughts and Experiences**

These questions will ask you about living with MS. They cover a range of topics from how you feel about your MS, talking about your MS with others, and how you feel about the attitudes that other people have towards people with MS.

As you know, social support is an important part of living with MS, so please be as honest as you can when answering these questions. Remember, there is no right or wrong answer.

If you have any questions about how these updated survey questions apply to you, don’t hesitate to call us at 1-800-253-7884 (toll-free US) or emailing MSregistry@narcoms.org.

*Have an idea for Survey 101?*

Please contact us, via telephone, email or at www.narcoms.org.
OBESITY AS A RISK FACTOR FOR MS

Are you a young woman carrying a few extra pounds? That weight could be cause for concern when it comes to MS. In a recent study in the journal *Neurology*, researchers reported that being overweight or obese was associated with an increased risk of developing MS or clinically isolated syndrome (CIS—a first clinical episode suggestive of MS, indicating increased MS risk) in girls. The study compared 75 children or teens with MS or CIS with the health records of more than 900,000 healthy children or teens. The finding, if confirmed, raises the possibility that reducing obesity could reduce some risk of MS in girls. Annette Langer-Gould, MD, PhD, and colleagues (Kaiser Permanente of Southern California, Pasadena) and others report their findings in the January 30, 2013, online issue of *Neurology*. [http://tinyurl.com/b2c5zl2](http://tinyurl.com/b2c5zl2)

The frequency of obesity has increased dramatically over the past several decades, and is associated with an increase in immune system activity. Dr. Langer-Gould’s study set out to see if obesity was related to the risk for developing MS or CIS. MS occurs most commonly in adults, but also affects children and teens.

“If further research confirms these findings, excess weight could turn out to be a modifiable risk factor that influences the development of MS in children and adolescents,” says Nicholas LaRocca, PhD, Vice President of Health Care Delivery and Policy at the National MS Society. “Finding such risk factors and addressing them is a crucial step toward ending MS.”

The Study: Investigators identified cases of MS and CIS in the database of Kaiser Permanente Southern California, a health maintenance organization (HMO) with more than 900,000 members 18 years old or younger. They found 75 cases, reviewed charts to examine body size, and compared findings with 913,172 child or teen controls without MS or CIS.

The results show that half (50.6%) of the children with MS or CIS were overweight or obese before their diagnosis, compared with one-third (36.6%) of the healthy children. Compared to girls who were not overweight, the risk for developing MS was about one and a half times higher for overweight adolescent girls, and over three times higher for girls who were extremely obese. The increased risk with obesity was not found in boys. The study’s authors suggest that the increased MS risk in adolescent girls in particular may be associated with increases in sex hormones such as estrogen. They comment that although one strength of the study is the large number of healthy controls, the primary limitation is the small number of MS cases studied.

CLINICAL TRIAL STUDY RESULTS ANNOUNCED IN STUDY OF PEGINTERFERON BETA-1A

Drug company Biogen Idec announced that a phase III study of peginterferon beta-1a, injected under the skin either every two or four weeks, reduced the relapse rate significantly more than placebo in a study of 1,500 people with relapsing MS. Peginterferon is a new formulation of the interferon beta-1a molecule which enables it to maintain effects in the body for longer periods of time.
More data from this ongoing study, also called the ADVANCE study, will be presented at the American Academy of Neurology Annual Meeting in March. According to a press release, the company plans to file for regulatory approval in the United States and the European Union in 2013.

**LEMTRADA EXPECTED TO RECEIVE FDA RULING IN 2013**

French drugmaker Sanofi expects the U.S. Food and Drug Administration to rule on its application for multiple sclerosis treatment Lemtrada (alemtuzumab) by the second half of this year.

The injectable drug, which phase III trials have shown reduces relapses and disability progression in people who have not responded to other multiple sclerosis treatments, has already been submitted for review by the European Medicines Agency (EMA). In a statement, Sanofi said an expert committee at the EMA was expected to give its opinion on the medicine in the second quarter of 2013.

