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msconnection

Southern New York Chapter

Advocacy — An Awesome Experience

By Donna Deiner

I recently attended a Policy Conference in Washington, DC. I went as a multiple sclerosis (MS) advocate, along with 300 others from National Multiple Sclerosis Society chapters across the country.

The dictionary defines “advocate” as a person who argues for a cause. It is that, but it is so much more. Yes, we were in Washington to lobby for issues important to people with MS, however there were stories, experiences, tears and much laughter. The issues we lobbied for were:

Embryonic Stem Cell Research – we asked Congress to support Stem Cell Research Enhancement Act of 2007 (H.R. 3 and S. 5). Only 22 of the 70 approved lines are available to researchers. This needs to be expanded. Because we do not know specifically which types of Stem Cells will help people with MS, we need to be support all types of research.

Access to Life-Saving Medicine Act (H.R. 1038) - This act allows for a pathway for approving, lower-cost versions (generics) of the very



expensive biotech drugs, i.e., Avonex, Betaseron, Rebif and Tysabri. These drugs cost anywhere between \$16,500 and \$26,000 per year. Too many people with MS cannot afford the drugs.

Medicare Mobility Device Coverage –Congress will introduce legislation that would lift the Medicare “in the home” restriction on coverage of mobility devices and allow people to obtain wheeled mobility for use inside and *outside* the home. Originally this language was defined by Medicare for items such as oxygen tanks. People with MS need to be able to move around in the community, get to their jobs. Devices such as scooters and/or wheelchairs help them to stay involved, employed and engaged.

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MSConnection is published quarterly by
The Southern New York Chapter of the
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All resources published have been reviewed and approved
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Southern New York Chapter

2007, Issue 3 - Published Quarterly

President's Letter

All politics is local. All giving is personal. People give because someone asks them.

This was brought home to me most vividly this past month at an event in the village of Hastings on Hudson, in Westchester County. It is a place I know well as I live there. However, I knew nothing of the event or those who organized it until I received an invitation.

The organizers wanted to do something for their friend recently diagnosed with multiple sclerosis. They booked a restaurant attached to the tennis club where their friend had been a regular member of their weekly game until MS started to slow him down. They sent out their invitations by e-mail and by word of mouth and we were pleased to be included. All were there because someone asked them.

Over 50 people attended to show their friend how much they cared for him – I am sure he knew that anyway - and to help raise some funds for the fight against MS. Before the night ended, they raised over \$4,000 - and additionally, they also wanted to stay involved. I know, because I asked them.

It is a privilege to be part of an event such as this, where friends, colleagues or family gather and do something for a loved one. It makes it very special. We see it in events large and small. The Chapter organizes some of these events; our volunteers arrange others from start to finish.

Volunteers are our greatest asset. Over 70 percent of this Chapter's fund raising comes through volunteers. They ask their family, friends, colleagues, and employers to participate. Elsewhere in this issue, we will intro-

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Editor's note: There is nothing more important to the functioning of our Chapter than the support, ingenuity and compassion our volunteers bring to us every day. We believe that you would like to know a little more about some of these individuals and just what they do, so we will introduce one of them in each issue of MSConnection. We have continuing need for your help, and would appreciate hearing from you if you wish to volunteer.

Debi Giuliani — Orange County Volunteer

“My first MS symptom occurred on my daughter’s christening day, she was 5 months old and I had a house full of company. I so clearly remember standing in the doorway and telling my friends I’m having such a hard time talking— it’s like my tongue won’t move. As time went on, my left knee kept going out, I began tripping, I fell down stairs.”

So relates Debi Giuliani, an Orange County resident, MS client, a wife and mother of three, a school district administrator and Chapter volunteer extraordinaire.

“I’ve had MS for 28 years, with the highs and lows that go along with it. Over those years I have always been treated at the MS Care Center and always felt so fortunate to have a doctor who really knew how to treat MS and who also knew me.

“I began an MS support group in 1992. We first started in Middletown, but our location was a bit out of the way. We moved to Warwick and met on Friday mornings. I met Lucille Albertie at my doctor’s office and learned that we both lived in Orange County. We teamed up as partners and since Lucille worked at Arden Hill Hospital in Goshen, she was

able to arrange for our group to meet there.



“Facilitating this support group is the most worthwhile experience I have. To be able to witness one person share with another to help relieve their fear, uncertainty or pain is confirmation to me of what a support group should be. We have never canceled a meeting due to bad weather, as someone has always shown up, and if it is only one or two, there is still the opportunity to share in a more intimate way.

“I feel our group is successful when a newcomer can feel safe enough to open up and express their fears or ask the questions no one else would understand. It’s such an uplifting experience when I see group members reach out to one another and give personal encouragement or share advice. Two primary topics seem to come up: “What medication are you taking”, and “what doctor do you go to?” There is a desperate and continuing need for reliable, sensitive and knowledgeable neurologists.”

Now as a sitting member of our Advisory Board, Debi continues to provide leadership, enthusiasm and compassion to everyone in our Chapter.

