

NEWLY DIAGNOSED? TAKE STEPS

BY NANCY REITMAN, RN, PROFESSIONAL RESOURCE CENTER NURSE

You're in touch with the National MS Society (or you wouldn't be reading this). We hope you've signed up for the at-home course, "Knowledge Is Power," which is available by mail or e-mail. It's designed to answer a lot of your questions.

We also hope you've called us if you want to talk one-on-one with someone who's been where you are now. On the other hand, you may feel you've been given more advice than any one person could possibly absorb.

But there is one more thing. As a person with MS, you'll need to move it.



Courtesy of Moore, Ink.

Alayne, diagnosed in 1999

Two researchers at the University of Illinois, Urbana-Champaign searched the medical literature for studies on MS and exercise from 1960 to 2007. Of the 43 papers Dr. Robert Motl and his colleague Erin Snook found and reviewed, 22 had enough data to compute "effect sizes"—and "the weighted mean effect size was significantly different from zero."

At the 2008 Consortium of MS Centers meeting, the two researchers concluded: "The cumulative evidence supports that exercise training is

associated with a small but meaningful improvement in walking mobility in people with MS."

What does that mean in plain English?

Move it and you are much more likely to keep moving throughout your life with MS.

If you loved a sport before MS came along — any sport from golf to ice hockey — you may be in luck. Call us for help in finding associations that promote adaptive programs in your sport. The chances are that there is one — or you may find another sport just similar enough to the one you loved to take up instead. Even if your sport is too intermittent to work at every week (skiing for example), or too inaccessible (no hockey rinks nearby), you still can develop a habit of pleasure in exercise that is something to build on.

But if you are in the majority, and sports are so in your past or so not in your life ever, you have a challenge. Dr. George Kraft, professor of Rehabilitation Medicine at the University of

(continued on next page)

STUDIES HAVE ALSO SHOWN

Exercise has positive effects for people with MS who have

- fatigue (yes, MS fatigue)
- cognitive problems
- depression
- weight control issues
- poor balance
- muscle weakness

Courtesy of Moore, Ink.



Mary, diagnosed in 1997

Washington, says, “You need a prescription for a regular exercise program just as much as you need one for medications to slow down your disease or control your symptoms.”

You may need to ask your physician for that prescription — and for a referral to a physical therapist or a rehabilitation physician — and you may need to educate the therapist about MS. As Dr. Kraft points out, many PTs are trained in sports medicine or how to deal with the aftereffects of accidents or stroke. Ask about their experience with MS. It’s appropriate to invite a PT to contact the Society’s Professional Resource Center at HealthProf_info@nmss.org to learn more about MS.

It’s also appropriate to develop an exercise program that fits your lifestyle and appeals to you personally. The Illinois researchers analyzed studies on exercise, not formal physical therapy sessions.

LIVING WITH MS

READ ALL ABOUT IT IN SOCIETY BROCHURES

Whether you’re recently diagnosed, or managing “an old friend” of a symptom, the Society offers brochures on a range of issues related to MS. These brochures are reviewed by experts in MS and regularly revised for the most accurate information possible.

Some brochures updated in 2009 include **Living with MS; Multiple Sclerosis and Your Emotions; Research Directions in MS; Win-Win Approach to Reasonable Accommodations; Food for Thought: MS and Nutrition; A Guide for Caregivers; Solving Cognitive Problems; and Depression and Multiple Sclerosis**. In addition, a number of brochures are now available in Spanish. Además, tenemos disponibles folletos en español.

WHERE TO FIND

You can read or download PDFs of Society brochures at nationalMSSociety.org/brochures. Or call 1-800-344-4867 for print copies. For easy searching, brochures are divided into eight categories: General Information, Newly Diagnosed, Employment Issues, Staying Well, Managing Specific Issues, Managing Major Changes, For Children & Teenagers and Información en Español. You can also download a PDF catalog with brief descriptions of all the publications the Society offers clients.

EXTRA! EXTRA!

One brochure regularly updated with breaking news is **Disease-Modifying Drugs**. The online version (nationalMSSociety.org/DMD) includes the most recent information possible on the disease-modifying drugs Avonex, Betaseron, Copaxone, Novantrone, Rebif and Tysabri. The booklet covers how they are taken, their benefits, side effects, and how to pay for them. Check back regularly for new reports on DMDs.