Sanofi’s biotech subsidiary Genzyme developed Lemtrada, which was sold until September 2012 under the name Campath as treatment for leukemia. When used for leukemia it is given more frequently, and at a higher dosage. Sanofi withdrew it from the market while it seeks to get it approved as a treatment for MS, although it remains available free of charge to leukemia patients.

**MEDITATION MAY IMPROVE MOOD AND QUALITY OF LIFE FOR MS PATIENTS**

We all know we should slow down, take a deep breath, and take it easy from time to time, but a new study strengthens the argument that meditation may actually improve health. An article in the February issue of *Frontiers of Neuroscience* reports that the use of “mindfulness practices,” including meditation and cognitive therapy, have been shown to reduce distress in chronic pain and decrease risk of depression relapse in patients with illnesses including MS.

The article, “Mindfulness starts with the body: somatosensory attention and top-down modulation of cortical alpha rhythms in mindfulness meditation,” [http://tinyurl.com/cd7ubd5](http://tinyurl.com/cd7ubd5) states that over the last two decades, mindfulness meditation—a practice involving the cultivation of experiential awareness of the present moment—has become an increasingly common component of the healthcare system in developed countries. Such meditative techniques include yoga, sitting meditation, and body scan.

The article states that a standardized form of mindfulness mediation—referred to as “ST-Mindfulness” has shown clinical benefits in trials demonstrating it significantly reduces the risk of depression relapses (with high-risk patients showing the greatest benefit) and it reduces pain-related distress and increases mood and quality of life in severe chronic pain.

*From the article:*

“Based on multiple randomized clinical trials, there is good evidence for the efficacy of these ST-Mindfulness programs for preventing mood disorders in people at high risk of depression, improving mood and quality of life in chronic pain conditions such as fibromyalgia and low-back pain, in chronic functional disorders such as IBS and in challenging medical illnesses, including multiple sclerosis and cancer.”

The authors are: Catherine E. Kerr, Matthew D. Sacchet, Sara W. Lazar, Christopher I. Moore, and Stephanie R. Jones.
IN REMEMBRANCE: National MS Society Staff Member Dr. Patricia O’Looney, Vice President of Biomedical Research

Patricia A. O’Looney, PhD, passed away on February 16, 2013, after a long illness. As a member of the National MS Society’s Research Programs Department for nearly 25 years, O’Looney helped drive many significant research funding programs and initiatives that have improved the lives of people affected by MS.

As Vice President of Biomedical Research, O’Looney oversaw the administration of a large portion of the Society’s research portfolio and provided leadership in expanding many research initiatives.

She led a task force on gender differences in MS, resulting in a scientific strategy article and funding initiative that galvanized the field and led directly to the first large clinical trial of a sex hormone to treat women with MS. She also developed the Society’s Collaborative MS Research Center Awards that serve as incubators of new talent and innovation, encouraging collaborations across scientific disciplines.

O’Looney also enhanced the Society’s fellowship programs, designed to attract, encourage, and train the most promising talent in MS research and care. Under her leadership the Society launched the Sylvia Lawry Physician Fellowship, which trains doctors in designing and conducting MS clinical trials. She was also pivotal in establishing the Tykeson Fellowship Conference, which brings together funded fellows with seasoned researchers to enhance collaborations and help retain multiple sclerosis as a career focus.

“Patricia will be remembered by friends and colleagues for her cheerful demeanor, her generous mentorship to research applicants, and her unstinting willingness to take on new challenges to forward MS research efforts,” commented Cyndi Zagieboylo, the Society’s Chief Executive Officer. “We are deeply grateful for her abiding commitment to the MS movement.”

To honor O’Looney’s substantial role in forwarding MS research and her particular interest in nurturing the careers of postdoctoral research fellows, the keynote lecture at National MS Society’s upcoming Tykeson Fellowship Conference will be named “The Patricia A. O’Looney Memorial Lecture.”