Following caregiver articles are reprinted from the web, with permission of the National Family Caregivers Association, Kensington, MD, the nation's only organization for all family caregivers. 1 800 896-3650; www.nfcacares.org

10 TIPS FOR FAMILY CAREGIVERS

- 1** Caregiving is a job and respite is your earned right. **Reward yourself** with respite breaks often.
- 2** **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
- 3** When people offer to help, **accept the offer** and suggest specific things that they can do.
- 4** **Educate yourself** about your loved one's condition and how to communicate effectively with doctors.
- 5** There's a difference between caring and doing. **Be open** to technologies and ideas that promote your loved one's independence.
- 6** **Trust your instincts.** Most of the time they'll lead you in the right direction.
- 7** Caregivers often do a lot of lifting, pushing, and pulling. **Be good to your back.**
- 8** Grieve for your losses, and then allow yourself to **dream new dreams.**
- 9** **Seek support** from other caregivers. There is great strength in knowing you are not alone.
- 10** **Stand up for your rights** as a caregiver and a citizen.

Improving Doctor/Caregiver Communications

There is much to be gained by improving communications between family caregivers and health care professionals, especially physicians. Positive outcomes include: better care for the patient, less stress and illness for the caregiver, more efficient use of doctors' time, reduced costs for the health care system, and more satisfaction for all concerned.

In order to reap these benefits, family, caregivers and physicians need to gain a better understanding of each other's worlds. Both need to try, as hard as it is, to "walk in each other's shoes". The following guide is offered as a path for doing just that.

Tips for Doctors from Family Caregivers

- Be open and forthright.
- Think about the practicality of the treatments you suggest and consider their effect on the entire family, not just their medical efficacy.
- When you prescribe medications, be sure caregivers understand potential side effects so they know what to expect.
- In non life threatening situations, assure caregivers that every decision doesn't have to be made on the spot. Respect the right of the caregiver and the patient to think things over.
- Now and then ask the caregiver: How are you? Let them know you understand that illness and disability are a family affair.
- Be accessible—especially when a caregiver is opening his or her heart.

- Reach out to the caregiver—literally. A simple touch can mean a great deal.
- Be sensitive about where you talk to caregivers about difficult subjects—waiting rooms and corridors are not appropriate.
- Always explain as completely as possible all of the legal ramifications of life-saving actions.
- Be prepared to point caregivers toward helpful resources. Living with a chronic illness or disability requires more than medicine has to offer.

Tips for Family Caregivers from Doctors

- Write questions down so you won't forget them.
- Be clear about what you want to say to the doctor. Try not to ramble.
- If you have lots of things to talk about, make a consultation appointment, so the doctor can allow enough time to meet with you in an unhurried way.
- Educate yourself about your loved one's disease or disability. With all the information on the Internet it is easier than ever before.
- Learn the routine at your doctor's office and/or the hospital so you can make the system work for you, not against you.
- Recognize that not all questions have answers—especially those beginning with "why."

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THE MS TECHNOLOGY COLLABORATIVE: MAKING TECHNOLOGY WORK FOR YOU

The new **MS Technology Collaborative** wants to raise awareness of how technology can help people with MS live well. It wants to break down barriers for those who aren't comfortable using technology and educate people on how to choose, use, and maximize the impact of technology on their lives no matter how MS affects them. The collaborative plans to

- Explore how people with MS currently use technology, including computers, cell phones, PDAs, and Web communities;
- Identify techniques and applications that can solve individual problems;
- Increase everyone's awareness of available solutions; and
- Develop new solutions to fill in the gaps.

Visit mymsmyway.com to learn more.

Access for all

The MS Technology Collaborative is a unique initiative by the National MS Society, Microsoft, and Bayer Healthcare Pharmaceuticals, a division of Bayer Schering Pharma AG (formerly Berlex). The three partners are creating a future where technology can be used by anyone living with MS. That includes people who have blurred vision, uncooperative fingers, iffy memories. It includes those who are newly diagnosed or have progressing MS-related symptoms. The MS Technology Collaborative is founded on the belief that improved technology can help people with MS move their lives forward. From telephones to global positioning systems, technology provides access to the world—

offering entertainment, education, employment, and personal connections.

Technology has even more potential for those living with MS. Health-care systems will increasingly use computer communication for partnerships in self-care and health education. So computer use may soon be a link to healthy living with MS.

Preparing the way

Before mymsmyway.com went live, the collaborative first formed a steering committee of diverse people living with MS across the country. That committee is providing ongoing input. Next, the collaborative fielded a nationwide survey to get the big picture into focus: What is the role of technology in the lives of people with MS?

The survey asks pointed questions about how people currently use technology, what limitations they experience, and whether technology helps them to live better. Survey results will be posted on both mymsmyway.com and the Society's Web site as soon as analysis is final.

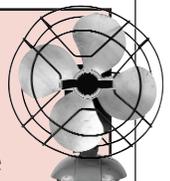
The MS Technology Collaborative hopes to develop a personalized, interactive Web experience that can deliver information tailored to the needs of a specific individual. Just how that will work is very much a work in progress.

Be part of the future. Visit mymsmyway.com today, and join in.

