Wow! It has been a full year since we launched the NARCOMS Now “Living with MS” photo contest, and you have submitted some fantastic pictures. We received dozens of entries from you, our readers and participants, all of which offer a unique perspective on your MS lives. One picture was chosen to be featured in the magazine and online.

Now it’s your turn to vote! Pick your favorite online at:

www.narcoms.org/narcomsnow/photogallery

You can vote for the magazine winner and a Reader’s Choice winner from other submitted photographs. You can vote only once, now until January 30th. Winners will be announced in the Spring 2015 issue and will receive a NARCOMS prize pack.

Log on to the website and vote for your favorites! While you’re there, enjoy viewing and reading about fellow NARCOMS participants’ life experiences.
Letter from the Director: Being Well in 2015

NARCOMS Info Corner

Feature Focus: Diet, Nutrition & Living Well

Feature Focus: Writing & Thriving—Blogging About Life with MS

Survey 101: Smoking & Alcohol Questions

NARCOMS Messenger: CMSC in Indy; Ann Romney’s Neurology Clinic

NARCOMS Snapshot: The NARCOMS Marijuana Survey—Early Results

MS Reflections: Specialized Housing for MS Patients

MS News: Lemtrada Approval; Vaccines & MS

Q&A: MS Research Projects; Social Media

Play: Be Well

Faces of NARCOMS: Attitude Adjustment

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Greetings,

Happy New Year 2015! We know we’re not quite there yet but we can’t contain ourselves—we are so excited to be starting our fourth year of publishing *NARCOMS Now* magazine. We’re looking forward to a year where we can continue to bring you news of advancing MS research and treatments. We hope to connect with you in 2015 and as always to respond to your questions and concerns. Please let us know what you’d like to see in *NARCOMS Now* in the future by emailing us at: narcomsnow@narcoms.org.

In this issue we talk about wellness, which can mean many things to many people. Living well often includes elements of a healthy diet and exercise, and we spoke with Denise Nowack, Registered Dietitian for the National MS Society, about how to achieve that balance. (Spoiler alert: there is no magic bullet! But you knew that.) Cathy Chester, a writer and blogger who often tackles the tough topic of all that life with MS can bring, discusses how writing and moderating online communities helps her stay balanced in life.

Alternative therapies can be a way to help achieve wellness in life, and you may have taken part in our marijuana survey this summer. In this issue’s “Snapshot” we present some of that survey’s preliminary results. We hope to present additional findings at scientific conferences this year, and will report that work to you later. NARCOMS’ Scientific Director Dr. Robert Fox conducted an interview with the NMSS blog, “MS Connection” on the topic, published in October 2014.

Did you notice a change in our Fall Survey format? We are asking additional questions in an attempt to better understand your experiences with disease-modifying therapies. Thank you for working through the flow chart and answering these important questions, which will help us tailor our research to the issues that you report matter to you.

In “MS Reflections,” Dr. Malachy Bishop provides an overview of some important research he and his colleagues are conducting, largely using NARCOMS data, on specialized housing issues and needs. Look for updates on their work in future issues of *NARCOMS Now*.

We’re wishing you a happy and healthful new year in 2015. We look forward to continuing to work with and hear from you in our surveys, and as always, by phone or email.

Best,

Dr. Ruth Ann Marrie
Managing Director, NARCOMS
NARCOMS INFORMATION CORNER

Have an idea?

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

Call: 1-800-253-7884 (toll-free US)

Email: narcomsnow@narcoms.org
Online: www.narcoms.org/contact

Who you’ll hear on the phone: Chad or Chasity

NARCOMS Promise

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.

View Past Surveys

Go to: www.narcoms.org

Click on: Participant Log in Here

Enter your username and password.
Select the correct picture, click Login.
Click the Form Summary link.

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.

En Español

Para acceder a nuestro sistema a línea:

www.narcoms.org/es
Nuestro sitio de web es de alto seguridad a para su confidencialidad.

Para solicitar la envía de un cuestionario de inscripción por correo, llame al Registro NARCOMS al (800) 253-7884.

Become a part of NARCOMS:

WWW.NARCOMS.ORG / 1-800-253-7884

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!
No matter where you are in life, diet and nutrition are an important aspect of everyday living—after all, you’ve got to eat. It can be hard to make healthy eating choices, or even understand what they are, in a world where food fads constantly change. Combining healthy eating choices and an exercise regime with the complications that living with MS can bring can be perplexing. Is there a best diet for MS?