Patricia O’Looney, PhD
Multiple Sclerosis has puzzled neurologists for more than a century. It affects almost any function of the body, comes and goes (or stays) at its own will, and can show up at the most inconvenient times. In the later stages, MS may affect almost every part of life. As a neurologist whose career has focused on MS, I thought it would be useful to share a little of the neurologist’s view of MS.

At its core, MS is a disease where (we think, anyway) the immune system attacks the brain, spinal cord, and optic nerves—the cables that connect the eyeballs to the brain. The attacks can cause a vast range of neurologic symptoms, from numbness to weakness to walking difficulties—even bladder, bowel, and sexual dysfunction. Typically episodes, also called relapses, resolve after several weeks or months, but often leave behind symptoms. In many patients, these relapses are replaced after 10–20 years with a gradually progressive decline in function—the so-called secondary progressive phase of MS. About 10-15% of patients go straight to the gradually progressive phase—so-called primary progressive MS.

Neurologists typically approach MS treatment in a three-pronged fashion: treating inflammation attacks, preventing inflammation, and treating leftover symptoms.

**TREATING INFLAMMATION**

MS relapses (also called exacerbations) arise from a pocket of inflammation affecting the brain, spinal cord, or optic nerve. Neurologists only know that you’re having a relapse because of the symptoms you tell us about. Therefore, it’s helpful to be as precise as possible about your symptoms—their location, characteristics (including frequency), and when they occur. It’s not always easy to know what is an MS relapse and what is something else; so the more information you can share with your doctor, the better. Sometimes there can be a lot of active inflammation on an MRI without any symptoms. This MRI inflammation is also called “gadolinium-enhancing lesions,” detected by using gadolinium dye injected by the MRI technician to find out whether it leaks out of the blood vessels and infiltrates the brain tissue. The dye doesn’t harm the tissue, but its appearance on an MRI is points to active inflammation.

The typical treatment for an MS relapse is a course of intravenous (IV) steroids—often methylprednisolone (also called Solu-Medrol). Steroids reduce inflammation and speed up recovery. Neurologists administer steroids by IV so they can give a large amount to aggressively reduce inflammation. After 3–5 days of IV steroids, a tapering schedule of oral steroids (typically prednisone) is often prescribed to finish the job. If symptoms are mild enough, some neurologists will use oral steroids instead of IV. At the same time it is important to recognize and treat ongoing infections (like bladder infections, for example), which can reduce the beneficial effect of steroids, or remove the need for steroids altogether.

**PREVENTING INFLAMMATION**

There are many approved therapies to prevent inflammation—both clinical relapses and new lesions on MRI. These “disease modifying therapies,” or DMTs, are typically started at the time of diagnosis of the relapsing remitting form of MS.
MS—often after a single episode, called Clinically Isolated Syndrome (CIS). There are many different DMTs available, each with advantages and disadvantages. Perhaps more important than which DMT is started is that some DMT is started. Also, it is important to monitor to ensure the DMT’s efficacy, by assessing clinical relapses— their frequency, severity, and recovery. Most neurologists also use MRI, since new MRI lesions during therapy are a strong predictor of future disability—even in the absence of clinical relapses. The large number of effective treatments has made clinicians more likely to change therapy for either persistent clinical relapses or new MRI lesions while on a DMT.

It is important to have the right expectation from a DMT, and that is: preventing relapses and new lesions on MRI. DMTs are not restorative, and thus are not expected to relieve ongoing symptoms. Also, they don’t typically “make the MS better.” Some patients get a year into therapy and say, “I don’t feel any different or any better,” to which I respond, “You shouldn’t—they’re preventative.” No DMT is 100% effective in preventing relapses and new lesions on MRI in everyone.