COOL TIPS FOR HOT DAYS

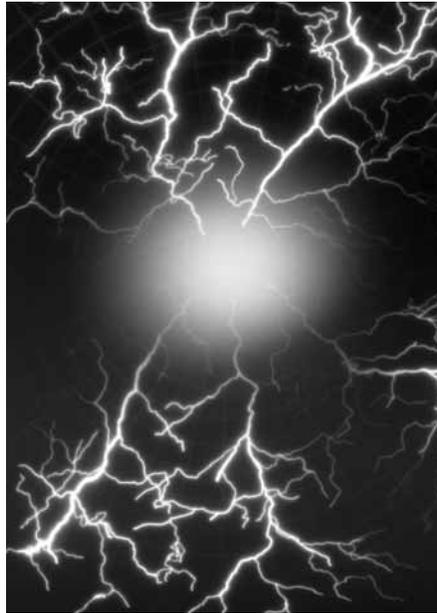
Avoid the hot seat

Keep your car cooler with reflective shades for the windshield and fabric car seat covers. Available at auto supply stores.



Nerve pain is different

All pain is transmitted by nerves, but nerve pain is different. “Phantom limb pain” is a vivid example of “neuropathic” or nerve pain. This type of pain originates in the central nervous system in injured nerve pathways, not in the bones or muscles. A person with phantom limb pain feels pain in a body part that was amputated in the past.



MS lesions can injure nerve pathways and produce neuropathic pain—or unpleasant sensations called dysesthesias (or “di-es-THESE-ee-ahs”). The burning, aching, stabbing, prickling,

or itching may start and stop or drag on. MS lesions may also cause “allodynia” (“Al-oh-DIN-ee-ah”)—which is pain from something that shouldn’t be painful. A soft touch, the weight of bed covers, even a cool breeze can be the trigger.

Neuropathic pain is not soothed by the over-the-counter medications that work on muscle pain. Even powerful prescription medications such as

Percocet, Lortab, Oxycontin, or Darvocet are not effective for this kind of pain.

Instead, physicians need to prescribe medications that work on nerves. They may be anti-convulsants (such as Tegretol, Dilantin, or Neurontin), antidepressants (such as Elavil), or new drugs approved for diabetic pain (such as Lyrica or

COOL TIPS FOR HOT DAYS

Water and

Keep a plastic water bottle half filled in the freezer. Top it off and you’ll have a drink that stays cool all day.

Herbals teas—fruity blends, peppermint, and ginger—are good chilled and have little or no calories if you make your own.

Avoid sugary drinks. They leave you thirstier—and heavier too, because of all the calories.

Drink fruit juice the light way by extending with ice, water, or a fruity herbal tea.



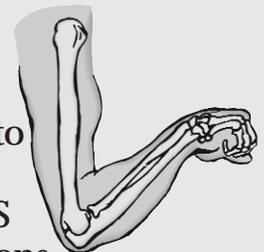
Muscle and bone pain happen too

People who have difficulty walking may develop pain from the stresses placed on muscles, bones, and joints.

Sitting also stresses

body parts. Muscle and bone pain responds to physical therapy—and to standard pain medications.

A person with MS might have more than one kind of pain. The first step to pain control is a professional diagnosis.



*Funded by the Neuropathic Pain Network and Pfizer, Inc.

(continued next page)

Nerve pain is different (continued)

Cymbalta). It's not uncommon to try out drugs to find what works best.

Global survey shows communication critical to pain relief

A seven-country survey by Harris Interactive* shows that doctor-patient communication is essential for diagnosis and treatment of nerve—or neuropathic—pain.

The survey found that many general practitioners (family doctors) did not find it easy to recognize this type of pain. The survey also found that people with nerve pain waited from 5.7 to 19.5 months

before talking to a physician about it. Many believed the pain would go away by itself.

Language matters

Success involved two-way communication. People who were able to describe intensity, duration, location, and how a pain feels—and physicians who asked for these descriptions—were far more likely to have successful outcomes. They used descriptive words like dull, throbbing, stabbing, numb, achy, prickly, burning, pins and needles, and shock-like.

The survey contacted approximately 700 people diagnosed with nerve pain because of MS, diabetes, herpes, cancer, stroke, or other conditions and 700 physicians in Finland, Germany, Great Britain, Korea, Italy, Mexico, and Spain.

Try nondrug approaches right away

While you and your physician investigate meds, pain specialists say it's smart to add complementary therapies right away. Nerves can become habituated to pain, making the pain harder to control.

Consider relaxation techniques, meditation, guided imagery, self-hypnosis, prayer, or music therapy. Joining a support group, pursuing a hobby, or having a good laugh watching comedy videos are also known to minimize pain.

Experiment with applications of heat, cold, or pressure. Try massage, acupuncture, yoga, tai chi, or physical therapy.

Oddly enough, neuropathic pain does **not** mean the MS is getting worse. But it could make life worse.

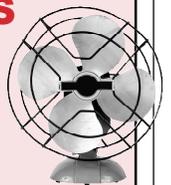
Tell your doctor

The National MS Society's Professional Resource Center **Clinical Bulletin**, "Pain in Multiple Sclerosis" by Heidi Malone, PhD, RN, can be downloaded at nationalmssociety.org/PRC. It includes charts on pharmacological management and an extensive bibliography.

COOL TIPS FOR HOT DAYS

Snackin' cool

Smoothies and slushies pack a cool nutritional punch. In a blender, combine banana, melon, strawberries, or peaches with low-fat milk or fruit juice. Then pile in the ice. Add a few drops of vanilla for an exotic touch.



