National
Multiple Sclerosis
Society

CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Volume 3• Issue 1 Upstate New York Chapter

Creating Success One Step at a Time

Did you ever wonder what factors create success? Some people believe that being at the right place at the right time is what it takes. Others believe that hard work and competency counts most. A few believe that it's just a matter of luck. I believe it's all three.

Over the past two years, I have observed our team of employees and volunteers across 50 counties manage our exciting fundraising events while gaining valuable insight and knowledge into how to make these events more successful. They learned by being hands-on; in essence, there is no substitute for real-life experience.

This year, our first three fundraising events, the Women Against MS (WAMS) Luncheon in Albany, the Dinner of Champions in Rochester, and the Team Up 4 MS campaign with the Buffalo Bills, have all exceeded their goals. One reason for this success is that the teams took full advantage of their collective experience to grow each event. Another reason for these successes is that the right team of staff and volunteers came together at just the right time and collaborated in an extraordinary manner to ensure success. Finally, you could say we were lucky to have such a great team of individuals at the Chapter and that our Upstate New York weather patterns cooperated.

The same logic applies to a unique array of client programs and services our programs team has developed and delivered across the state. We continue to reach more clients and truly understand their requirements to create the highest quality of life possible while managing this unpredictable disease. Our programs team is constantly assessing the needs of our clients and creating the services that our clients deserve. In this arena, there is no substitute for hard work, collaboration and commitment.

While we can appreciate good luck, the key to our future success comes down to

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Chapter Offices

Rochester Office - Headquarters
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Rochester, NY 14620-3901

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Albany, NY 12205-3838

Binghamton Office
457 State Street
Binghamton, NY 13901-2399

Buffalo Office
4245 Union Road, Suite 108
Buffalo, NY 14225

North Country Office
P.O. Box 2336
Plattsburgh, NY 12901

Syracuse Office
3532 James Street, Suite 104
Syracuse, NY 13206-2558

Upstate New York Chapter
email: Chapter@msupstateny.org
www.msupstateny.org
www.nationalmssociety.org

All offices can be reached by calling 1.800.FIGHT MS

Adult Day Health Program

Multiple Sclerosis Achievement Center (MSAC)
2300 Buffalo Rd., Bldg. 600 B
Rochester, NY 14624
Phone: 585.368.6470

Clinics/Health Centers

MS Clinic (Albany)
Center For Disability Services
314 South Manning Blvd.
Albany, NY 12208-1794
Phone: 518.453.2273

MS Care Center (Albany)
Albany Medical Center
Department of Neurology
47 New Scotland Ave.
Albany, NY 12208
Phone: 518.262.5226

Baird MS Center (Buffalo)
The Jacobs Neurological Institute
University at Buffalo
Buffalo General Hospital
100 High St. E2
Buffalo, NY 14203
Phone: 716.859.7521

Pediatric MS Center (Buffalo)
Jacobs Neurological Institute
University at Buffalo
Women & Children's Hospital of Buffalo
219 Bryant St.
Buffalo, NY 14222
Phone: 716.878.7367

Rochester MS Center [RMSC] (Rochester)
University of Rochester
Strong Memorial Hospital
601 Elmwood Avenue, Box 605
Rochester, NY 14642-0002
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MS Clinic (Syracuse)
UHCC - Neurology, 4th Floor
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Jeanne Marino

Creating Success

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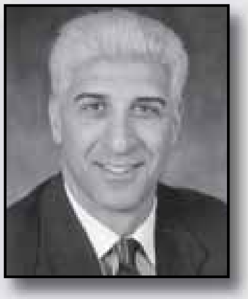
applying the right strategy at the right time and continually improving based on what we learn from each event and program.

To that end, our staff and volunteers have set out to make 2008 the most successful year yet for the Upstate New York Chapter. Today, our Walk MS teams are fully mobilized, raising money for the ultimate goal of creating a world free of MS. However, to achieve our goal, we need your help. Please go to our website at www.msupstateny.org and follow the easy step-by-step process to create your own team or to volunteer to help at one of our 21 Walk MS sites across Upstate New York. Yes, we can always use good luck, but we really need you to be successful. Thank you.



Randal A. Simonetti
President & CEO

To keep you informed and to keep our records current, please forward your current email address to

office@msupstateny.org

Be sure to include the incorrect address as well.

Be Williams Koch Conference Room Is Dedicated

The Upstate New York Chapter was the recipient of a generous gift of $125,000 from the Bernice W. Koch Charitable Trust. In consideration of this gift, the main conference room at the Rochester office has been named in her honor. On January 17, a ceremony commemorated the occasion. Presiding at the ribbon cutting were (right to left) John Buttrill, Elizabeth Buttrill, Linda Buttrill (daughter of Be Williams Koch), Chapter President Randal Simonetti, and Board Chair Thomas Muller.