Another important aspect of DMTs is that they are not very effective in progressive MS. They still can stop active inflammation (relapses and new brain lesions), but the current DMTs are not very good at slowing the gradual, little-by-little decline in function that is seen in primary or secondary progressive MS. This is huge unmet need in MS, but there has been an increasing amount of research and attention towards progressive MS.

Another tricky area with DMTs is how to know when someone doesn’t need them anymore. MS inflammation typically quiets down as patients get older (i.e. over 50 years), and many patients will “graduate” from needing DMTs at some point—but when? Currently we have no way of knowing in whom inflammation will be reactive if DMTs are stopped and in whom it will not reactivate. Because it’s hard to know, some neurologists will leave patients on DMTs long term—so long as they are not having significant side effects. If patients start having increasing side effects from DMTs, some neurologists will take patients off DMTs, and monitor them for a return of inflammation.

**TREATING SYMPTOMS**

Despite the benefits provided by DMTs, lingering symptoms are common in MS. The list of symptoms is long and varied—basically, MS can adversely affect anything that the nervous system controls. Sometimes-forgotten or -ignored symptoms include depression, anxiety, bladder problems (urgency, frequency, and frequent infections), constipation, and sexual difficulties (decreased libido and impaired function). Although it is often not possible to get rid of these symptoms permanently, almost all of them have some treatment options that can be helpful. Treatments can include medications, therapy (i.e. physical therapy, occupational therapy), adaptive devices, and counseling. Many symptoms have multiple treatment options, so patients shouldn’t give up after only one.

No matter where you are in your MS, the importance of regular visits with your neurologist and ongoing, open conversations about your symptoms as they change, recede, or progress, cannot be overstated. There are therapies available to manage MS symptoms, so maintain close contact with your healthcare providers to keep them in touch with how you’re living—day to day—with this challenging condition.
BRAIN AND SPINAL MRRIS

In 2006 NARCOMS began asking at enrollment if you have had an MRI to confirm your MS diagnosis. In fact, we ask about two types of MRIs: brain and spinal. Did you know you have 33 vertebrae in your spine? The spine or spinal column is divided into 5 sections of vertebrae starting from:

- the top, with 7 cervical vertebrae in your neck
- the upper back, with 12 thoracic vertebrae
- the lower back, with 5 lumbar vertebrae
- the sacrum, with 5 fused vertebrae (forms a single bone)
- to the end, called the coccyx with 4 fused vertebrae

The two types of MRI take images of different parts of your brain and spinal column:

- Brain: usually includes images of your brain and part of your neck
- Spinal: usually includes images of your cervical (neck) or thoracic spinal cord and vertebrae (back), and may include the lower back (lumbar) area

In NARCOMS, of those that have answered the MRI questions, 93.9% have indicated having a Brain MRI and 75.1% a Spinal MRI.

A slightly higher percentage of those that reported a relapse when they enrolled have had a Brain or Spinal MRI compared to those that did not report a relapse at enrollment.

Make sure to read our Feature Focus interview with neurologist Jerry Wolinsky on pages 4–7 on the use of MRIs in MS.
**NARCOMS Now Online Content: Now Exclusively for NARCOMS Participants**

Have you visited *NARCOMS Now* online lately? If you’re familiar with the site you know that in its first year, all articles were available for free on the web.

Now in our second year of publication, we would like to reward our outstanding NARCOMS participants for their efforts by providing you with unlimited access to all content for each issue. Beginning with our Summer 2013 issue, all of the magazine content for each issue will be still be available online, but only for NARCOMS participants. You will need to log in to the site—using your NARCOMS username and password—to view each article in its entirety, or download a PDF of the entire issue. Non-NARCOMS participants that visit the site will see previews of the full content for each issue. The “Letter from the Director” and “Feature Focus” pieces will be always be available online to everyone.

If you have any questions or comments about the new system, please contact us at: narcons@narcomsnow.org.