The better question might be, is there a “best” diet for you, suggests Denise Nowack, Registered Dietitian with the National Multiple Sclerosis Society. Nowack has worked for the NMSS’s Southern California & Nevada Chapter for 18 years, out of Los Angeles.

“Nutrition is always an area of interest, no matter what condition you’re living with,” Nowack says.

Prior to joining the team at the NMSS, Nowack had no experience in working with MS patients or clinicians. Today she is working to translate nutrition information that is widely available into practical programs for addressing MS. She works with community partners in MS care and local universities such as the University of California Los Angeles and University of Southern California.

“Trying to help people understand how to make healthy choices to live their best life with MS is a really big part of what I’m trying to do,” she says.

“Nothing is Conclusive”

Regarding the ideal MS diet, Nowack says, “the honest truth is we don’t have that research yet, and nothing is conclusive.” In fact researchers are still working to understand how dietary factors may influence getting MS and how they may impact disease progression.

A recent study presented at the 2014 joint ACTRIMS-ECTRIMS meeting in Boston found that none of three dietary indices measured at baseline—the Alternative Healthy Eating Index-2010 (AHEI-2010), the Alternate Mediterranean Diet Index (aMED), and the Dietary Approaches to Stop Hypertension Index (DASH)—was significantly associated with the risk of developing MS in two longitudinal cohort studies. The study, conducted by Dalia Rotstein, MD, Clinical Fellow in Neurology, Brigham and Women’s Hospital, Cambridge, Massachusetts, prospectively followed more than 185,000 women from the Nurses’ Health Study (NHS) and the NHS II.
Prior studies yielded inconsistent or insignificant results with respect to the role of diet in MS development. Rotstein’s study is the first large, prospective, population-based study to investigate the relationship, and it shows no evidence of an association between overall dietary quality and MS.

Vitamin D and MS

Studies have been conducted suggesting those with lower levels of vitamin D may have greater disease progression. Dr. Alberto Ascherio of the Harvard School of Public Health published research in early 2014 showing that among patients mainly treated with interferon beta-1b, low vitamin D levels early in the disease course are a strong risk factor for long-term MS activity and progression. (JAMA Neurology, March 1, 2014).

A study published in July 2014 out of Sweden reported no links between levels of vitamin D present at birth and the risk of developing MS later (Annals of Neurology). Clinical trials are ongoing in this area, looking at specific effects of vitamin D on patients with relapsing-remitting MS, for example (NMSS).

Vitamin D is a fat-soluble vitamin that is naturally present in very few foods, but can be found in some fish, in fish oil, egg yolks and in fortified foods such as milk, orange juice and breakfast cereals. Your body also produces vitamin D from the sun. Ask your doctor if you should have vitamin D blood levels tested (the NMSS recommends this: tinyurl.com/ows6b8p.

Exercise and Weight

It has been noted that changes in mobility and activity due to MS, and symptoms like depression, can cause some MS patients to gain weight. Carrying around extra weight can increase fatigue symptoms. Lifestyle changes promoting exercise may be as helpful for overall well being as dietary choices, Nowack says, and she urges people with MS to be proactive, and not fearful about exercise.

“With exercise, you meet the person at his or her function level and modify where necessary,” she says. “Together with a physical therapist and knowledgeable fitness professional, you can develop an exercise plan that can work for you.”

A Complex Combination

There is more to good nutrition than the quest for a perfect diet, Nowack says, because “there’s a lot going on with MS. You have your symptoms that impact nutritional well being, then vice versa, and other health conditions that you can’t neglect.” The level of manageability of a healthy diet is nearly as important as the diet itself, she says, because despite best intentions, it can be difficult maintaining the plan you have in place during MS relapses.

“Diets cycle. People jump easily on a trend and sometimes it’s even a detriment, especially to their economics,” Nowack states. Factors such as how dietary choices can interact with medications taken for MS must also be taken into consideration.
Advocating for Wellness

Finding advocates for diet and exercise plans for MS patients as part of their care can be a challenge, Nowack says. She questions whether it’s realistic to expect a neurologist, for example, to discuss dietary issues with his or her MS patients, given time limitations on appointments. But she insists, “Conversations around eating well, exercising and lifestyle habits are all important for MS clinical teams to have with their patients as part of their disease management.”