Lou Piccone

The Upstate New York Chapter is proud to announce the appointment of Louis J. Piccone to its Board of Directors.

Lou was a member of the Buffalo Bills for 7 years and the National Football League for 10 years. He is past president of the Buffalo Bills Alumni Association and serves on the Executive Committee. Recently, Lou received the prestigious Ralph Wilson Humanitarian Award. He has been very involved in community service since his playing days and has been a member of several noteworthy organizations including the NFL Players Association, Rotary Club of Buffalo and SAVE – Students Against Violence Education.

Lou is extremely well known and respected in the western NY community and promises to be an outstanding asset to the Upstate New York Chapter.

Congratulations to Drs. Sternberg and Tanner

We are pleased to recognize Dr. Zohara Sternberg, Ph.D., Department of Neurology at The Jacobs Neurological Institute in Buffalo, and Dr. Daniel Tanner, Ph.D., Department of Biomedical Genetics, University of Rochester Medical Center, School of Medicine and Dentistry on their recent grant awards from the National Multiple Sclerosis Society of $44,000 and $102,324 respectively.

The National MS Society supports more MS research, offers more services for people with MS, provides more professional education programs and furthers more MS advocacy efforts than any other MS organization in the world.

Congratulations and best wishes to Drs. Sternberg and Tanner.

Howitt House: Accessible, Affordable Housing

The Upstate New York Chapter has one and two bedroom apartments available for individuals with MS and their families. They are fully accessible units located off of South Avenue in the South Wedge area of Rochester. Central air conditioning is just one of the many features. Residents with MS must be able to live independently, or be able to independently arrange for services to assist them.

For information about additional features, financial and household eligibility, rental and utility costs, please contact Debbie Houck, Program Coordinator at 1.800.FIGHT.MS / 1.800.344.4867 or at dhouck@msupstateny.org

Save the Date

Dr. John Richert, Executive Vice President, Research and Clinical Programs, for the National Multiple Sclerosis Society, will be the keynote speaker at this year's annual meeting in Syracuse on October 23, 2008. Please watch for notice of meeting location and time.

Walk MS Sites and Dates

Albany	May 4
Batavia	May 18
Bath/Corning/Elmira	May 4
Binghamton	May 4
Buffalo	May 3
Canandaigua	May 4
Dunkirk	May 18
Geneseo	May 4
Greece	May 4
Ithaca	May 4
Jamestown	May 4
Lake Taghkanic	May 4
Lockport	May 18
Mohawk Valley	May 4
Oneonta	May 4
Poughkeepsie	May 4
Rochester	May 4
Saratoga Springs	May 4
Syracuse	May 4
Watertown	May 4
Wellsville	May 4

Classified Online Ads

Our classified advertisements appear on our website and can be viewed at www.msupstateny.org. Scroll down to the "Resources/related" links button and click on "Classified Ads". Or, you can type the following address into your browser: http://nyr.nationalmssociety.org/site/PageServer?pagename=NYR_Classified_Ads

If you wish to post a classified ad, email chapter@msupstateny.org or call 1.800.344.4867, option 2 and ask for extension 5327.

2007 Rochester Dinner of Champions

The 2007 Dinner of Champions, with its theme "A Celebration of the MS Family" and led by Committee Chair Lorrie Modica, was an unqualified success in every way! With the support of the Modica family, title sponsors, and presenting sponsors PAETEC, Parlec and the Nuccitelli Family, the event significantly exceeded its target goal. Close to 400 attendees joined the Upstate New York Chapter in raising MS awareness and funds in support of programs, services and research.

Martha Lightfoot, adult nurse practitioner at the Rochester MS Clinic at Strong Memorial Hospital since 1990, was honored with the MS Achievement Award for her incredible dedication and service to those living with MS in the Rochester community. Also recognized were the outstanding contributions of past chairs of the Upstate New York Chapter's Board of Directors who each received the Distinguished Service Award for their commitment to the Chapter through every aspect of its 59-year journey.

This premier event featured entertainment by the Showvinistics, a national premiere acappella group; magician Chris Wilkinson; and party band, Nik Lite. The silent and live auctions offered an array of generous donations from the Rochester community.

Steven Modica presents Martha Lightfoot with the MS Achievement Award.

