EVOLVING MS
Looking Forward with an Eye on the Past
Congratulations to NARCOMS Now Photo Contest Fall 2014 Winner, J. Sidney from Storrs, CT.

“Adaptive Skiing”

“Skiing into the sunset.”

— J. Sidney
02 Letter from the Director: A History of MS, and Switching Medications
03 NARCOMS Info Corner
04 Feature Focus: An Evolution of MS Treatments
10 Survey 101: Fall 2014 Updates on Therapies
12 MS Reflections: Patient Perspectives on Switching DMTs
14 NARCOMS Messenger: Media Cover NARCOMS / Photo Contest
15 NARCOMS Snapshot: DMTs in the Fall Update Survey
16 MS News: HIV Drugs Fighting MS? A New MS Drug
18 Q&A: How Big IS NARCOMS? We Hear You!
19 MS Apps & Blogs: Treatment Tracking Apps
20 Play: Find the following words… Discovery, research, therapy, progress…
21 Faces of NARCOMS: Mindset and Living Well With MS

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Hello,

We’re back to fall again, hopefully finding you relaxed after a summer of fun. School is in session and here at NARCOMS the research is year-round. You may have noticed we’ve been ramping up our efforts with a new online survey about marijuana use. Thank you to all who participated; we look forward to sharing the results of that with you in future issues of NARCOMS Now. As always we appreciate your participation in the Spring Survey, and hope you’ll contribute again as we distribute the Fall Survey in October.

This issue touches on the history of MS research developments and disease treatments. Two giants in the field of MS research, Dr. Thomas “Jock” Murray and Dr. Robert Herndon, discuss how the strategies to understand and treat MS have evolved over the past 60 years. Both posit that the future in MS research looks bright.

This issue’s “MS Reflections” tackles a topic to which you may have responded on a NARCOMS survey: switching disease-modifying therapies (DMTs). NARCOMS researchers Amber Salter and co-authors Ruth Ann Marrie, Stacey Cofield, Gary Cutter, and Tuula Tyry all contributed to this recent publication about why patients change DMTs.

Recent “MS News” includes a study looking at the lack of comorbidity between HIV and MS, and asking whether the virus or the antiretroviral treatments for it may protect against MS. Also a large survey of physical activity levels in individuals living with MS shows that despite the challenges, exercise may improve overall wellbeing.

Finally, our fourth NARCOMS Now photo contest winner of the year is featured on the magazine’s inside front cover. We have extended the photo submission period through the fall, so please continue to email us your images at: narcomsnow@narcoms.org. You will have the opportunity to vote on an overall winner in our Winter 2015 issue.

We welcome fall and hope you will enjoy this issue. As always, we invite your feedback at: narcomsnow@narcoms.org.

Sincerely,

Dr. Robert Fox is the Managing Director of NARCOMS, the Medical Director at the Mellen Center for Multiple Sclerosis and a practicing neurologist at the Cleveland Clinic in Ohio.
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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Enter your username and password. Select the correct picture, click Login. Click the Form Summary link.

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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!
Robert M. Herndon (above, left), MD, Professor of Neurology at the University of Mississippi Medical Center, has studied multiple sclerosis for nearly 50 years. In that time he has seen drastic changes—for the better—in our knowledge of the disease. As the science and technology available to study the disease improve, so do the methods with which we tackle this chronic illness. There have been some missteps along the way; but recent years have brought advances, including imaging and oral treatments, to name a few.

In spring of 2013, Herndon presented the opening lecture, “60 Years of Neurology and MS,” at the Consortium of Multiple Sclerosis Centers (CMSC) /Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) annual meeting in Orlando, Florida. We spoke with Herndon about the changes he has seen in the research and treatment of MS over the course of his career, and what the future holds.

Herndon first began studying MS in 1968 by looking into an electron microscope. “When I saw myelin bits and pieces, I thought we had a new diagnostic test,” he says.

This method led directly to the myelin basic protein assay, a test that is positive in MS, “but unfortunately it’s positive in anything that breaks down brain tissue—it’s too broad,” Herndon says.