Filing for SSDI Benefits

If you have MS and are unable to work due to an MS-related disability and/or other conditions, you may be entitled to **Social Security Disability Insurance (SSDI)** benefits. To receive these benefits, you must have worked at least five of the 10 years immediately before the disability and paid FICA taxes. The disability or impairments must be expected to last for at least 12 months.

Step One: Get familiar with the process

See "Loosening the SSDI Knots" in the April-May 2007 **InsideMS**. Go to nationalmssociety.org, click on **Library** in the gray menu bar in the upper right hand corner, and then on **InsideMS** in the box on the left-hand side—or call us for a copy.

For a more detailed review, check out the Society's new **SSDI Guidebook for People with MS** at nationalmssociety.org/SSDI. If you do not have Web access, call us.

The exact requirements for SSDI are detailed in the Social Security Administration's **Blue Book (SSA No. 64-039)**, or www.ssa.gov/disability/professionals/bluebook).

Step Two: Get prepared

Keep a detailed journal of your MS symptoms and how they limit your ability to work.

Visit your doctor and let her/him know you plan to apply for SSDI benefits.

Offer your doctor the Society's template letters to make the documentation of your symptoms easier. (Go to nationalmssociety.org/SSDI and scroll down to "Worksheets and Sample Letters.")

Step Three: Strengthen your chances

Don't hesitate to ask for help from an SSA representative, a family member, staff in your doctor's office, or a knowledgeable person at the Society.

Don't delay if you can't complete certain general information on the application. Sufficient medical information is the most important.

The best source of your medical information is your doctor. Be sure your doctor is aware of all of your symptoms.

Step four: The waiting game

Recent data indicates that nationwide roughly 62% of initial claims for SSDI were denied, and that most applicants who went on to file a written appeal called the "reconsideration" were also turned down. Only 16% of these second-level claims were approved.

The third level provides a face-to-face hearing before an administrative law judge called the ALJ hearing. Nearly 60% of recent hearing decisions were in favor of the person seeking benefits.

A final level is also available: the Appeals Council of the Social Security

Contacting the Social Security Administration

Toll-free: **800-772-1213**,

7 AM to 7 PM, M–F

Toll-free TTY: **800-325-0778**,

7 AM to 7 PM, M–F

On the Web: www.ssa.gov

Mailing address: Social Security Administration, Office of Public Inquiries, Windsor Park Building, 6401 Security Blvd., Baltimore, MD 21235

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NATIONAL RESEARCH STUDY NEEDS VOLUNTEERS

The Sonya Slifka Longitudinal MS Study, sponsored by the National MS Society, has collected information from some 1,600 people with MS since 1999. Because the Slifka Study provides such valuable information to the MS community, it has just been expanded and extended for another five years. Now it needs 2,500 more people with MS.



Beverly, diagnosed in 2001

Specific populations with MS will be “oversampled” in this phase of the study to ensure that their experiences are adequately represented. The target populations are African-American, Hispanic, and people diagnosed with MS after September 2006.

Most participants will be selected at random from the National MS Society’s database. However, to ensure that the study adequately covers people with MS who are **African-American, Hispanic, and/or are very recently diagnosed**, we

are asking for volunteers. If you are a member of one or more of these groups, please consider joining this important study. Call **1-800-305-8013**.

Participation involves telephone interviews every six months, plus keeping a log of your health status, the medical services and therapies you use, the money you spend on MS-related needs, and the impact MS has on your life. The calls are made in English, so volunteers need to be comfortable talking on the phone in English.

All the information collected is confidential. Those who use data from the study will not be able to identify individual participants.

MS researchers are already using data from the first phase of the study to identify ways to improve quality of life and manage MS symptoms more effectively. The study data also helps the Society advocate for public policies that address the issues most important to people with MS.

The second phase of the study will lead to more important information about how people live with MS over time.

Sonya Slifka and her son Richard

The Sonya Slifka Longitudinal MS Study is supported in part by a generous gift from the Society’s past National Chair, Richard Slifka, and in part by the Society’s Promise: 2010 campaign. The study is named for Richard’s mother, who developed MS when he was still a boy. The grown-up Richard Slifka has been a leadership volunteer for the Central New England Chapter for more than 25 years as well as serving on the National Board since 1988. He has generated more than \$3 million in personal donations and solicitations.

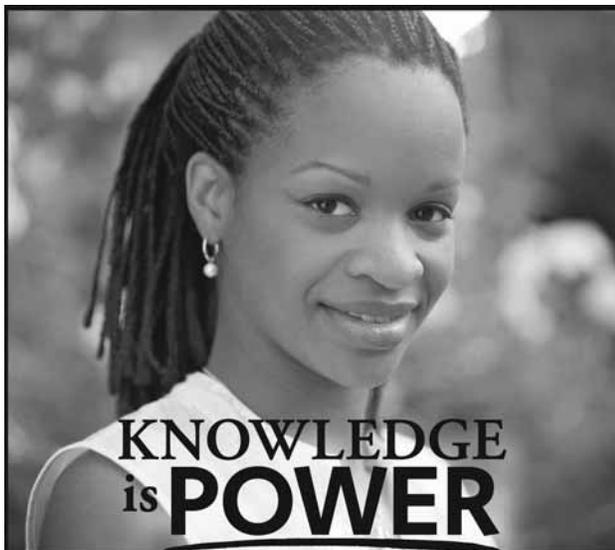
GET GOING WITH TWO NEW RESOURCES

Begin with MS Learn Online

Fearful, depressed, confused? A person can feel all of this after an MS diagnosis. But perspective—and hope—are available in the MS Learn Online webcast **Where do I begin? Newly Diagnosed with MS.**

Three people, with more than 30 years of living with MS between them, talk about their lives and recall their feelings at the time of their diagnosis. They discuss relationships and support, becoming one's own health-care advocate, and the possibility of reinventing oneself while managing life with a chronic illness.