Left to right: Thomas Muller, Ted Streppa, John Weider, Charles Cleary, Richard Mengel, Barry Culhane, James Metzler, Eric Zaenglein, Richard Kazel, Thomas Trevett, Karen Gallina, Jay Quinn, Allen Illig, and Randal Simonetti

3rd Party Events

Event	County	Amount
Seneca Falls Central School District's Dress Down Day	Seneca	$61
Dress Down Day at Horseheads Middle School	Chemung	$85
Suntrust Charitable Giving Campaign	Ramsey	$100
Hudson Valley Neurology Picnic 50/50 Raffle	Dutchess	$205
Mary Kay Spa Night	Saratoga	$250
Christmas Gift Wrapping @ Borders – Colonie	Albany	$638
Holiday Wishes Walk to Cure MS	Rensselaer	$600
Bartending for MS	Monroe	$775
2007 Masters North Golf Tournament	Clinton	$1,100
Cornell Women's Lacross Dodgeball Tournament	Onondaga	$2,000
Ladies of the Rotterdam Elks Card Party	Schenectady	$2,004
The Dig	Onondaga	$3,677
B2 Technologies Christmas Party	Erie	$4,400
Golf Fore MS- Jim's Restaurant	Monroe	$14,003
Golf For A Cure	Albany	$4,300

The 2007 "Team Up 4 MS" Campaign is a Huge Success!

Thanks to everyone who supported this effort through their generous pledges and gifts which helped us raise close to $18,000.

Our gratitude to Jacquie Walker, WIVB News 4 Anchor, Larry Norton, from WGRF-FM97 Rock, Josh Stamer, Buffalo Bills #57 and Lee Evans, Buffalo Bills #83 for their time, talent, and resources in making this campaign so successful. A special thanks to WIVB for producing and running an ad in support of this promotion.

If you haven't already, please return your pledge with your invoice so we can push the campaign over the top! Questions can be directed to Phil Urban at 716-634-2573 or e-mail phil.urban@nyr.nmss.org

Utica Massage Therapist Meets with MS Support Group

Licensed Massage Therapist Alice Kenly recently demonstrated massage therapies to members of the Upstate New York Chapter's Utica support group.

Ms. Kenly, who is a graduate of the Onondaga School of Therapeutic Massage in Syracuse and holds a Bachelor of Arts degree from SUNY New Paltz, is certified in Lymph and Decongestive Physiotherapy. She demonstrated to the group how Swedish massage, Lymphatic Drainage and CranioSacral Therapy relax the body's central nervous system and help alleviate stress and pain.

From left, members of the Utica area support group, Dick Mariani, Dawn Goering, Lisa Ostrander and Debbie Staring join speaker Alice Kenly, LMT, and other group members Marlene Harvey, Vi DuCatte and Phil DeFasio. Missing from the photo is Tina Wiermus.

Peer Support Program

Looking for someone to talk to?

You may be interested in the Chapter's Peer Support Program. If you are in need of a few words of encouragement or someone to express your thoughts and feelings to, this program may benefit you. Our volunteers are trained individuals who have MS or are affected by MS and can offer a confidential, one-on-one experience via telephone. You can be matched with someone who shares your interests and/or background. Volunteers do not take the place of professional help, but can aid in finding ways to deal with feelings and to cope with the issues that MS presents.

Peer Support

Interested in becoming a volunteer?

A peer support volunteer provides the opportunity for someone who has been recently diagnosed or who is having difficulty coping with multiple sclerosis to talk to "someone who understands." The next training will be held this spring!

To learn more, please contact 1.800.FIGHT.MS/1.800.344.4867.

Bike MS Champions

The Bike MS Champions program is a mission–based society–wide program, designed to "put a face on MS". It connects people living with MS to event participants and makes both the participant and the person living with MS, a Bike MS Champion.

Both help us move toward a world free of MS. Both want to do something about MS now.

Being a Bike MS Champion is as easy as 1, 2, 3, 4!

1. Email the event participant and thank them for riding.
2. Send the event participant a thank you and ask them to fundraise earlier.
3. Call the event participant, introduce yourself, and ask them if they are training and ready for the ride.
4. Send the event participant a thank you email for riding.

To sign up and become a Bike MS Champion call 1.800.FIGHT.MS

2008 Golf Fore MS

Over 144 golfers will tee off at the Golf Fore MS Tournament on June 16 at Blue Heron Hills Country Club where a full country club experience will welcome golfers of all levels. We are please to announce that Trident Precision Manufacturing is title sponsor of this year's tournament.

The Upstate New York Chapter is proud to be honoring long time MS supporter and advocate Jon Ludwig who will be recognized for his many years of volunteer service. Jon has been the driving force behind the Golf Fore MS Tournament since its inception.