The methods used in the race to understand and treat MS over the past 60 years are too vast to outline in one article—books have been written on the topic—but here we take a look at some of the high- and low-lights of MS treatment and research over the years.

- Read more about MS history for Dr. Thomas “Jock” Murry (above, right) on page 8.
1950s
- Oral steroids are used to treat acute attacks.
- In 1955 Dr. John Kurtzke develops the Disability Status Scale (DSS), designed as an interval scale.

"We have now reached a point where we can begin to define what we mean by complete arrest of the disease process, and can achieve it in a substantial number of our patients."

1960s
- 1962: First report of remyelination in animals—the phenomenon by which new myelin sheaths are generated around axons in the adult central nervous system (CNS). This follows the pathological loss of myelin in diseases like MS.
- 1963: Oligodendrocytes are identified in electron micrographs. These cells maintain homeostasis, form myelin, and provide support and protection for neurons in the brain. Herndon and his colleagues made this identification.
- The first anti-spasticity agents (diazepam, methocarbamol) are introduced.
- 1969: The first successful MS clinical trial occurs in ACTH (corticotropin, an immunosuppressant), which remains an approved treatment for acute attacks.
- Valproate is introduced in Europe then the U.S. to treat seizures.

1970s
- Introduction of intermittent catheterization for bladder management, which decreases bladder infections.
- The hot bath test comes into wide use. “We’d put the patient in a warm water tank until their temperature reached 102 degrees (F) and it would bring about neurological changes,” Herndon says. “We were getting them hot to find out what sort of problems we could elicit to help make the diagnosis, because we didn’t have any imaging.”
- 1970: A formal study is conducted on the effect of cooling on symptoms.
- A major expansion of the search for viruses in MS
- 1971: Clinical trial of azathioprine—an immunosuppressant agent
- The use of computers for managing clinical trials begins to come into wide use.
- The introduction of muscle relaxants for spasticity, including Baclofen and Dantrolene
- Improved scanners develop rapidly, and for the first time, doctors can see intracerebral hemorrhage (ICH).
1980s

- **Magnetic Resonance Imaging (MRI) is introduced:** “The MRI showed the brain with far more plaques than we would’ve thought possible,” Herndon says. “Initial scans were crude but it quickly became clear the MRI was important for diagnosing MS.”

- **1982:** First International Conference on Therapeutic Trials in MS takes place in Grand Island, NY; with co-chairs Robert Herndon and Jock Murray.

  “This set the stage for more and better-quality clinical trials in MS—it really was the beginning of the modern era for MS,” Herndon says.

- **1983:** The EDSS or Extended Disability Status Scale is developed.

- **1983:** Washington Conference (Poser) diagnostic criteria developed

1990s

**The age of Phase III Clinical Trials**

- Interferon beta-1b (Betaseron - 1993)
- Interferon beta-1a (Avonex - 1994)
- Interferon beta-1a (Rebif)
- Glatiramer acetate (Copaxone – 1996)
- High dose methylprednisolone (ONTT trial)—optic neuritis

2000s

- Mitoxantrone (Novantrone)
- Neuromyelitis Optica (NMO) antibody is discovered
- Natalizumab (Tysabri)
- Fingolimod (Gilenya)
- Anti-CD20 (Rituximab)
- Teriflunomide (Aubagio)
- Dimethyl fumarate (Tecfidera)

- **2012**—The Cleveland Clinic holds a conference on complete arrest of the disease process. “This was the first time we ever talked about complete arrest as a goal,” Herndon recalls, “and we now think we’re well on our way.”

TODAY

“We have now reached a point where we can begin to define what we mean by complete arrest of the disease process, and can achieve it in a substantial number of our patients,” Hendon says. “Believe me, if you’ve been in the field as long as I have it’s truly wonderful.” Herndon points out that for relapsing-remitting MS there is already a halt of progression. “I think right now if we work it right, we can probably get a complete arrest in about half the patients, and think within five years it’s going to be 85-90% complete arrest.”

He says researchers are focused on some work that could make a big difference in primary progressive MS, reiterating that major strides have been made. “It used to be that after 10–15 years about 80–90% of patients moved into secondary progressive MS—now that’s less than 50%.”
WHAT DOES THE FUTURE HOLD?