\$19 MILLION FOR MS RESEARCH

Fast Forward, LLC, a program of the National MS Society, recently garnered \$19 million for early-stage MS research through a new partnership with EMD Serono.

"This partnership will provide critical resources to underfunded stages of the drug development process," said Dr. Timothy Coetzee, Fast Forward's executive director.

For more information, visit fastforward.org.

MAY 27, WORLD MS DAY: A CALL TO ACTION

A minimum of two million people worldwide live with MS. This year, for the first time, 80 MS organizations around the globe are taking part in World MS Day on May 27, 2009.

In the United States, with the opportunity for health care reform a real possibility, the Society is asking all supporters of the MS movement to contact their federal legislators on World MS Day and voice support for universal health care coverage.



"There should be one global standard of health care to ensure that all people with MS can lead a life of possibility, dignity and fulfillment," said Joyce Nelson, President and CEO of the National MS Society. "On World MS Day, Americans can do their part by showing their support for national health care reform."

To learn more about the Society's National Health Care Reform Principles and tips on contacting your legislators, visit nationalMSSociety.org and click **Government Affairs & Advocacy** in the gray bar at the top.

For more information on participants and activities, visit worldmsday.org.

MOMENTUM IS ONLINE

Want to meet other people living with MS? Read about the latest MS research and therapies? **Momentum**, the

national magazine of the Society, offers this and more.

Each issue of **Momentum** is online in convenient PDF format, free, and often before a print copy can reach your mailbox. Clickable links give you immediate access to more info on a given topic and allow you to respond to stories with your own thoughts and tips. Download and send any story to others via e-mail.

Go to nationalMSSociety.org/magazine and click on **Current Issue** or **Find a Back Issue**.

FOR READERS WITH LOW VISION

Click on the magnifying glass icon to enlarge any **Momentum** page, two, three, even five times bigger.

PHIL RIDES FOR MS

Phil Keoghan, host of CBS's "The Amazing Race,"

is cycling across America—and he's taking the Society with him. Join Phil on his ride as he raises awareness for MS. Visit

philridesacrossamerica.com for more information.



NERVOUS SYSTEM PROTECTION AND REPAIR CONFERENCE

BY ERIC HÜBLER, STAFF WRITER



Odette Veneziano

From left to right: Drs. Peter Calabresi, Gavin Giovannoni, Charles ffrench-Constant, and Ian D. Duncan.

Let's be clear: to the layperson, the presentations at the Nervous System Repair and Protection in MS Conference might not have seemed very clear. The meeting, in New York City in January, consisted of over 70 scientists talking to scientists and showing each other slides with titles like "RXRs and RA signaling."

So let's be clear about something else: for anyone interested in MS, the event was historic. The Nervous System Repair and Protection Initiative involves more researchers, at

more labs worldwide, than any other MS research initiative. So bringing so many participants together to share their results — and their hopes for continuing the work beyond 2010, when the original grant from the National MS Society concludes — was a milestone in collaboration.

CREATING MILESTONES — TOGETHER

Collaboration is at the heart of everything the Society does—including research. "The

questions these days are so big, the lone scientist in the corner lab doesn't cut it anymore," said Patricia O'Looney, the Society's vice president of Biomedical Research. "You need collaborations."

The initiative consists of four projects, each with the common goal of discovering ways to protect and repair brain tissue from the damage caused by MS.

In the United States:

- Peter Calabresi, MD, and his team at Johns Hopkins University are investigating better ways to detect and quantify tissue injury. They are also testing agents that may protect the nervous system from further damage.
- Ian D. Duncan, BVMS, PhD, FRCPath, FRSE, and his team at the University of Wisconsin at Madison are developing better imaging technologies to follow damage—and detect repair, which is essential for tracking whether repair strategies are working. They are also working on potential cell therapies.

And across the "pond":

- Gavin Giovannoni, MBBCh, FCP, PhD, of Queen Mary University of London, and his

team are attempting to turn cells into vehicles that can deliver “repair” molecules to injured areas.