Multiple sponsorship opportunities are available. For more information about the Golf Fore MS Tournament, to register, to become a sponsor, please contact Andrew Muldoon at 585-271-0801 x 5330 or e-mail: amuldoon@msupstateny.org

2008 Public Policy Conference

This February, the Upstate New York Chapter, as a member of The National Multiple Sclerosis Society New York State MS Coalition Action Network (NYS MS CAN) representing New York's four NMSS Chapters and 34,000 families affected by MS in the state, participated in the 2008 Albany Public Policy Conference. On the first day, volunteers and members of the NYS MS CAN participated in a debriefing of the 2008 legislative agenda. The debriefing was facilitated by Randal Simonetti, Upstate New York Chapter President and CEO, and legislative representatives from Manatt, Phelps, & Phillips, LLP. Guest speakers included Assemblymember Michelle Titus, Chair for the Assembly Task Force on People with Disabilities, and David Chatel, Executive Vice President of Advocacy with the National MS Society. On the following day, several Chapter volunteers and staff representing the North Country, Albany, Buffalo and Rochester visited 15 of their representatives in the House and the Senate, as well as 5 key members of the Senate and House Majority and the Governor's administration. Legislative agenda items included urging a full expansion of the Elderly Pharmaceutical Insurance Coverage Program (EPIC) to include people with disabilities, regardless of age, who meet income eligibility and expanding community-based long-term care and affordable, accessible housing options for people with disabilities. Volunteers also had the opportunity to speak with legislators and their staff as hosts of the NYS MS CAN legislative breakfast attended by over 50 Assembly members and Senators. Participating Chapter volunteers included Eva Gigandet, Marla Eglowstein, George Hines, Joseph Miller, Patrick Vanderpool, Lou Ann Holt, Carol Rusinski, Deb Duminuco and Rich Hasselberg. Chapter staff included Courtney Totter, MSSMC, Manager of Advocacy Programs and Services, Charity Shoen, Director of Programs and Services, and Program Coordinators, Laurie Booth-Trudo, and Lori Miner.

For additional information about the 2008 Albany Public Policy Conference, or about how you can get involved in advocacy through the Upstate New York Chapter, please call 1.800. FIGHT MS/ 1.800.344.4867 or visit our website- www.msupstateny.org.

Left to right - First row: Rich Hasselberg and Deb Duminuco
Second row: Patrick Vanderpool, Courtney Totter, Joseph Miller and Carol Rusinski

Left to right - First row: George Hines and Lori Miner
Second row: Lauri Booth-Trudo, Eva Gigandet, Charity Shoen and Lou Ann Holt

Looking Good

By Madeleine Prince

Beauty is only skin deep, but feeling attractive can lift your spirits and help you face the world. So whether the staff at Frédéric Fekkai salons knows you on sight or you're a "wash-n-go" type, here are some tips for looking your personal best.

- **Start with the basics.** Eating right and getting enough sleep are the foundation for looking good. Not even fashion models can get away with dark circles under their eyes.
- **Take care of your smile.** An MS diagnosis doesn't mean you can skip going to the dentist—don't you wish! A great smile can go a long way in brightening your day, so keep those appointments. And check out energy-conserving devices like electric or battery-operated toothbrushes.
- **Pamper yourself.** Take time to do something nice for yourself, out of your usual routine: a massage, a good haircut, a bright scarf or new cap.
- **Get tips and tricks from the pros.** "Occupational therapists can help you with ideas and little tricks, such as how to shave safely or hold your hairbrush if you're having numbness in your hand," said Gail Hartley, a nurse practitioner with Neurology Consultants in Arcadia, California.

- **Accessorize!** Turn assistive devices into great-looking accessories. Decorate devices with colorful fabrics. Splurge on a carved cane. "Men in particular like hiking sticks, because they look cooler than canes," Hartley told **MSConnection**. But first consult a physical therapist to make sure you're using the safest and most appropriate device and using it properly.
- **Ask for help.** Hartley remembered a person with MS who showed up to each appointment perfectly groomed. Her stylist? Her husband, who learned to do all of her makeup. Ask partners, friends, or family to help with hair, makeup, nails or clothes. They like it when you look good.
- **Be who you are.** If pedicures weren't part of your life before your diagnosis, then don't feel obliged to have them now if you won't really enjoy them. As Hartley said, "You are the same person today that you were before you got the diagnosis."

Madeleine Prince is a freelance writer and editor.

600 Walks /100 Rides … and some are right here!

It's Walk MS and Bike MS season again. Time to train, time to plan. Our chapter Walk and Bike events welcome movers of every kind.