When patients are first diagnosed with MS, Nowack says she finds many of them are proactive and take charge. They seek benefit in the situation to say, “this helped me to refocus on what matters most.” This is an ideal time for a dietitian nutritionist to step in and help guide food choices because when a person presents with a new symptom, their first thought likely won’t be their diet. It helps to have a plan in place.

Nowack points out that nutrition and exercise are currently not medically reimbursable, and suggests this is an area worthy of advocacy. “It’s not easy to get in front of a registered dietitian,” she points out. That said, she suggests patients always ask their clinician for a referral to a dietitian, “for pitfalls in their diet where there might be nutritional gaps.” Patients may also have access to nutrition and other lifestyle programs hosted by the community or area medical centers. Even programs designed to treat diabetes or heart disease, for example, could benefit.

“Health care professionals can be partners in helping people, to support them when they get off track,” she says. “It’s my goal on the professional side to help them understand.”

Nowack and her NMSS team in Southern California, in conjunction with the UCLA MS team, designed a program called “Living Well” for the newly diagnosed. This 12-week course addresses nutrition, exercise, spirituality and understanding the disease at a pace that is dosed so that someone who is newly diagnosed can absorb. Participants have an ongoing dialogue with the diagnosis team, including psychologists and spiritualists. The program charges a nominal fee for registration and touches on stress, social support, sleep and other factors that put people at an overall health risk, then offers strategies for coping.

Look for an interview with Denise Nowack and Dr. Ellen Mowry on “Diet & Nutrition” on the National MS Society’s blog, “MS Connection.”
Words of Wellness

Cathy Chester is a 50-something New Jersey writer who has turned her love of the written word into a voice for people—and particularly women—living with MS. She has a blog called “An Empowered Spirit: Living a Healthy and Vibrant Life After 50,” and she is a contributing writer for the Huffington Post. She also writes for and moderates the online community at MultipleSclerosis.net.

Chester was diagnosed with MS in 1987, six years after she graduated from college. It took a serious car accident followed by numbness in her foot, to her shoe falling off mid-stride in a Manhattan bus terminal (without her noticing) before she went to a neurologist and learned she had a disease she knew nothing about. “I had never heard of it before,” she recalls.

Chester went from being a vibrant young professional living and working in Manhattan, back to living with her parents and taking heavy doses of steroids—one of the only MS treatments available then.

Chester’s neurologist was not a specialist in MS. He referred her to the National MS Society, to whom she wrote “by snail mail,” and requested brochures. “That was about the extent of the support available for MS at that time,” she says.

Times, of course, have changed—as has Chester’s preferred mode of writing, which is now online. “When I was diagnosed it was not easy to keep up with MS news and information—there was nothing,” she exclaims. Now she writes and moderates MS online communities daily, and stays current by subscribing to Google alerts and following MS trends on Twitter.

“The one group I moderate has extraordinary people in it, who are always sharing the newest information—they are a huge source,” she says. “Sometimes you find out more about what’s going on with MS on Facebook than anywhere else. It’s a robust community.”

Chester began writing in earnest when her son went to high school. She started out writing about midlife issues, but soon moved into writing about life with MS and “using our ability despite our disability,” she says. She quickly found herself a member of a very large and robust blogging community of more than 1,000 “midlife women,” as she calls them. They meet online and also in person.

“It’s been extremely gratifying, following my passion and growing by learning,” she says. “I moderate the MS community online everyday in a private group and for MultipleSclerosis.net. I feel like I’m their voice sometimes, and that’s the most gratifying of all.”

“I don’t always want my writing to be about MS because that’s just a small part of me,” she adds. “There’s so much to write—life is delicious.”
In every NARCOMS update survey we ask whether you smoke and/or drink alcohol. These questions may seem repetitive, especially if your answers to these questions are the same every update. However, current information on these topics is really important in MS research. A search of the US National Library of Medicine of the National Institute of Health (www.pubmed.gov) for “smoking and multiple sclerosis” returns 346 research papers about the relationship between smoking and MS and 993 articles on “alcohol and multiple sclerosis.”

Smoking is associated with an increased chance of developing MS. Persons with MS who currently smoke tend to experience faster disease progression than those who have quit smoking or who have never smoked. So when NARCOMS studies progression of MS, it is very important to include both current and past smoking status, and to report any change in smoking habits.