- Charles French-Constant, PhD, FRCP, of the universities of Cambridge and Edinburgh, and his team are working on identifying and amplifying natural repair factors in the brain.

Each has spawned new experiments and swept in more researchers. At Johns Hopkins, 22 people were receiving Promise: 2010 funding, yet 62 people were participating — meaning, in effect, 40 free brains for the MS movement.

SUPPORTERS AND RESEARCHERS CONNECT

Several donors also attended the conference to learn where their aid is going.

“It’s just great to see this kind of progress. You can get a sense of the enthusiasm, the magnitude of it,” said longtime Society supporter and Honorary Life Director Charlie Goodyear.

“It was remarkable this morning, seeing someone from London ask a question of someone from California and establish an immediate

rapport,” said the San Francisco-based architect and architecture professor Peter Thaler, who lives with MS. “It’s not unlike teaching architecture: talking about what happened in the past and what could happen in the future.”

E.J. Levy, an active fundraiser who lives with MS and closely monitors research progress, said she was grateful for so many scientists trying to cure her, but she also wished the initiative had yielded more clinical trials by now.

“I realize that research can be a tortoise, but I’d rather have the hare,” she said.

As if in answer, researchers at the conference announced several small trials on cell therapy, two years ahead of the original plan of Promise: 2010.

Cambridge’s Siddharthan Chandran, MD, PhD, described one such trial involving the optic nerve, which he hopes will benefit the “missing tribes” of MS — those with advanced disease who have few medical options.

“It would be terrific to come back here in two years’ time and tell you the final outcome of that,” he said.

More trials are coming, the project leaders promised. “I’m a big believer in getting your feet wet. As we get into these clinical trials, we’ll learn,” Dr. Calabresi said.

MOTIVATION TO KEEP MOVING

Volunteers are essential to clinical trials; without them, clinical trials either take years to complete or are not completed at all. Dr. Chandran wished MS patients could be enrolled in trials routinely, as has been done in oncology for decades. Some existing drugs that could be tested in MS are off-patent and “cheap as chips,” he said.

Dr. Calabresi spoke about a patient who was diagnosed at 17 after experiencing foot drop while jogging, and who at 26 uses a wheelchair.

“She looks at me and says, ‘Can’t you do anything for me?’ It just makes me sick, but it’s also an incredible motivator to take that energy and put it back into the work.”

For the latest research developments visit nationalMSSociety.org/Research and click on **Research News**.



ARE YOU GETTING ENOUGH VITAMIN D? DOES IT MATTER?

BY ALLEN C. BOWLING, MD, PHD

Recent studies have significantly changed our understanding of the role of vitamin D in health and disease, and some of these new understandings have important implications for people with MS.

In the past, it was assumed that most people had adequate vitamin D levels and that the effects of vitamin D were restricted to regulating calcium absorption and maintaining

bone health, including the prevention of osteoporosis (thinning bones). Studies over the past decade have shown that these views are incorrect and that up to 90% of American children and seniors may be vitamin D deficient.

YES, IT MATTERS

In addition to effects on calcium absorption and bone health, vitamin D exerts important actions on many other body systems, including the immune system. Adequate levels may improve muscle strength and prevent or decrease the severity of MS. Inadequate levels have been implicated in several forms of cancer, heart and lung diseases, depression, schizophrenia and a number of other autoimmune conditions.

Much additional research on vitamin D is clearly needed. But based on current information, there are options for people with MS to consider. One is to have a blood test known as “25-hydroxyvitamin D.” The test shows how much vitamin D is actually in a person’s body — and that’s the real measure of a deficient or adequate level. If the vitamin D level is low, supplements in appropriate doses can be taken.

Another option is simply to take vitamin D supplements without the blood test. The disadvantage of this “blind” approach is that vitamin D supplements may be unnecessary or the doses too small or too large.

The final option is to do nothing. People who take this option won’t spend money on testing or supplements, but if they are vitamin D deficient, they won’t obtain the potential benefits.

To determine an appropriate vitamin D strategy, people with MS should discuss their situation with their health-care provider.