- Hard to move? Ask us about an accessible walk, a route that's friendly to wheelchairs, baby carriages, and slow walkers.
- Less than Olympic cycling skills? You may be able to consider electric bikes, recumbent bikes, or tandems, those bicycles built for two.
- Training is a bore? Ask us about starting a team—and get the spirit that gets you going.
- Getting pledges is a chore? Ask us about easy online fund raising—with just a few clicks!
- Just coming out helps us move. Call our office about volunteering to greet finishers with ribbons, medallions, and thank-yous. (Oh yes, and water and bananas.)

Bike MS and Walk MS events are not one-shot deals. They take preparation and practice—and they grow team spirit. If you have MS, talk to your health-care provider about what you can do.

A DOUBLE DESTINATION ←

With nearly 600 Walks and 100 Rides all over the country, many people are planning a double destination—raising money to fight MS and having a reunion with family or far-flung friends. For information on events where and when, visit mapmyride.com.

NEWS Flash

- **Success!**
  The President signed the Defense Appropriations funding bill (H.R. 3222) on November 13, 2007, in response to the voices of more than 100,000 MS activists urging Congress to increase federal funding for MS research. MS research is now eligible for funding under the Department of Defense (DoD) for the first time ever. Get the full story at **nationalmssociety.org/advocacy**.
- **MS films available on YouTube**
  View five short films by and about people living with MS shown in the first annual "Moving Forward Film Festival" sponsored by the Society. Go to **youtube.com** and search for "Moving Forward Film Festival."

- **Proof that the MS drugs delay disability**
  There's been ample proof that Avonex, Betaseron, Rebif, and Copaxone decrease both the number of active MS attacks and "silent" damage in the brain or spinal cord as seen on MRI for people with relapsing forms of MS. Now a team of Canadian researchers has published a review of clinical experience over more than 20 years, before and since DM drugs came

into use. According to their estimates, these drugs also delay disability—significantly. Visit **nationalmssociety.org/bulletins**.

- **The MS Technology Collaborative survey results**
  People with MS may not take advantage of features that could make their computers and electronic devices easier to use. Even so, technology plays a vital and increasingly important role in their lives. These are some of the key facts that surfaced in an important survey this spring. Read the results at **mymsmyway.com/survey.html**.

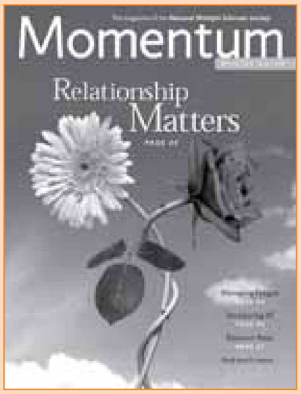
- **Take a personal tech snapshot**
  Get a quick pic of solutions to problems, such as reading text on the screen or using a mouse. Visit **mymsmyway.com** and answer a few simple questions on the Snapshot quiz. You'll get customized information detailing solutions—including many that are low cost.

- **International MS meeting reports on new therapies**
  Last October the European Committee for Treatment and Research in MS (ECTRIMS) met in Prague and reported on studies in MS development that are building a better picture of the differences between progressive and relapsing forms of MS. The meeting also reported on new drugs just beginning their trip through the long process of testing. Among them are MS vaccines, monoclonal antibody treatments, blood or bone marrow transplantation, and a drug composed of a synthetic fragment of myelin protein, the material that insulates healthy nerve fibers.

  To learn more about the findings, visit **nationalmssociety.org/bulletins** and look for **Research Progress Reported at International ECTRIMS Meeting**, or ask us for a copy.

  In September 2008, ECTRIMS—along with its counterparts in North America (ACTRIMS) and Latin America (LACTRIMS)—will meet in Montréal for the World Congress on Treatment and Research in MS. As the organizing body for ACTRIMS, the Society is pleased to provide logistical support for this important meeting of MS researchers and clinicians.

- **Momentum is the new InsideMS**
  The Society's national magazine is now **Momentum**, an 80-page quarterly. If you have MS, **Momentum** is a Society benefit. Others may request it with their contributions. Call us for information.



  Some back issues of **InsideMS** (which began publication in 1983) are available at **nationalmssociety.org/magazine**.

Handling an MS attack

An exacerbation (also called an attack, a relapse, or a flare) is caused by inflammation in the central nervous system, which leads to a sudden worsening of an MS symptom or symptoms, or the appearance of new symptoms. An exacerbation usually lasts several days to several weeks.