Alcohol depresses the central nervous system and can have an increased effect for people living with MS. Alcohol can also have dangerous interactions with some medications, including some used for MS, like antibiotics and antidepressants. Both smoking and alcohol use may be associated with decreased mobility and increased depression.

MS is a complex disease that affects everyone differently. Accounting for health behaviors like smoking and alcohol use may help to explain differences in how the disease changes over time. Making positive changes like quitting smoking or reducing alcohol consumption are important steps in managing your disease. Make sure to speak with your health care providers about these issues and how they can assist you.

As always, thank you for taking time to complete these questions!

NARCOMS Research on Health Behaviors:

Health literacy association with health behaviors and health care utilization in MS: a cross-sectional study tinyurl.com/oke6j5e

A cross-sectional study of bone health in MS tinyurl.com/lkbql3x

Smoking status over two years in patients with MS tinyurl.com/kh4cooy

High frequency of adverse health behaviors in MS tinyurl.com/n3gddfj

For more information on health behaviors and MS:

National MS Society: tinyurl.com/lwqyg53
Make Sure Your MS Health Care Team Knows About the CMSC Annual Meeting

There’s nothing like the smell of burning rubber to get you revved up! Taking place in Indianapolis just after the Indianapolis 500 from May 27–30, 2015, the CMSC Annual Meeting is among the most important educational events on the latest MS treatments and emerging therapies, research, models of care, epidemiology, genetics, rehabilitation, and much more.

The CMSC Annual Meeting agenda includes lectures, workshops, symposia, roundtables, and networking opportunities and provides continuing education credit for physicians, nurses, pharmacists, and social workers. Specialty tracks focus on rehabilitation, patient advocacy, symptomatic management and skills development, to name a few. We urge you to remind your health care providers about this opportunity to learn more about the latest in MS research and care.

To register and for more information, have your health care providers visit: www.annualmeeting.mscare.org.

Ann Romney Launches Neurology Center in Boston

Ann Romney, wife of former Massachusetts Governor and presidential hopeful Mitt Romney, has announced the opening of the Ann Romney Center for Neurologic Diseases at Brigham and Women’s Hospital in Boston. The Center has announced plans to fund research in five of the world’s most complex neurologic diseases: MS, Alzheimer’s disease, ALS (Lou Gehrig’s disease), Parkinson’s disease and brain tumors. The center is set to open in 2016, and will be co-directed by Dr. Howard Weiner.

Romney says she had to drop off her husband’s presidential campaign in 2012 when her MS symptoms became overwhelming. Now in remission, Romney and her husband say they plan to raise $50 million for research.

The center plans to bring 200 scientists under one roof to study these neurologic diseases. For more information visit: tinyurl.com/ovv9z2j

NARCOMS will be hosting booth L11 near the exhibit hall entrance, plus presenting research based on NARCOMS data—provided by you!—in presentations and posters. Look for more details as we get closer to the date.
NARCOMS’ Marijuana Survey—Early Results

In August 2014, we invited NARCOMS participants to complete the “NARCOMS Survey on Marijuana and MS.” We are pleased to report that over 5,600 participants responded! The full results of the survey will be available later in 2015 but here are a few highlights:

**Gender**

While more women than men completed the survey, these response rates are consistent with the gender breakdown for MS in general.

**Progressive:**
- I’ve never had a relapse

**Progressive:**
- But I used to have relapses

**Relapsing Stable:**
- I have not had a relapse in at least 2 years

**Relapsing Active:**
- I’ve had a relapse in the last 2 years

**MS Type**

10% indicated their MS as progressive without ever having had a relapse.

The largest group of participants indicated their relapsing MS is stable.

90% of participants reported they have had relapses in the past.

Most (91%) reported that they think marijuana or medical marijuana should be legal.

But 58% think it should be legal only with a prescription.
Participants were asked their opinions on marijuana use and medical marijuana products. They were asked if they have ever used marijuana, considered using marijuana, and if they have discussed using it for their MS with their doctor.

They were also asked about all ways of taking marijuana: smoking, oral (in the form of a pill or oil), topical (like a lotion or a patch), or a spray like Sativex®. If marijuana or medical marijuana were legal where they lived, participants indicated they would prefer a pill (47%) or topical form (28%), while 18% said they wouldn’t use it even if it was legal.