To view the 23-minute webcast and explore the full roster of MS Learn Online offerings, go to nationalmssociety.org/mslearnonline.

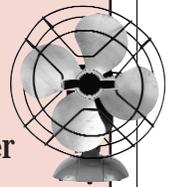


Knowledge Is Power is a six-week free, at-home educational program for people who are newly diagnosed. Mail or e-mail formats. To register, call 1-800-344-4867, or visit nationalmssociety.org/knowledge.

This is why we're here.



COOL TIPS FOR HOT DAYS



Dress light and loose

Loose cotton blends and microfiber fabrics allow perspiration to evaporate. Try a wide-brim hat. Canvas or mesh sneakers are cooler than leather.

Cool clothing

Commercial cooling garments, such as vests, bra inserts, and headbands, can help you stay cool for hours. Search ABLEDATA (www.abledata.com or call 800-227-0216) or call us for referrals.

Spray instead

Sweat evaporating on skin is how your body stays cool. Carry water in a spray bottle and wet your shirt and hat for the same effect. Stand in front of a fan for instant A/C.

New! KIP Teleconference Series

The **Knowledge Is Power** home study program (KIP) for people newly diagnosed and their family members answers many questions. But you may still have more. KIP is beefing up by offering a series of free telephone conference calls hosted by MS experts.

Neurologists and other MS professionals will answer questions on topics such as symptom management, relationships, employment, and more. These calls not only provide information, they offer a chance to interact with others who are also facing a new MS diagnosis—all from the privacy of home.

Register for KIP and receive a teleconference schedule as part of this free, six-week course. See ad this page for details.

SAFE AND EASY: GIVE ONLINE

“The Internet is a tremendous tool to help people join the MS movement,” said Joyce Nelson, president and CEO of the Society. “We hope to cut administrative costs, make giving easier, and better tailor information to suit our constituents’ interests.”

“Tremendous” is no exaggeration: According to a **USA Today** report, online donations to the nation’s biggest nonprofit organizations increased 63% from 2003 to 2005. The Society has led the way on the Web since 2001 when we first made it possible to sponsor Bike and Walk participants online.

To pledge online, go to **nationalmssociety.org** and click on the heart-shaped button (“**Pledge/Sponsor a Participant**”). Then use the search engine to find the person or the team you’d like to sponsor.

New online opportunities

The Society recently expanded its Web site to make it easy to give in other ways. At **nationalmssociety.org**, click on the gift-box shaped button (“**Donate to the Society**”) to access the **Donate** page. Visitors may choose:

Donate Now, to safely and securely give a one-time gift to the Society. You can also search to see if your employer is one of the many companies that will match an online gift with a contribution of their own.

Tributes and Memorials, to create a personal page to honor a loved one, to give a one-time contribution, or to set up

an automatic annual or monthly tribute or memorial gift.

Workplace Giving, where you may sign up to have a regular payroll deduction dedicated to the MS movement. The payment is sent to us automatically.

Planned Giving, to learn about other ways to support the Society through a will, gift annuities, charitable trusts, and more.

A SPARKLING WAY TO GIVE

Check out the new line of jewelry at Christopher & Banks and CJ Banks stores. There are nearly 750 stores nationwide—and this May and June they are offering the sparkling new “MS Collection.” The moderately priced earrings, necklace, and bracelet are created with genuine Swarovski crystals--and the National MS Society will receive 50% of the proceeds. Just in time for gradu-

ations, weddings, Challenge Walks, and other special summer events. For store locations, go to **www.christopherandbanks.com**.

**COOL TIPS FOR HOT DAYS****Pre-cool**

“Pre-cooling” may lessen the heating effects of strenuous activity. Submerge in a tub of cool water for optimal benefit. Use mint soap for a cool skin sensation.

For information on heat sensitivity, go to **nationalmssociety.org/sourcebook**. Click on heat/temperature.



Critical Short-Term Services

Our Chapter is pleased to provide direct services to people with MS, who may need short-term assistance. These services are provided to those with limited financial resources, when insurance coverage or Medicare and Medicaid are limited. There are funding limits for each service as well as guidelines to follow ensuring need. This program is based on availability of funds. Following is a listing of services and the person to contact for more information.

DURABLE MEDICAL EQUIPMENT – ext. 38
Financial assistance toward the purchase of new durable medical equipment or insurance co-pays. Loaner closet with used equipment.

HOME/AUTO MODIFICATION – ext. 38
Removing barriers from a home or vehicle.

EMERGENCY FINANCIAL ASSISTANCE – ext. 38
This is a means based service providing financial assistance for unexpected situations like utility shut-offs.