Today Herndon’s main research focus is neuromyelitis optica, which is considered in the same family of disease as MS and is prevalent in Dr. Herndon’s home state of Mississippi. He emphasizes that he is glad to see quality of life issues come to the forefront in disease treatment—particularly in MS. “This is a great improvement over the glossing over that occurred back in the earliest days of MS diagnosis and treatment,” he says. “We have come so far in a lifetime, it is truly amazing,” Herndon says.

Dr. Herndon’s List of Treatment Fads Over the Years

“These have been a major distraction because every time they come along, we have to prove whether they work or not, and it diverts funds that would be better used in other trials,” Herndon says. “Some new treatment works on somebody, they pass word around, and next thing you know you’ve got another fad going.”

- Calcium orotate—A form of calcium
- Snake venom
- Cow’s colostrum—A milky fluid emitted by the breast in the first few days after giving birth
- Royal jelly—A honey bee secretion
- Amalgam removal—Removal of amalgam or metal fillings in teeth
- DMSO—Dimethyl sulfoxide, an industrial solvent and byproduct of making paper
- Chelation therapy—Most often involves the injection of ethylene diamine tetraacetic acid (EDTA), a chemical that binds, or chelates, heavy metals including iron, lead, mercury, cadmium, and zinc. Effective for lead poisoning—not MS
- Mega-dose vitamins
- Procaine—A topical anaesthetic similar to novocaine
- Ultrasound stimulation of the lymphatic system
- Gluten-free diet—No one diet has been proven effective for MS treatment
- CCSVI (chronic cerebrospinal venous insufficiency) treatment—A surgical opening of the veins, believed to increase blood flow to the brain and spinal cord and alleviate MS symptoms; currently under study in the US, Canada, and other countries. For more information see ClinicalTrials.gov (http://clinicaltrials.gov/ct2/results?term=CCSVI&Search=Search).
Dr. Thomas “Jock” Murray is considered one of the foremost experts in the history of MS. He is the author of *Multiple Sclerosis: The History of a Disease*, which reviews 150 years of MS, including how our knowledge and understanding of the disease has changed over time.

“I’ve been a medical historian throughout my career in medicine,” Murray says. “Since I was involved in the care of MS patients it was only natural for me to write it. It took me about 20 years of research to write that book.”

He was President of the Canadian Neurological Society and a founder and President of the Consortium of MS Centers (CMSC). Murray is retired from clinical practice but remains very active teaching, lecturing, and publishing articles and papers on medical history.

Despite a conception that the treatment of MS is relatively recent, Murray says, there were hundreds of treatments for the disease as far back as the 1920s and 1930s. “They didn’t change the outcome of the disease at all, and most didn’t have any benefit,” he says. “In those days they didn’t do randomized clinical trials. If you believe something will help and you give it to someone and they say they feel better, you keep giving it to other people.”

Dr. Jock Murray
OC, ONS, MD, FRCPC, FAAN, MACP, FRCP, FCAHS, Honorary LLD, DSc, D.Litt, DFA, LL.D
Professor Emeritus, Dalhousie University

Dr. Murray is the former Dean of Medicine at Dalhousie University. He was a founder of the Dalhousie MS Research unit, and also of the Consortium of MS Centers, and of the Canadian Network of MS Clinics. He initiated the medical humanities Program at Dalhousie.

He served as President or Chairman of many organizations, including the Consortium of MS Centers, The Canadian Association of Medical Colleges, The Canadian Neurological Society, the Canadian Society for the History of Medicine, the American College of Physicians and the American Osler society. He received many awards for contributions to MS, medical education, medical humanities and medical history, and five honorary degrees. He is an Officer of the Order of Canada, and has been inducted into the Science Hall of Fame, and the Canadian Medical Hall of Fame.
After WWII the concept of the randomized controlled trial developed, in the 1960s. “It was a relatively new idea that you could design the trial that could truly judge whether something had benefit,” Murray says.

“Before that, if you had a new treatment you gave it to a bunch of people and tried to guess whether or not it made a difference.”