While you may not be able to change the fact of an exacerbation, you can work on changing how you respond to it. Here are some tips:

- So you missed your workout, had a fight with your spouse, and ate a giant piece of chocolate cake—none of those **caused** your exacerbation. An exacerbation doesn't mean you did something "wrong," so don't stress trying to figure out why it happened.
- Most exacerbations resolve on their own. Or your doctor may prescribe a course of steroids if your symptoms interfere with work or life at home. It's important to get the rest you need and talk to your doctor about the best way to manage whatever symptoms you are having.
- An exacerbation doesn't mean your disease-modifying medication isn't working. In fact, none of the available medications stops the disease completely. Work with your doctor to decide if your current medication needs to be changed.
- "Pseudoexacerbations"—temporary aggravations of MS symptoms—can happen if you get overheated, overtired, or run a fever. The symptoms will gradually disappear as your body temperature returns to normal. But if you're worried—or the symptoms don't get better—don't hesitate to call your doctor.

Adapted from "The Emotional and Psychological Impact of Multiple Sclerosis Relapses," by Rosalind Kalb, published in the 2007 *Journal of the Neurological Sciences*, Volume 256, Pages S29-S33.

If You or Someone You Know Has MS

Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with multiple sclerosis. Sign up today for an e-Newsletter by e-mailing Chapter@msupstateny.org.

Would you prefer to receive your MSConnection in your inbox rather than your mailbox? Sign up today for an e-Newsletter by e-mailing **chapter@msupstateny.org**, and your name will be added to our cyber list. Thanks for helping us save printing, postage, and trees!

New on our Web site

New Video: The Clues of Epidemiology

Are you more likely to have MS if you're a man or a woman? Over 30 or under 30? If you live at the beach or in the mountains? What do "clusters," or high concentrations of people with MS in specific geographical areas, tell us about the disease?

Discover the answers—and the relevance of these questions for people living with MS—in the Society's new MS Learn Online video series, **The Clues of Epidemiology**.

Emmy Award-winning broadcast news anchor Anne Trujillo explores epidemiology, or the study of disease patterns, in this two-part documentary, featuring internationally renowned epidemiologists.

To view the two 15-minute segments, go to **nationalmssociety.org/mslearnonline**.

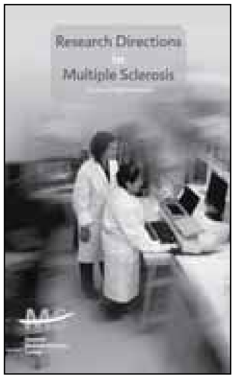
Focus on Employment: How to Stay in the Game

This PDF-only Web publication is a reprint, with updates, of a special section of *InsideMS* from 2006. Read about:

- When to disclose—and why you may or may not want to
- The Americans with Disabilities Act
- Managing fatigue and cognitive issues at work
- Working from home on the phone.

To download a free copy, go to **nationalmssociety.org** and visit the Brochures section of the Library. No Web access? Call us and we'll send you a copy.

Research Directions in Multiple Sclerosis



This brand-new publication—written by Drs. John Richert and Diana M. Schneider—explores recent advances in MS research: what we know now, and where research will be headed for the next decade. Dr. Richert is the executive vice president of Research and Clinical Programs at the Society and Dr. Schneider is president and CEO of DiaMed, LLC/DiaMedica Publications.

To download a free copy, go to **nationalmssociety.org** and visit the Brochures section of the Library. Or call us to have a free copy sent to you.

Progress made in repairing MS damage

With aggressive funding from the National MS Society and many other sponsors, researchers are pursuing ways to reverse the damage done by MS to nerve fibers and the protective myelin coating that surrounds them.

Encouraging results have emerged from two recent laboratory studies.

Mayo Clinic zeroes in on an antibody

It may not have the most memorable name, but **rHIgM22** recently made news when Dr. Moses Rodriguez and his Mayo Clinic team reported success in repairing myelin when they injected a single dose of this monoclonal antibody into mice with an MS-like disease.

The results were presented at the 132nd Annual Meeting of the American Neurological Association in October 2007. Although these findings will need to be confirmed by further animal and human studies, the results take us one step further to stimulate myelin repair in people with MS.

Block that LINGO

Researchers funded by Biogen Idec, Inc., which makes the MS disease-modifying drug Avonex, recently reported success in repairing myelin in mice by blocking a myelin molecule called LINGO-1. Dr. Sha Mi and colleagues wrote about their findings in the September 30, 2007, online edition of **Nature Medicine**.