**Considered Marijuana**

Just over half of the participants (53%) reported having considered using marijuana or medical marijuana for treatment of their MS.

20% have discussed it with their doctor.

**Legal?**

Most (91%) reported that they think marijuana or medical marijuana should be legal.

But 58% think it should be legal only with a prescription.

Thank you to everyone who participated and look for more results soon!
Researchers have found that maintaining independence and safety in the home is a major concern for adults with multiple sclerosis (MS). Although MS symptoms are highly individualized, many commonly experienced symptoms of MS—including fatigue, mobility problems, numbness, diminished strength and coordination, chronic pain, and visual impairments—can make it increasingly difficult to function safely and independently in the home, and participate in valued activities outside the home.

Unfortunately, although the home is a centrally important place in one’s life, there has been relatively little research attention on the housing experiences of people with MS. Specifically, there is very little information available concerning the extent to which people with MS need, have access to, and utilize specialized housing options. Specialized housing is a term that refers to housing that is, or has been made to be accessible and that includes any needed supports. This includes housing that has been modified or adapted, such as with the addition of ramps, grab bars, and widened doorways, as well as housing that was purposefully designed to be accessible. We recently completed a National Multiple Sclerosis Society–funded research project to comprehensively evaluate (1) the need for specialized housing for people with MS, (2) the resources available to meet these needs, and (3) the barriers people with MS face to accessible housing. We have published several articles on this project in special issues of the Journal of Rehabilitation and the Journal of Vocational Rehabilitation, and are publishing additional findings in upcoming issues of Rehabilitation Research, Policy, and Education, and Work: A Journal of Prevention, Assessment, and Rehabilitation.

INTRODUCTION

We collected data from over 5,000 participants with MS, primarily recruited through the NARCOMS registry. We asked a wide range of questions related to household structure and composition, the level and form of assistance required in the home, the level of mobility and functional capacity in and around the home, current residential accessibility, the need for housing modifications, and knowledge and awareness of various housing laws, services, and resources.

The sample included participants from each US state, the District of Columbia, and Puerto Rico. Most of the participants were female (77.8%). The average age was 54. The majority of the participants were married (67.4%). The average age at MS diagnosis was 38.27 years and the mean number of years since diagnosis was 15.8. The majority of the sample reported the course of their MS as either relapsing-remitting (57.8%) or secondary progressive (22.1%), followed by primary progressive (7.9%), and progressive relapsing (4.3%).
FINDINGS

A number of important findings resulted from this research, and will be used to inform policy, practice, and services for people with MS. They will help promote advocacy and resources development in specialized housing. Some of the key findings included:

1. Over 70% of the participants reported some degree of mobility limitation that affected their ability to function in their homes and participate in their communities.

2. Almost 1 in 5 surveyed Americans with MS said that they are limited in their home because it is not accessible. Participants over age 50 were significantly more likely to report that they were limited by inaccessible homes.

3. Although about 44% of participants said they had made renovations or changes to their home to make it more safe or accessible, 26.3% said that their financial situation prevented them from doing so.

4. Of particular concern was the high number of people who said that they need, but do not have, safety and accessibility features such as grab bars in the bathroom (15.2%), or such basic necessities as an accessible bathroom, an accessible kitchen, or an accessible entrance to their home (about 10% each).

5. Although there are many programs and resources available to help people afford making their homes safer and more accessible, most people were unaware of these programs.

6. 12.2% were not confident they would be able to live independently in their residence in two years’ time.

7. About 10% reported having experienced housing discrimination, primarily with respect to rental housing and restrictions in making housing modifications.

8. Regardless of the severity of the MS, people whose residence was fully accessible reported a higher quality of life and were more confident that they would be able to live independently in their home in the future.

Several findings led us to conclude that although functional limitations will likely increase over time for most people with MS, the impact of increasing functional limitation on residential accessibility and independence can be significantly reduced by residential modifications, renovations, or the installation of accessibility features.
CONCLUSIONS

Based on what we learned in this project, and what we know about MS, we recommend that housing accessibility be a consideration in any long-term housing decision for people living with MS. This is especially true for people near or over the age of 50, because people over 50 were significantly more likely to report having a mobility limitation, to be limited in their residence, and to say they are not confident that they will be able to continue to live independently in their residence in the near future.