Most treatments didn’t, he says. Only steroids showed limited benefit in reducing severity and duration of an acute attack, but they didn’t show a difference in patient outcome, he says.

Murray marks the next major treatment breakthrough decades later, in the early 1990s, with clinical trials of interferons. Since then, there have been a series of drugs that continue to improve outcomes, but also come with increasing risks. “However, very often the risk is small and the benefit is worth it,” Murray says. “Now you have to balance that and ask—given that risk, is the benefit worth it?”

Another consideration is financial cost, Murray says. “If you decide that the benefit is worthwhile you have to say, ‘Yeah but is the cost of the benefit worthwhile?’”

Add to that accessibility, or the fact that a drug can be approved in one country and not another. “In Canada we had Rebif a couple of years before the U.S., for example, but in England you couldn’t get it because they judged that the drug didn’t make enough of a difference to justify the cost,” Murray says.

Each country makes a decision about what drugs they will approve. Once a country decides they’ll approve a drug, the insurance companies have to decide they’re going to pay for it.

Murray offers his prediction for the future of MS treatments. “We will see a step-wise development of better drugs that have greater benefit, and we will also be able to show that the drugs have a long-term benefit in terms of disability,” he says.

“**We will see a step-wise development of better drugs that have greater benefit.**”

Murray notes what he calls a “remarkable interest in MS compared to back in the early 1970s, in which there were very few centers or clinics and very few interested in the disease.” He credits the development of new drugs to the tremendous interest by clinicians in MS. “Before that it was spoken of as an untreatable disease,” he recalls. “Initially you had general neurologists who might develop an interest in an area. Now many young neurologists will do a fellowship and study MS.”
The Fall 2014 update survey will focus on the decisions you make about treating your MS with Disease Modifying Therapies, also called DMTs or immunotherapies. In every survey you answer questions about your recent DMT use, but this time, you will be asked about how you have used DMTs over the entire course of your MS – including not taking DMTs.

You’ll be asked to pick your pattern of DMT use based on this picture:

Once you have selected your group (A, B, C, D, E, F, or G), you will be asked questions about how you made the decision to: never take a DMT (group A); take the same DMT (group B); take a break from your DMT (group C); switch DMTs (group D); or completely stop all DMTs (groups E, F, and G).
What Kind of Questions Will Be on the Survey?

For each answer group (indicated in BLOCK letters), there will be questions about:

- Who was involved in making the decision: Did you make the decision alone, did your doctor make the decision, or were family and friends also involved?

- Choosing the most important reasons for your decisions: Questions that ask you to choose the most important reasons for your decisions.

There are two steps in answering these questions:

1. Read the list and check the reasons that were not important in making the decision.

2. Rank and number all the remaining reasons in order of importance—with the most important reason being number 1. For example:

<table>
<thead>
<tr>
<th>Did Not Apply</th>
<th>Rank</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3</td>
<td>Reason A</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Reason B (a ‘1’ means this is the most important reason)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reason C</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Reason D</td>
</tr>
</tbody>
</table>

Why is This Information Important?

Making treatment decisions is not an easy process. Among other things it involves trying to understand changes in formulas and doses of medicines, changes to insurance coverage, and how well each medicine works. Personal preferences, physician recommendations, and new medication options may have a major impact on the decision, so it is important to understand how all factors affect treatment choices.

The answers you provide will help NARCOMS generate a more complete picture of the challenges faced by patients navigating treatment options. We thank you in advance for completing this special section.
With the advent of new therapies for multiple sclerosis, the complexity of managing disease-modifying therapies (DMTs) has increased. From decades-old first-line injectable DMTs to the latest oral therapies, all DMTs have benefits, and side effects. As treatment options expand, the need becomes greater for physicians to understand their patients’ preferences for switching medications.

In a recent supplement to the NARCOMS surveys, NARCOMS polled qualified participants on their perspectives on switching DMTs. The results were published July 4 in the journal, Patient Preference and Adherence.

INTRODUCTION

Switching among DMTs in the case of break-through disease appears to be a common practice. Adverse events, adherence, cost, and risk tolerances are all factors in the decision to switch medications.