**NARCOMS at CMSC/ACTRIMS Annual Conference**

In late May, several of the NARCOMS staff will head to Orlando, Florida, to take part in this year’s Consortium of Multiple Sclerosis Centers/Americas Committee for Treatment and Research in Multiple Sclerosis cooperative meeting. Also known as the CSMC/ACTRIMS meeting, *NARCOMS Now* will be there to report on the events of the conference—one of the world’s largest annual meetings of MS researchers, clinicians, patients, and patient advocates alike—including several presentations and posters on NARCOMS data.

On Friday, May 31, 3:15–4:45 p.m., NARCOMS researchers will present a workshop on “NARCOMS in Action.” The course will touch on the history of the NARCOMS registry and our current goals; the use of NARCOMS data for research—what is available and who can use it; using NARCOMS data from a researcher’s perspective; and what NARCOMS plans for the future. For more information, visit the meeting website: http://annualmeeting.mscare.org.
Find the following hidden words:

informed, consent, decision, symptom, treatment, therapy, research, risk, tolerance, option, improving, knowledge, dialogue, medication, meditation

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:
www.narcoms.org/narcomsnow/play/answers
HAPPY TO BE A “ZERO” By John Fiske

A chart in the Winter 2013 issue of Narcoms Now illustrated that the average time to go from 0 to 4 on the Patient Determined Disease Steps (PDDS) scale is 6-1/2 years. I was diagnosed with MS in April 1998, and my PDDS category is still zero. I have no disability, and no symptoms. I have wondered if I actually have MS, and have challenged my neurologist. I dutifully give myself an injection of interferon beta-1b every other evening.

My first symptom—optic neuritis—occurred in October 1990. I was climbing Krakatoa, a volcanic island that sits between Java and Sumatra, when I noticed blurred vision in my left eye. I paused briefly, cleaned my glasses, blamed the antimalarial medication I was taking, and moved on.

In 1996 and 1997 I experienced blurred vision in my right eye when I played hockey. I had a battery of tests, and was diagnosed with recurring optic neuritis. Then in 1998, the neuritis occurred in my left eye. With symptoms in two separate locations, I reached the threshold for a diagnosis of MS. At that time I started interferon medication. In 2001 I had another bout with optic neuritis, and had some intravenous steroid therapy. The neuritis cleared up, and I continued to play hockey.

Since that time, I have had no MS symptoms. When I exercise, the vision in my left eye becomes blurry, but that is a result of Uhthoff’s Phenomenon, a byproduct of a previous attack on my left optic nerve. I stopped playing hockey in 2009. Blurred vision was part of that agonizing decision, but age was a bigger factor—I was 46.

In 2006, a few of my hockey friends were talking about flying—I learned they were pilots. Their conversations rekindled an old interest of mine, and I started flying lessons. Every pilot must have a Federal Aviation Administration medical certificate, and I applied without knowing that MS is a nearly automatic disqualifier. I disclosed the MS in the application, and the FAA denied it. I figured that was the end of that.

A couple of years later, however, I tried again (flying is infectious). This time I submitted results of a driving vision exam, my neurologist’s exam report, and more. I was confident that with these documents proving the mildness of my disease, the FAA would issue a medical certificate. When a fat envelope arrived from the FAA, I tore it open and found a “special issuance” medical certificate, and I restarted flying lessons the next day.

On August 15, 2009, I passed the flight test with a designated flight examiner in Sanford, Maine, and came home with a private pilot’s license! Each year I submit the results of my neurologist’s exam, and the FAA grants me the special, one-year medical certificate. I have joined the U.S. Coast Guard Auxiliary and fly Maritime Domain Awareness patrols along the Maine coast. So far, MS has not been a factor in my life. Yes, I gave up hockey, but I have found other things to replace it. I am more than happy to be a “zero” on the PDDS scale.

John Fiske lives in Massachusetts, teaches writing at Bunker Hill Community College, and is an active private pilot. He can be reached at johnfiske@comcast.net.
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NARCOMS is a project of the CMSC. For more information on the CMSC visit www.mscare.org.