*Dr. Allen Bowling is the medical director of the Multiple Sclerosis Service at the Colorado Neurological Institute (CNI) and clinical associate professor of Neurology at the University of Colorado-Denver and Health Sciences Center. Additional information about unconventional medicine may be found in his book, **Complementary and Alternative Medicine and Multiple Sclerosis** (2nd edition, Demos Medical Publishing), and on his Web site, **NeurologyCare.net**.*

SOURCES OF VITAMIN D

- Sunshine, BUT
 - Most people with MS need to avoid overheating
 - All people need protection from skin cancer (sunscreen, sunblock, hats, etc.)
- Fortified foods, including brands of orange juice, cereals, dairy products
- Oily fish, such as salmon
- Supplements

MS LEARN ONLINE TEACHES JOB STRATEGIES

Seventy percent of people with MS are unemployed and at least half of these people would like to be working. If you're one of them—or know someone who is—check out the latest offering from MS Learn Online, **MS in the Workplace**. This free two-part webcast presents strategies to help you reenter the workforce—and maintain your place once you're in it. **MS in the Workplace** is on nationalMSSociety.org/webcasts.

Part 1 is targeted toward the employee or potential employee with MS. Rehabilitation counselor Dr. Kurt L. Johnson addresses issues as varied as how to harness energy and improve cognition to how to navigate your health care and the human resources department in a prospective company.

Part 2, targeted to people in hiring positions, gives employers the basics on MS, and features some who have employees with MS. "Their personal stories show that people with MS are as productive as anyone else," said John Aden, senior manager of Program Development for the Society. It also shows what "reasonable accommodations" mean, and under what circumstances an employer is responsible for putting them in place.

"This video clears up misgivings an employer might have," said Aden. "Someone with MS, or a member of his or her family can send this link to an employer."

Other employment resources include nationalMSSociety.org/momspr08 for **Momentum** magazine's article, **For A Successful Job Interview**.

And even before you've landed that job, check out: **Disclosing MS in the workplace**.



Getty Photodisc

MS Learn Online

Other MS Learn Online programs address research, intimacy and symptom management. They are all accessible any time of day or night. No registration is required. Go to nationalMSSociety.org/mslearnonline.

Click through the menu on the right for a program to help you make an educated decision on whether or not to disclose your medical condition—and to whom.

Rehab counselors often advise their clients to ask themselves: Why am I telling? Who am I telling? How much am I telling? What are the positive and negative results? If the anticipated results fall more often in the positive than negative category, that will help you decide. Remember the bottom line: Once you disclose, you can't take it back. Go to nationalMSSociety.org/disclosework for more information.

HONOR SOMEONE SPECIAL OR CELEBRATE A SPECIAL EVENT

When Doug and Joann tied the knot last spring, they also established a scholarship fund. In lieu of wedding gifts, they asked for contributions. The donations allowed the couple to realize their dream of providing a four-year scholarship to a worthy student living with MS. It was easy. They used the Society's Honorary Fund page.

Anyone can join the movement and honor special people and events.

The Society's Honorary and Memorial Fund page lets you create online tributes or memorials that can be personalized with photos and stories. Fund pages allow colleagues, friends and family to make online donations on behalf of the honoree. Tools help you get the word out and track the progress of your fund.



Luis, diagnosed in 2005

Go to nationalMSSociety.org and click on **Donate**. From there, click on **Create a Fund**. From there you can:

- **Create an honorary fund** to recognize an accomplishment, a milestone, or just say thank you. Commemorate a birthday,

wedding, anniversary, or help someone celebrate Mother's Day or Father's Day.

- **Create a memorial fund** in memory of a loved one who has passed.

HONOR SOMEONE—LONG-TERM

Ellen and David recently set up a charitable gift annuity to provide retirement income to Jen, their caregiver of many years. To learn how to establish a charitable gift annuity in tribute to someone special, contact planned giving specialist Gillian Smith at 1-800-923-7727 or visit nationalMSSociety.org/plannedgiving.

Are you up for the challenge? And ready for the ride of your life!

The sense of accomplishment that you'll feel as you cross the finish line can only be matched by the difference you'll be making in the lives of people affected by MS.

**An unforgettable ride.
An unbeatable destination.
Bike to create a world free of MS.**

visit bikeMS.org

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riding in Bike MS since 2004