We also recommend that healthcare providers have a more active role in evaluating residential accessibility and safety, and in providing information on specialized housing resources. Safe and accessible housing for people with MS is important to their health, safety, and quality of life. Unfortunately, previous research has shown that medical and rehabilitation professionals rarely discuss residential accessibility with their patients.

Although our analyses of the data are ongoing, as the first national analysis of the specialized housing needs of Americans with MS, this project has already provided important information about the relationship between residential accessibility and a variety of rehabilitation outcomes, including independence, quality of life, and physical and psychological health. This research suggests that addressing barriers to residential accessibility for persons with MS should be made a rehabilitation research and advocacy priority. The researchers wish to acknowledge the support of the NARCOMS participants and National Multiple Sclerosis Society. This study was made possible by a Health Care Delivery and Policy Research grant from the NMSS.

To read the full text of the scholarly article where these results were published, visit: www.ncbi.nlm.nih.gov/pubmed/23752298

Visit the National Multiple Sclerosis Society’s website to read an interview with Dr. Bishop about “Housing Needs of People with MS” - tinyurl.com/o3y8gms

Malachy Bishop, Ph.D, CRC, is Professor of Rehabilitation Counseling and Rehabilitation Counseling Doctoral Program Coordinator at the University of Kentucky, Lexington. Dr. Bishop’s clinical background includes rehabilitation counseling, rehabilitation psychology and neuropsychology in physical medicine and rehabilitation and other health care settings. He conducts research in the employment and psychosocial aspects of chronic neurological conditions, including multiple sclerosis, epilepsy, and brain injury. Dr. Bishop is on the editorial board of several professional rehabilitation journals. He has authored over 95 professional journal articles and book chapters in rehabilitation and health care, edited 3 books, and made over 60 research and training presentations throughout the U.S., and internationally.
SPECIALIZED HOUSING RESOURCES:

» **Centers for Independent Living**
Community-based nonprofit organizations that provide services related to: Peer Support, Information and Referral, Individual and Systems Advocacy, and Independent Living Skills Training. Local Centers for Independent Living can be found at: tinyurl.com/keedxct

» **State Assistive Technology Act Programs**
Provide information on a range of programs to help people access assistive technology resources. The programs also support activities designed to maximize the ability of individuals with disabilities and their family members, guardians, and advocates to access and obtain assistive technology devices and services. tinyurl.com/kbpl2j4

» **State and local Housing Authorities**
The Department of Housing and Urban Development, including the Office of Fair Housing and Equal Opportunity, can provide information about affordable and accessible housing, and housing rights for persons with disabilities. www.hud.gov

» **National Multiple Sclerosis Society**
Your local chapter of the National MS Society can be located at: www.nationalmssociety.org/chapters

» **Social Security Administration**
People receiving Supplemental Security Income (SSI) may use PASS plans (Plan to Achieve Self-Support) for home modifications. tinyurl.com/lhvazne

» **Americans with Disabilities Act (ADA) Accessibility Guidelines**
These guidelines establish accessibility and design requirements for the construction and alteration of facilities subject to the ADA, including places of public accommodation, commercial facilities, and state and local government facilities. tinyurl.com/p3mg6xs

Kathy Sheppard-Jones, Ph.D. is the training director at the Human Development Institute, Kentucky’s University Center for Excellence in Developmental Disabilities. She directs several projects related to increasing accessibility, including Belonging in the Community, Home Assessment and Modification Services, Driver Rehabilitation, and Technical Assistance to the Kentucky Office of Vocational Rehabilitation. Her research interests include quality of life, consumer satisfaction, and agricultural applications of rehabilitation technology.
FDA Approves Lemtrada for Treatment of Relapsing MS

In a reversal of its original decision, the U.S. Food and Drug Administration on November 15, approved Lemtrada (alemtuzumab, Genzyme, a Sanofi Company) as a disease-modifying therapy for people with relapsing forms of MS. The decision comes 11 months after the FDA originally declined approval of Lemtrada, which is approved for use in Europe, Australia, and Canada (see “MS News,” Summer 2014 / tinyurl.com/qxvz555).

Lemtrada is recommended for consideration in patients with relapsing MS who have had an inadequate response to two or more MS therapies. It is given as intravenous infusions, first for 5 consecutive days, then for 3 consecutive days, 1 year later.