HEMOCARE/RESPITE/CHILDCARE – ext. 33
Activities of daily living (dressing, bathing, toileting, etc.) or non-medical homecare - up to 50 hours (per fiscal year)

MEDICAL TRANSPORTATION – ext. 38
Round-trip transportation - up to four visits annually, to a healthcare professional.

CARE MANAGEMENT – ext. 45
This program is available to assist people who may be unable to identify community resources that can help cope with the challenges of MS. A social worker can

assess, plan and coordinate needs related to entitlements, long term care and financial management -up to five sessions.

COUNSELING – ext. 45

Up to five sessions of counseling for people with MS or a family member who may be having difficulty coping with issues related to MS.

PT/OT – ext. 38

Up to five sessions of physical therapy and/or two sessions of occupational therapy. A letter of medical necessity is required.

Contact Debby Bennett, ext. 38, Chris Benvenga, ext. 33 or Joan Damiani, ext. 45 at 914 694-1655 for more information

Free Financial Planning Resources

One part of navigating MS is managing your money and planning wisely for the future. Just as your MS symptoms are not exactly like someone else's, your financial situation also is unique. Now more than ever, you will need to take a clear look at your income, assets, debts, benefits and other resources. A financial planner can assess your individual situation and make recommendations to help you plan your finances and protect you or your family from having to divest assets in order to receive long-term care services at some point in the future.

The National MS Society and the Society of Financial Service Professionals have joined forces in a partnership called the Financial Education Partners to help people with MS and their families address financial planning and insurance issues. Call 1-800-FIGHT-MS (1-800-344-4867) to be referred.

Professionally Led and Self-Help Groups

Please contact the facilitator prior to attending meetings.

WESTCHESTER COUNTY

White Plains – Newly diagnosed and for those with little or no symptoms. Family and friends welcome.
Westchester Independent Living Center
– 200 Hamilton Ave
2nd Wednesday, 6:30 – 8:00 pm – Call Ed (203) 445-0118

Scarsdale
Scarsdale Library – 50 Olmstead Rd
3rd Wednesday, 7:00 pm – Call Chris (914) 694-1655 ext. 33

Scarsdale
Scarsdale Library – 50 Olmstead Rd
2nd Wednesday, 5:30 pm – Call Gordon (914) 948-4630

Pleasantville – Newly diagnosed
Pleasantville Library – 350 Bedford Rd
2nd Monday, 6:30 pm – Call Donna (914) 245-3029

Mount Vernon
Dole Center – 250 South 6th Ave
Last Thursday, 5:00 -7:00 pm – Call Tracey (914) 664-3472

Valhalla
Hebrew Home – 61 Grasslands Rd
2nd Thursday, 3:30 – 5:00 pm – Call Ed (203) 445-0118

Social Group
Location and time determined monthly
– Call Laura (914) 793-8733 or Greg (914) 690-9199

Health/Mental Health Professionals w/MS
Call for location details
3rd Wednesday, 6:30 – 8:00 pm - Call Rob (914) 747-2008

Phone Connections – Professionally led conference call for people who seldom leave home.
Westchester Jewish Community Services – Call Debbie, MSW (914) 632-6433

ROCKLAND COUNTY

Pearl River
Pearl River Library – 80 Franklin Ave
2nd & 4th Tuesday, 7:00 – 8:30 pm - Call Laurie (845) 352-7189 or Ian (845) 365-2652

West Haverstraw – For in-patients & those exhibiting symptoms
Helen Hayes Hospital – Rte. 9W, 4th floor conference room
4th Thursday, 6:15 pm – Call Dianne (845) 425-3520

ORANGE COUNTY

Castle Point
Castle Point VAMC, Bldg. 13-12511
Route 9D
3rd Tuesday, 4:00 – 5:30 pm – Call Don (845) 565-2240

Cornwall
Cornwall Hospital, Conference Room
B-19 Laurel Avenue
1st Wednesday, 6:30 – 8:00 pm – Call Kathy (845) 787-4723

Goshen

Orange Regional Medical Center, Arden Hill Campus- 4 Harriman Dr.
3rd Saturday, 9:00 – 11:00 am –
Call Debi (845) 986-6497 or
Lucille (845) 783-1071

Newburgh – Residents of facility and
community friends

Elant Nursing Home, 56 Meadow Hill Road
1st Tuesday, at 2:30 pm – Call Don
(845) 565-2240

New Windsor

Marasco Center-244 Union Ave.
2nd Monday, at 7:00 pm – Call Don
(845) 565-2240

Port Jervis – Professionally Led
Bonsecours Community Hospital –
160 East Main St, 3rd fl. Conf. Rm
2nd Wednesday, 12:00 – 1:00 pm – Call
Barbara, (845) 856-5351 ext. 7122

Warwick – Residents and community
friends

Schervier Pavilion – 20 Grand St.
Wednesdays, 11:00 am – 12:00 pm –
Call Michael (845) 986-0802

PUTNAM COUNTY

Carmel

Putnam Hospital Center, Room 270-
Stoneleigh Ave.
2nd Thursday, at 6:30 pm – Call Alice
(845) 628-9792

Kent Lakes

Kent Public Library – 17 Sybil's
Crossing
3rd Wednesday, at 6:00 pm – Call
Kristen (845) 228-5607 or
(845) 264-0085

SULLIVAN COUNTY

Liberty

Boces Cornell Cooperative – 64
Ferndale Loomis Rd
3rd Thursday, at 7:30 pm – Call Judy
(845) 292-5539

Filing for SSDI Benefits

(continued from page 9)

Administration. This rarely results in an award of benefits. Beyond this point, a person may file a complaint in the U.S. District Court.