NARCOMS mailed a “Patient’s Perspective” survey to registry participants who had reported switching a DMT in 2011. It asked about reasons for switching DMT, origin and discussion of DMT change, and which factors influenced the decision.

Participants identified their current DMT and the length of use, how often they took it, and how well it worked. Also, participants reported which DMT they had taken just before their current DMT, and how long they took the prior DMT.

DMTs were grouped as injectables, oral therapies, infusion therapies, or other (such as intravenous immunoglobulin, or IVIG).

RESULTS

Four hundred and seventy of the 691 potential candidates (68.6%) responded to the supplemental survey. Eighty-three percent of the responders were women. On average they were 52 years old, with a median Patient-Determined Disease Steps score of 4-early cane (of a range of 0-Normal: mild/no symptoms to 8-Bedridden). Those participants who responded to the survey were more likely to be Caucasian, older, and have a longer disease duration than those who did not respond to the survey.

We included 308 of these responders in this analysis. Participants who were included were taking first-line injectables (35.4%), infusion (23.1%) and oral (41.6%) DMTs. Overall, three-quarters of participants had been on their prior DMT for a year or more before switching.

The discussion to switch DMT was started almost equally by physicians (48.7%) and participants (49%). A higher proportion of participants started the discussion when switching to an oral DMT compared to those switching to a first-line injectable or infusion therapy.
The participants who started the discussion to switch were asked why they did so. The main reason for choosing a new DMT was based most frequently on physician’s recommendation (24.5%) and the patient’s perception that the treatment was not working (13.7%). Patient-initiated switching showed a higher proportion of doing so because of a dislike of the infusions or injections.

In the supplemental survey, 74% of the participants would not consider switching back to their previous medications or trying something else. Those on an oral DMT were more likely to prefer staying on their DMT (81.3%) than those on an infusion (77.5%) or first-line injectables (63.6%). Eighty-nine percent of participants felt they had enough information about their new treatment at the time of the switch. Only 14.4% reported using information from the internet as a source for initiating the discussion to switch.

CONCLUSION

Newer therapies have different risk–benefit profiles compared to the first-line therapies, but all are used to prevent relapses, changes on MRI and progression of disability. Physicians must consider many factors when managing DMTs, including how to tailor therapy to the needs of the patient.

Almost 85% of responders to the supplemental survey ranked the physician managing their MS as their most trusted source of treatment option information.

Shared decision-making (SDM), a concept that focuses on patient and physician communication in the medical decision-making process, is well suited to practice in MS. It involves the exchange of information between the physician and patient, where the patient communicates their values, risk attitudes, and treatment goals. Its importance will likely increase in the management of MS over time, as treatment options evolve.

Amber Salter received her Masters in Public Health (MPH) in Epidemiology from University of North Texas Health Science Center in 2005. After 3 years as a Research Coordinator at the UT Southwestern Medical Center Multiple Sclerosis Clinical Center in Dallas, TX, Ms. Salter moved to the University of Alabama at Birmingham as the Research Manager and Senior Statistician with NARCOMS and to pursue a PhD in Biostatistics. While at UAB, Ms. Salter has been involved in over 60 presentations and publications related to MS research.
Media Cover NARCOMS “Switching” Presentation at CMSC/ACTRIMS

Switching to fingolimod (Gilenya, manufactured by Novartis) or an injectable therapy after two years of treatment with natalizumab (Tysabri; Biogen Idec Inc) is associated with an increase in disability progression reported by patients with multiple sclerosis (MS), according to a recent study.

That research, presented by NARCOMS’ own Dr. Stacey Cofield, at the 6th Cooperative Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and the Americas Committee for Treatment and Research In Multiple Sclerosis (ACTRIMS), received significant media coverage. The work was funded in part by Biogen Idec.

“Discussions on continuing, switching, or stopping medications should happen frequently between MS patients and their physician,” says lead researcher Stacey S. Cofield, PhD, associate professor, School of Public Health, University of Alabama at Birmingham. “The conversation should weigh the benefits and the risks for each individual patient.”

The new study looked retrospectively at disability progression using data collected in the NARCOMS surveys. Specifically, questions included in the section on immunotherapies, where NARCOMS asks what participants have taken in the previous 6 months, and if they have switched therapies.