“The FDA approval of Lemtrada is a significant milestone for people living with relapsing MS in the United States,” said Dr. Timothy Coetzee, Chief Advocacy, Services and Research Officer at the National MS Society (www.mssociety.org). “We are pleased that that the voices of the MS community have been recognized and that people with relapsing MS will now have access to a new, needed treatment option.”

Lemtrada is an antibody directed at CD52, a protein on the surface of immune cells. It causes depletion of white blood cells. It was originally approved, at a significantly higher dose, for the treatment of B-cell chronic lymphocytic leukemia. Its ability to target immune cells led investigators to test its potential as a treatment for relapsing MS.

“The approval of Lemtrada provides an important and immunologically powerful new therapeutic option for people with relapsing MS,” said Bruce A. Cohen, MD, Professor, Davee Department of Neurology and Clinical Neurosciences at Northwestern University’s Feinberg School of Medicine. “Its long-lasting effects may profoundly influence the course of relapsing MS, but will require careful and sustained monitoring for side effects which people receiving the medicine must follow. Individuals with MS who are considering treatment with this medicine should thoroughly educate themselves on its potential benefits and risks,” he added.

All patients prescribed Lemtrada will be required to be enrolled in a Risk Evaluation and Mitigation Strategy (REMS) program to ensure that ongoing periodic monitoring will be maintained to detect potential problems.

**Potential benefits:** The FDA approved Lemtrada based on the results of two large, phase III clinical trials that confirmed its ability to significantly reduce relapse rates over two years over standard subcutaneous dosing of Rebif (interferon beta-1a, EMD Serono Inc. and Pfizer). One of the studies also suggested that Lemtrada may reduce worsening of disability. Alasdair Coles, FRCP (University of Cambridge) and Jeffrey Cohen, MD (Cleveland Clinic) and colleagues published the complete results of CARE-MS I and CARE-MS II in The Lancet (2012;380:2819 / tinyurl.com/q9mf9sd).

**Potential risks:** Prescribing information for Lemtrada includes a boxed warning about the potential for serious, sometimes fatal, autoimmune conditions such as immune thrombocytopenia (a rare bleeding condition) and anti-glomerular basement membrane disease (which impacts the kidneys).
Genzyme executives said Lemtrada will be priced at $158,000 for two courses of treatment over two years. Rebif, a drug compared with Lemtrada in clinical studies, costs $134,600 for a similar treatment regimen, or 17 percent less. But the Genzyme executives pointed out that patients on Lemtrada suffered 50 percent fewer relapses than those taking the other drug.

**Vaccinations Not Linked to Increased Risk of MS, Study Says**

A new study published in *JAMA Neurology* (Oct. 20, 2014 / tinyurl.com/ndztqtg) finds no association between certain vaccinations and increased risk of central nervous system (CNS) disorders, including MS. The findings contradict previous research that indicated some vaccines could increase risk for CNS disorders.

“The concern that vaccinations could induce a small increased risk of multiple sclerosis and other acquired central nervous system demyelinating syndromes (CNS ADS) remains controversial,” notes the research team, led by Dr. Annette Langer-Gould of Kaiser Permanente in California.

In particular, concerns have been raised about MS risk following vaccinations for hepatitis B, after studies claimed the vaccine could break down myelin (a fatty substance that protects nerve fibers)—a process believed to contribute to MS. Some studies have also suggested a link between the human papillomavirus (HPV) vaccine and increased risk of CNS disorders.

Dr. Langer-Gould and her team say such studies have been subject to important limitations, such as a small number of vaccinated cases and incomplete case-finding methods.

In this latest study, the researchers set out to assess the link between vaccinations and MS and other central nervous system disorders in more detail. The researchers analyzed health records from members of Kaiser Permanente Southern California (KPSC). They identified 780 patients with central nervous system disorders, and 3,885 controls.

The researchers analyzed electronic vaccination records to identify vaccines the patients received, and to assess the relationship between vaccinations and subsequent development of MS or central nervous system disorders.

They found no link between any studied vaccines—including HPV and hepatitis B vaccines—and an increased risk of MS or any other central nervous system disorder up to 3 years following vaccination.

However, they did find a link between vaccines and increased risk of central nervous system disorders among younger patients in the 30 days after vaccination, but the association disappeared after 30 days. The researchers say this indicates it may trigger a relapse in people who were bound to develop MS a month or two later.