Optional: Retain a representative
The law permits SSDI applicants to retain a representative on a contingency basis, meaning that the fee is based on the outcome of the claim.

The representative, who may or may not be a lawyer, is a professional with expertise in Social Security rules and regulations. Applicants may pay a representative out of the Social Security benefit check when the claim is approved. The fee will be 25% of the retroactive benefit, but cannot exceed \$5,300.

COOL TIPS FOR HOT DAYS**Tax deduction**

With a doctor's prescription, you can claim a new air-conditioner as a tax-deductible medical expense.

W A M S Luncheon

Women Against MS (WAMS) is a nationwide education and fundraising program. The mission is to raise awareness of Multiple Sclerosis and the work of the Society in bringing hope and help to people with MS, while acknowledging and encouraging the advancement of women philanthropists. More than twice as many women than men are diagnosed with MS.

The monies raised from the event will bring direct services and programs to the thousands of persons with MS in our area, and contribute to worldwide research and clinical trials into the cause, prevention and treatment of MS.

The second annual WAMS Luncheon will be held at the Hilton Rye Town in Rye Brook, NY on September 20, 2007, and will feature nationally recognized stress



expert and Fox News Channel host and contributor, Dr. Georgia Witkin. The program will begin at noon and includes a silent auction, a presentation entitled "Hope for the Future in Managing MS," featuring Dr. Aaron Miller, Chairman of the Medical Advisory Committee of the National MS Society, and a presentation by Dr. Witkin with easy-to-understand scientific information and humor.

Dr. Witkin's topic will be *The Female Stress Syndrome Survival Guide*, which draws from the coping mechanisms she learned from her mother, a six-time cancer survivor. Dr. Miller's program will address the promising therapies

becoming available to people with MS in the next several years.

Tickets are \$100 - \$500, and include a three course luncheon, a Judith Ripka gift for all attendees, and the exciting and informative program. Higher level ticket prices include a gift and reception with the guest speaker. Table sponsorship is also available.

Acorda® Therapeutics, a biotechnology company whose mission is to develop and market therapies to restore neurological function in people with spinal cord injury (SCI), multiple sclerosis and related conditions of the nervous system, has generously underwritten WAMS this year. Acorda's lead clinical product, Fampridine-SR, is being evaluated for its effects on walking ability in people with MS.

To learn more about the WAMS Luncheon, please contact Anne-Marie Annunziato at 914-694-1655 ext 40 or by email: Annemarie.annunziato@nyv.nmss.org

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.

Talk to your health care professional or contact the National MS Society at www.nationalmssociety.org or 1-800-FIGHT-MS to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

FIT TO FIGHT MS, a supervised program of exercise specifically for people with MS. This unique program is administered by a staff of licensed physical therapists and exercise physiologists who work closely with each client to set goals that are consistent with their specific abilities and needs. The therapists are experienced and knowledgeable about MS. **There is no fee for this program.**

WHERE: Forme Rehabilitation and Sports Medicine
1075 Central Park Ave,
Suite 301
Scarsdale, NY 10583

WHEN: Thursdays from 12:00 – 1:00 pm

For more information and to register contact:
Carol Giordano 914-694-1655 x 31
Email: carol.giordano@nyv.nmss.org

MS Night of Baseball

Join us for a fun night of baseball when the minor league **Hudson Valley Renegades** play at Dutchess Stadium, Route 9D, Wappinger Falls on August 5th.

Picnic at 5PM Game at 6:05
\$10/adult - \$5 Child (under 12) Price includes admission to game and "All you can eat" pre-game buffet.

Contact: Carol Giordano
914 694-1655 ext. 31 or carol.giordano@nyv.nmss.org

Don't wait. This event sells-out!

Web Travel Help

There are two websites for current, up-to-date travel information. For overall advice, visit the Department of Homeland Security's Transportation Security Administration at www.tsa.gov.

Travel news articles are available at the Society for Accessible Travel and Hospitality at www.sath.org/index.html?pageID=9856.

For any specific information, email to nsip@umb.edu



SPRING FLING

Carolyn and Frank (shown above) were so happy to spend an evening out together. Laurie and her husband danced all night and Nick danced with all the women! The comedian had some of us laughing so hard, we cried and everyone made new friends. This all took place at the Spring Fling on May 11 at the Crowne Plaza where 75 people kicked off their shoes and let down their hair. We have already been charged with finding a larger room for next year. Hope you'll join us then.

Thank You, Thank You, Thank You!

More than \$700,000 has been raised to date by the Chapter's MS Walk and that continues to grow...daily!

A big thank you to all our great teams, our sponsors, our Champions Against MS and to You...yes YOU!... for tremendous work and generosity. You do it all. We just try to help and could not do it without YOU!

Each MS Walk site had a great turn-out and the weather was glorious, with maybe one exception... but that didn't hamper the spirits of everyone at Bear Mountain!

But we are not done yet. We know some of you are still collecting. And you can still earn incentives for money turned in up to August 1, 2007... With your continued support we can still reach our goal of \$800,000!