The researchers categorized the participants who had taken natalizumab for at least 2 years into 3 groups: (1) those who remained on natalizumab (n = 406), (2) those who transitioned to fingolimod (n = 60), and (3) those who switched to an injectable therapy: either glatiramer acetate (Copaxone, Teva Pharmaceutical Industries Ltd) or an interferon β-1a (n = 71).

Cofield stressed that all participants must have been receiving natalizumab at least 2 years before switching to fingolimod or an injectable medication.


Cofield will present a poster on the findings at the upcoming ECTRIMS-ACTRIMS 2014 Annual Meeting, taking place in Boston September 10–13.

For a link to the presentation abstract, click here: https://cmscactrims.confex.com/cmscactrims/2014/webprogram/Paper2602.html

NARCOMS Now Photo Contest Winners

You have submitted some wonderful photos for our “Living with MS” contest. We will run images of winners from previous issues in Winter, and ask you to vote for a winner! Look for details in the next issue of NARCOMS Now.
Thank you to everyone who completed the Spring 2014 update! With nearly 8,000 completed surveys, you have provided almost 4,000 “person years” of information on living with MS. Person years is a measurement that takes into account both the number of people in NARCOMS and the amount of time each participant provides information. The number of people and the amount of time are equally important in determining what happens over the entire course of MS—so thanks again for volunteering your time and information!

In every update, you are asked questions about Disease Modifying Therapies (DMTs), including not taking them or switching to new ones. In this update:

• 61% of participants reported using a DMT in the prior 6 months

• Of those taking a DMT, 22% reported some kind of change, with switching to a new DMT the most common reason for a change.

For those who had a change, the number-one reason for making the change was “Intolerable Side Effects,” followed by “Lack of Efficacy (Not Working),” and “Financial Reasons.” In the Fall 2014 update NARCOMS will be asking you for more information on why you have or have not taken DMTs, and the reasons you make these choices. For more information on the Fall 2014 Update, see “Survey 101” on Page 10.
Comorbidity: HIV Infection—or Drugs Used to Fight It—May Prevent Against MS?

Julian Gold, researcher at The Albion Centre of Prince of Wales Hospital in Sydney, Australia, recently published findings of a study showing that HIV infection—or the drugs used to combat it—may prevent against MS. Dr. Gold, who treats individuals with HIV, noticed in his years of work with the disease that none of his patients had MS. The study was published in the *Journal of Neurology, Neurosurgery and Psychiatry*—a journal of the *BMJ*.

There are more than 1 million peer-reviewed studies documenting HIV and/or MS. Among these, there has only ever been one case report of an individual with both conditions who was treated with HIV antiretroviral drugs. After one year of treatment, the patient’s MS improved.

Danish researchers looking at that patient’s case hypothesized that the antiretroviral HIV treatments may have treated the MS or halted its progression.

Gold and colleagues analyzed data from English Hospital Episode Statistics between 1999 and 2011, involving 21,207 patients in England with HIV and more than 5 million controls. (The data lacked information on patients’ ethnicity and how many were exposed to antiretroviral treatment.)

The rate of onset of MS suggested that among that cohort, there should have been 18 cases of MS. Gold found 7—a statistically significant result. It indicates, his study suggests, that those infected and undergoing treatment for HIV are 60% less likely to develop MS than their uninfected peers. Moreover, further analysis showed this value leapt to 80% among those who had been infected and treated for more than five years.

Gold’s article remains cautiously optimistic and suggests additional studies are needed. “If subsequent studies demonstrate there is a causal protective effect of HIV and/or its treatment,” he writes, “and if the magnitude of it proves to be similar […] this would be the largest protective effect of any factor yet observed in relation to the development of MS.”

The research team suggests that immunodeficiency triggered by HIV, even without antiretroviral treatment, could prevent development of MS. They note that antiretroviral drugs used to treat HIV may also curb other pathogens linked to MS, such as herpes viruses and human endogenous retroviruses (HERVs).

The next step, as suggested in an editorial accompanying the journal article, may be “to directly examine the association between exposure to antiretroviral therapy and the development of MS (Mia van der Kop, epidemiologist, University of British Columbia in Vancouver, Canada).