“In this nested case-control study, we found no long-term association between vaccines and MS or other CNS ADS,” the researchers comment. “Our findings do not warrant any change in vaccine policy.”
**Q:** Why isn’t every NARCOMS research project offered to every NARCOMS participant? I read about NARCOMS research and wonder why I wasn’t invited to participate.

**A:** What a great question! One of the reasons that NARCOMS is instrumental in MS research is the diversity of our participants. There are newly diagnosed participants and those who have been contributing information for almost 20 years, all in various stages of the disease.

Some research is focused on specific aspects of the disease that may not apply to everyone. Some projects are limited to specific conditions, like those with tremor (tinyurl.com/khcl53o) and others are unrestricted and open to all participants (see “Snapshot” page 10).

Some surveys are available only online in order to reduce the cost associated with printing, mailing, and data entry of paper surveys. We try to make accommodations to those who complete updates on paper when we can and costs allow.

In order to be considered for additional research projects, please make sure you keep your contact information up-to-date and complete the semi-annual surveys so we can determine who is eligible for each project.

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**Q:** Does NARCOMS have a Facebook page—I can’t seem to find it? Can I talk about NARCOMS on my social media accounts?

**A:** NARCOMS does not have a Facebook page right now. There are a few reasons for this, most are related to the limited staff at NARCOMS to manage an account. To have a Facebook page, we would like it to be managed daily and kept up-to-date with the most recent NARCOMS and MS related information.

Since NARCOMS is a non-profit project, our staff is small and focused on carrying out the research projects. So until we can provide a top notch presence on Facebook, we will focus on our Twitter account, you can follow us @NARCOMS.

But just because we do not have an official NARCOMS Facebook page doesn’t mean you can’t talk about NARCOMS on your page! Please feel free to share NARCOMS research by including links to www.narcoms.org or share NARCOMS Now stories from www.narcoms.org/narcomsnow.
Be proactive and talk

Tell your healthcare professional about the largest North American meeting of multiple sclerosis clinicians and researchers.

The 2015 Annual Meeting of the Consortium of Multiple Sclerosis Centers
May 27 - 30
The JW Marriot Hotel * Indianapolis, Indiana
www.mscare.org/2015

Our meeting is unique in bringing together all groups committed to improving the lives of people with MS: neurologists, radiologists, physiatrists, clinical researchers, basic scientists, nursing professionals, rehabilitation specialists, mental health professionals, members of the non-profit community and the corporate supporters. By attending, your healthcare professional will learn state-of-the-art information on the latest treatments, research, models of care, epidemiology, genetics, and much more, to bring you the very best in MS care.
Find the following hidden words:
grow, thrive, breathe, explore, passion, health, sleep, exercise, nutrition, peace, walk, learn, love, exhale, enjoy

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:
www.narcoms.org/narcomsnow/play/answers
What I’ve Lost and What I’ve Gained

Like most everyone reading this article, I could fill many pages with what I have lost. But that doesn’t gain me anything. Instead, focusing on what I’ve gained gives me much more pleasure and endurance for tomorrow. Expecting—and accepting—the unexpected is very challenging.

I had probable MS for more than seven years before MRI results confirmed MS in 1997. As with everyone with MS, my version of the disease is not textbook. It’s ugly, no getting around that fact, but I have learned more about real patience. I always thought that I was a very patient individual (I had to be, I was a teacher). As it turned out, this has been, and continues to be, a major life lesson. I definitely haven’t arrived yet, but I hope others see real progress.

I have learned to express my love to my family (I’m a man, you see) and focus on how much they mean to me. Likewise, my friendships are much more meaningful to me. I’m more sensitive to pain others are experiencing (it’s much easier for me to relate now). Focusing on other people and their pain, not mine, has been very rewarding and a really nice change for me. Like most people, I was never rude to the challenged, just either unaware or not understanding of their problems.

People don’t want me to forget my disease, it seems. Once I get to know people better, they quit overreacting and relax, especially after I let them know I’m OK with my circumstances. Don’t get me wrong, I do wish it would have all been different for me, but it wasn’t—obviously. Life has not been a bed of roses, but focusing on what “coulda” been leads to focusing on self. So, I can grow old being a really good whiner, or I can enjoy the abilities that are left. My circumstances are what they are.

— Gary J.