Information provided by the Society is based upon professional advice, published experience and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National Multiple Sclerosis Society recommends that all questions and information be discussed with a personal physician.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any product or service mentioned.

TZ Bike Tour for MS

The 10th annual MS Bike Tour will be held on Sunday, September 30, 2007. The MS Bike Tour will begin at Kraft Foods in Tarrytown where cyclists will select either a 20 mile or a 60 mile route. Both routes offer a scenic ride over the Tappan Zee Bridge. Cyclists will stop at Rockland Lake State Park for snacks and refreshments. After a brief rest, 20-milers will ride back over the TZ Bridge to the finish line while the 60-milers will continue north to the Bear Mountain Bridge where they will cross back over the Hudson River. The cyclists then ride south along the Hudson River back to the finish line at Kraft.

Online registration is now open at www.TZBikeTour.org. In addition to the registration fee - \$20 on or before August 26, \$30 on or before September 26 or \$40 on the day of the event, all cyclists are required to raise a minimum of \$125 in donations to fight MS. Participants must be at least 12 years of age. Any cyclist under the age of 14 must be accompanied by an adult. All cyclists under 18 must have permission from a guardian.

There are many ways you can be a part of this exciting event - You can form a team, or cycle as an individual. If cycling isn't for you, you can volunteer on the day of the event, join the planning committee, help to spread the word and recruit more cyclists or you can simply come and cheer as the cyclists cross the finish line. For more information on how you can help, call the MS office at 914-694-1655 or email to carolann.mcowen@nyv.nmss.org.

Swim The Hudson For MS 2007!

The 2007 Swim the Hudson for MS will be held on Sunday, September 16, 2007. This year swimmers will choose a 3, 2 or 1 mile swim at Croton Point Park in Croton-On-Hudson.

Last year more than 150 participants joined us in the movement of funding research and treatment programs for people diagnosed with multiple sclerosis. We are delighted to join with Croton-On-Hudson, New York Waterway Tours, "Floating the Apple" and the Westchester County Department of Parks, Recreation and Conservation in providing a great day of challenge, fun and entertainment.

The official online registration site will open on Friday, June 29, 2007, but you can also call the Chapter beforehand if you plan to join us on September 16th – or if you need additional information about the event.

We are also in need of volunteers. If you are a kayaker or boater we can use your assistance in the water to insure the safety of the swimmers. If you are more of a land lover ... we also need volunteers for various stations for the event, including cheerleaders! We look forward to seeing you there! For further information check our Chapter web site or go directly to www.weswim4ms.org.

■ Advocacy — An Awesome Experience *continued from page 1*

Congressionally Directed Medical Research Program (CDMRP) -NMSS has asked members of Congress to support a \$15M appropriation for MS research. This program is funded through the Department of Defense via the Defense Appropriations Act. Between 1998 and 2003 over 25,000 veterans with MS enrolled with the Veterans Health Administration. Emerging evidence shows that Gulf War veterans might be at increased risk of developing MS.

Debby Bennett, Vice President of Programs for the Southern New York Chapter, and I traveled to Washington together. Upon arrival at the hotel we attended a reception where we immediately sensed the energy and a feeling of empowerment. Our cause was multiple sclerosis. There was a feeling of hope that we could make a difference and influence policy and unity.

Monday and Tuesday were spent learning about the issues and discussing how each issue impacts our lives. We had strategy sessions and objectives. We met and made new friends. We shared concerns, feelings of vulnerability, experiences and stories. Some stories were good and some painful. We cried and laughed. There was a feeling of bonding.

Wednesday we left for the hill. Empowered and focused, our mission was clear. We are *multiple sclerosis advocates*. With 15 other New York State advocates, we visited NY Representatives of both the House and Senate. They were gracious in giving us time to speak to the issues. We handed each representative a packet of information, which included our agenda and a CD containing over 100,000 signatures

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■ Improving Doctor/ Caregiver Communications— *continued from page 5*

- Separate your anger and sense of impotence about not being able to help your loved one as much as you would like from your feeling about the doctor. Remember, you are both on the same side.
- Appreciate what the doctor is doing to help and say thank you from time to time.

SAVE THE DATE

Jun 25	Dystel Memorial Golf Classic
Aug 5	Hudson Valley Renegades
Sep 16	Swim Across the Hudson
Sep 20	Women Against MS (WAMS) Luncheon
Sep 30	Great TZ Bike Tour
Oct 18	Annual Meeting
Nov 3	Discovery Day

■ President's Letter *continued from page 2*

duce you to Debi Giuliani, a volunteer, who we asked many years ago to initiate a support group in Orange County. She hasn't stopped since, and Debi's story is leading off our series of articles written by key volunteers.

We are truly part of a movement and more are joining daily. Why not ask someone today?

■ Advocacy — An Awesome Experience *continued from page 19*

requesting federal funds for MS research.

At the end of the day I watched as people left for home. There were a lot of smiles and people saying "see ya next year"...and we will. It is an awesome experience.

FOR SALE: Lift chair in excellent condition, asking \$250 – contact Valerie at 914 779-4859

FOR SALE: Two Pride Scooters, contact Terri at 914 271-5145



Southern New York Chapter

National Multiple Sclerosis Society
2 Gannett Drive, Suite LC
White Plains, NY 10604