LINGO-1 is part of a complex of molecules within myelin called the Nogo receptor complex that has been shown to inhibit the regeneration of nerve fibers. In an earlier study, published in the March, 2004, issue of **Nature Neuroscience**, Dr. Mi's team reported that remyelination occurred and the health of nerve fibers improved when LINGO-1 was disabled.

In the current study, the Biogen team first induced EAE, an MS-like disease, in mice with and without LINGO-1. Both groups developed EAE symptoms, but they were significantly milder in mice without the molecule. Studies of tissue samples showed significant myelin repair in these mice as well.

The team then administered a LINGO-1 antibody capable of blocking LINGO-1 activity to mice that already had symptoms of EAE. The treatment stabilized disease progression after two weeks. Tissue analysis showed that treatment reduced nerve fiber damage and enhanced myelin repair in the spinal cord, compared with untreated mice.

According to a recent Biogen press release, the company plans to continue researching this possible new approach to MS treatment.

Finding Legitimate Internet Jobs

An estimated 45 million Americans worked from home in 2006, up from 41 million in 2003*. For people with disabilities, telecommuting may offer a way to keep working despite mobility or fatigue issues.

The kinds of work that can be done at home include auditing, data entry, design, editing and writing, litigation coding, medical and legal transcription, and more.

Is telecommuting right for you?

"Most of our calls are from people with disabilities who want to work from home," Kim Cordingly, PhD, told **MSConnection**. Dr. Cordingly is a self-employment consultant at the Job Accommodation Network, (JAN), a service of the U.S. Department of Labor that provides information on job accommodations, self-employment and small business opportunities.

"Legitimate jobs exist, but it's important to be a good consumer when looking for online work," Dr. Cordingly advised. To help people avoid scams, the Federal Trade Commission's "Work at Home Schemes" page (**ftc.gov/bcp/menus/consumer/invest/workhome.shtm**) lists popular schemes, such as coupon scams and fraudulent medical billing opportunities, and how to avoid them.

"If for any reason you feel unsure about a company or what they're offering, feel free to investigate," Dr. Cordingly said. First, check with the Federal Trade Commission (**ftc.gov**) and the Better Business Bureau (**bbb.org**) to see if any complaints have been filed against the company. It is also okay to ask for references—contact information for other people doing similar work for the company so you can ask them about their experience.

Get ready

Teleworktools.org provides a comprehensive toolkit for potential teleworkers, including a self-assessment questionnaire, information on benefits and financial help, and an exhaustive list of links to telecommuting resources on the Web.

Get set up

Dr. Cordingly highlights two organizations that specialize in helping potential telecommuters find work.

The National Telecommuting Institute describes itself as "a unique educational/job-matching organization." NTI staff work together with employers, vocational rehabilitation agencies, and people with disabilities to help potential employees train for and work online.

CORA Works trains and mentors people with disabilities and matches them with the needs of employers.

Go: Resources

CORA Works
coraworks.com
Phone: 800-571-2397

Job Accommodation Network
jan.wvu.edu
Phone: 800-526-7234; TTY: 877-781-9403

National Telecommuting Institute
nticentral.org
Phone: 800-619-0111

According to a 2007 meta-analysis of 46 studies of telecommuting published in the* **Journal of Applied Psychology *(Vol. 92, No. 6).*

What will your legacy be?

People who include a bequest to the National MS Society in their will send a strong message: they believe in the work the Society is doing and want to help move us to a world free of MS.

A bequest is about more than supporting a great cause. What you put in your will is your legacy. It is one of the ways that people will remember you.

Estate gifts or bequests can be a donation of general support. Or they can be specific to your personal vision. For instance, a bequest might be restricted to research in a specific area, such as genetics or MS triggers. Or it can be earmarked for services, such as emergency loans, college scholarships, or educational programs.

Bequests may be a specific amount or they may represent a percentage of your total estate. "Residual" bequests can be set up to help fund the National MS Society after family and friends are provided for.

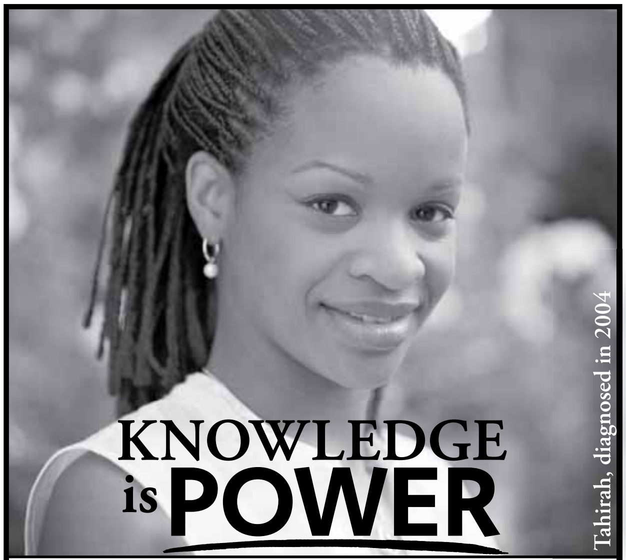
Estate planning experts suggest:

- Consider possibilities. Plan for life's uncertainties.
- Organize. Identify all your assets and liabilities.
- Inform your potential beneficiaries. By letting us know of your plans, we will thank you with recognition in our Pillars of Society program.
- Use caution. Consult a qualified estate planning attorney. Careful planning may save your loved ones from complex probate procedures and taxes.

The next step

Society staff can give you all the information and materials you and your advisor need to develop a bequest that reflects your values and fits your estate plan. Investing your assets to reflect what you consider most important can be deeply satisfying.

Ask for our brochure, "Creating a Legacy for Tomorrow." Call the Gift Planning Office at **1-800-923-7727**, or visit **nationalmssociety.org**, click on "Donate" and then "Planned Giving" for more information.



Knowledge Is Power is a six-week, free, at-home educational program for people who are newly diagnosed. Mail or e-mail formats. To register, call **1-800-344-4867**, or visit **nationalmssociety.org/knowledge**.

Join the movement.

National
Multiple Sclerosis
Society

Looking for Research Participants

What:
A study investigating strategies for maximizing speech articulation, voice quality and intelligibility for persons with multiple sclerosis is being conducted. Say sentences/read while being audio-recorded

Where:
Motor Speech Lab, Department of Communicative Disorders & Sciences, University at Buffalo, Main Street Campus

Time Commitment:
Two, 60-90 minute sessions

Compensation:
$10 per hour

Contact:
Dr. Kris Tjaden, Department of Communicative Disorders & Sciences, University at Buffalo; 716.829.2797 extension 639; tjaden@acsu.buffalo.edu

What:
A research study for people with multiple sclerosis who are sensitive to heat. Examining the effects of cooling and aerobic exercise on changes in temperature, exercise performance and fatigue.

Where:
Rehabilitation Physiology Lab at the University at Buffalo, South Campus
Time Commitment: Six times over a 6 week period for the testing; three times a week for 12 weeks for the aerobic exercise program.

Compensation:
Available

Contact:
Jeanne or Dr. Fisher at 716.829.3141, ext. 148

Please note:
You must have mild to moderate MS, heat sensitivity and your neurologist's written approval for you to participate in moderate physical activity

What:
A study investigating a once-daily oral medication being investigated by Novartis for the treatment of relapsing-remitting MS.

Where/Contact:

- University of Rochester Medical Center,
  Rochester, NY 14642
  Dr. Steven Schwid, Principal Investigator
  585.275.6673
- Albany Medical Center, Department of
  Neurology, Albany, NY 12208
  Dr. Michael Gruenthal
  518.262.5868
- SUNY Upstate Medical University,
  Syracuse, NY 13210
  315.464.4625

Time Commitment:
Initial screening visit can last up to 6 hours followed up by a ½ hour visit every 3 months; this will cover a 2 year period.

Please note:
Only the physician conducting the study can determine if patient is eligible for participation.

Restrictions:

- Study is open to males and females between the ages of 18-55 diagnosed with relapsing-remitting MS.
- At least one documented MS relapse during the last year or two documented MS relapses in the past 2 years, preceding their enrollment to the study.
- EDSS score of 0-5.5

Dates to Remember

For a complete list of upcoming events and programs, please refer to the chapter website at www.msupstateny.org

March 30	Art Lottery (Buffalo)
May 3, 4, 18	Walk MS (see page 5 for sites and dates)
June 13	Gala Event (Albany)
June 16	Golf Fore MS Tournament (Rochester)
July 12	Bike MS – Follow the Foothills (Gansevoort)
July 17	Women Against MS Luncheon (Buffalo)
September 6 & 7	Bike MS – Pedal to the Park (Buffalo and Rochester)
September 23	Women Against MS Luncheon (Rochester)
September 26	Women Against MS Luncheon (Syracuse)

If you would like to receive the MS Connection via email, please notify us at
Chapter@msupstateny.org

**National
Multiple Sclerosis
Society**
Upstate New York Chapter

National Multiple Sclerosis Society
1650 South Avenue, Suite 100
Rochester, NY 14620-3901

CHANGE SERVICE
REQUESTED

FREE MATTER
FOR THE
BLIND AND
HANDICAPPED

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