FDA Approves New Injectable Therapy Plegridy

The FDA approved use of a new injectable MS treatment on August 15. Plegridy, manufactured by Biogen Idec, will be marketed as a longer-lasting treatment for U.S. patients with relapsing-remitting multiple sclerosis.
The approval came less than a month after the European Commission approved Biogen Idec’s medicine for sale in 28 countries across the Atlantic.

Plegridy has the same active ingredient, interferon beta, as Biogen Idec’s first MS drug, Avonex, which is still being sold. Biogen Idec attached a polymer called polyethylene glycol, or “peg,” to Plegridy that increases the exposure of the drug, allowing patients to take doses less frequently. While Avonex has to be injected into the muscle once a week, Plegridy can be taken by injection every two weeks, administered under the skin with a prefilled auto-injector.

“As a proposition for patients, it’s a very attractive compound,” said Gilmore N. O’Neill, vice president of multiple sclerosis research and development for Biogen Idec. “It gives patients another choice.”

Physical Activity is Associated with Improved Quality of Life for People with MS

The idea that physical activity improves quality of life for those living with MS has been reinforced by a large international study. The study surveyed online 2,232 individuals living with MS via MS societies and social media platforms.

It is well documented that in healthy populations, regular or increased physical activity provides physical and psychological benefits. However, for those living with MS, researchers continue to debate the benefits of exercise. Fatigue partnered with balance and coordination issues can make exercise challenging for MS patients.

In this survey, participants answered a questionnaire in which they quantified their physical activity using the International Physical Activity Questionnaire, which asks about exercise and duration of sitting each day. Increasing disability was associated with lower levels of physical activity, with more than 80% of people in the high-disability group falling into the “low physical activity” category.

In the low-disability group, only 37% of people practiced a high level of activity. The remaining 63% were either moderate or low exercisers, with 36.5% practicing moderate activity, and the remaining 26.5% exercising little.

Physical activity correlated with gender, age, and BMI. Males were generally more active than females, but that difference only reached statistical significance in the low-disability group. Older participants were generally less active than younger, and participants with higher BMI scores were less active than those with lower scores.

Once they controlled for age, gender, disability, and physical activity, the researchers found no significant relationship between physical activity and relapse rate. The researchers also did not find any correlation between disease activity and physical activity levels.

The researchers found that physical activity and quality of life were highly associated with each other.

The study was published in BMC Neurology (Marck et al., 2014).

As always, talk with your doctor before starting a new exercise routine or other treatment/activities.
**Q:** I have been a participant in your online surveys since 2004. Is the NARCOMS survey that I do twice a year the largest ongoing survey relating to multiple sclerosis in the United States?

**A:** Thank you for your continued participation! And yes, NARCOMS is currently the largest, longest ongoing survey for MS in the U.S. With continued new enrollments and your participation, we hope to remain among the leaders in MS research.

**Q:** It would be great to see more MS research and fewer lifestyle pieces, is that possible?

**A:** For most issues we try to limit the lifestyle pieces to a single short feature. Sometimes, like with the recent summer issue, there are two lifestyles pieces that are better published together. We appreciate the feedback and will continue to strive to keep the issues balanced to appeal to all of our participants.

**Q:** I wanted to let you know that I really love reading NARCOMS Now and I really enjoy doing the large font word find that you have in the back. And, I am enjoying the thick pages that make it much easier for me to turn the pages! I’d like to shake the hand of the person that thought of doing that!

**A:** Well thanks! The word search has been a participant favorite for many years and is a great way to flex your brain. As for the paper, we actually did a touch test with the NARCOMS team just for that reason. We have tried to make the magazine easy to read with larger text, more space between lines, and switching to a paper that is easy to turn pages and less likely to tear.

For participants who have difficulty reading the magazine, it is available online in a PDF format that can be magnified or read aloud using reading software. Check out this article for more information: [http://tinyurl.com/8dq8ou8](http://tinyurl.com/8dq8ou8)

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If you ever have questions about the NARCOMS update surveys please call us and we will be happy to assist you: 1-800-253-7884

To submit a question for Q&A please email [narcomsnow@narcoms.org](mailto:narcomsnow@narcoms.org)
These suggestions for MS treatment–related apps came from our readers. NARCOMS and NARCOMS Now do not endorse the use of any particular drugs or treatments for multiple sclerosis. Have a favorite app or blog that makes your “MS Life” easier? Let us know about it at narcomsnow@narcoms.org. All of the apps featured below are available for download, free, on iTunes or Google Play.

These apps have not been evaluated for medical accuracy by NARCOMS Now and unless otherwise indicated, haven’t been approved by the U.S. Food and Drug Administration (FDA).

**Copaxone iTracker™**
*(By Teva Pharmaceuticals USA, Inc)*

From a NARCOMS Now reader: “Copaxone iTracker makes keeping current with my daily injection info much easier. It can also be adapted to 3X/week injections; it tracks frequency of site use, needle depth used for each site, and can email a log for record-keeping every few months. There is a reminder alert—although not audio for that, which seems odd.”

**SymTrac™**
*(by Novartis Pharmaceuticals UK Limited)*

SymTrac is designed to help people with MS track general well being and symptoms over time. Data entered on sleep, exercise, mood, symptoms, pain and more is translated into easy-to-read charts that can be shared with MS specialists. This allows for a quick snapshot on symptoms since the patient’s last visit. The app also contains a series of exercises designed specifically for individuals living with MS. A paper-based symptom tracker can be downloaded from www.symtrac.com.

**MS Self**
*(By Acorda Therapeutics, Inc.)*

This app aims to help the user keep track of symptoms and treatments, and coordinate that information for use by the user’s healthcare team. Key features include a Journal Entry screen, designed as a place to record symptoms, energy level, mood, mobility, activity and more, over time. Fact Cards provide facts about MS, plus helpful tips and tools for disease management.
Find the following hidden words:
research, study, school, science, survey, discovery,
outcomes, statistics, publication, findings, breakthrough,
treatment, therapy, progress, resource, laboratory

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:
www.narcoms.org/narcomsnow/play/answers
I was diagnosed with RRMS in summer 2006 and immediately began interferon treatments. For two years, I had no visible symptoms, then in mid-2008 my gait became impacted and has worsened. Today I suffer from secondary progressive MS and am fully ambulatory with the use of a cane. My MS is now visible to others, and I no longer can (nor try) to hide it.

I am determined not to let MS get the best of me. After a career change I teamed up with two partners and formed an advisory / consulting firm. Today, the business continues to grow and thrive.

My determination to deal with my MS and be ready for a cure is founded in five main principals:

1. **Remain Engaged in the Marketplace / Workforce.** It is critical to remain active and engaged in the workforce—an essential factor in my overall well-being. Working allows me to maintain relationships and network, and provides me with a sense of accomplishment. Most importantly, it helps maintain confidence. Working may undoubtedly present challenges for some, but improvising in order to remain engaged is critical.

2. **Be Physically Active.** Since my diagnosis, I joined a gym and work out 3 times per week, often with a physical trainer. Exercise is critical in that it keeps me active. Going to the gym is more difficult on some days than others, but I but push myself to get out of the house. Consistently exercising not only offers physical benefits, but it also helps to reduce stress and build confidence.

3. **Get Out There!** Enjoying all life has to offer is critical. Whether it’s taking a drive on a nice day, walking (or in my case “hobbling”) through the mall, or enjoying dinner with friends and family, “getting out there” is essential to enjoying life and not letting this disease get the best of you. Don’t let MS win!

4. **Stay Positive.** Since my diagnosis I do my best to remain optimistic about the future and stay confident that a cure is forthcoming. Viewing things as “partly sunny” vs. “partly cloudy” is key!

5. **Remain Knowledgeable.** Knowledge is power! With MS, this is essential. Progress toward a cure is being made at a rapid pace. Ask questions and remain informed. Do not become obsessed with seeking information, but do be inquisitive and stay current with news relating to MS.

When (not if) a cure is identified, I plan to be ready and take full advantage of all the little things that life has to offer.

—Vincent S.