



CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Volume 2008 • Issue 4

Long Island Chapter

2008 bikeMS® Wrap-Up



Team Schmoofus



Montauk Lighthouse lunch stop



Dolphin Fitness



Sunday cyclists on the North Ferry

Turn to pages 24 & 25 for our bikeMS® Wrap-Up!



bike to create a world free of MS

INSIDE THIS ISSUE:



Real Talk Page 10



Concert for a Cure Page 11



Fall Programs Page 19



Walk MS Page 27

November 2008

Publication of the National Multiple Sclerosis Society, Long Island Chapter
40 Marcus Drive, Suite 100
Melville, NY 11747

Pamela Jones Mastrotta
President & CEO

Stacy Bona
Vice President, Campaign Development

Barbara Travis
Vice President, Donor Development

Eugene Veigl
Director, Chapter Programs

Richard Palese
Director, Finance and HR

Valerie Delaportas
MS Connection Editor

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 1-800-344-4867 to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

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

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 National Multiple Sclerosis Society is dedicated to ending the devastating effects of MS.

© 2008 National Multiple Sclerosis Society,
Long Island Chapter

President's Message

With the New Year upon us, I want to take this opportunity to thank each and every one of you for your membership and participation with the National MS Society, Long Island Chapter. Whether you are a person with MS, a donor, an event participant, a volunteer, a caregiver, or someone who has joined the movement for another reason, we are so grateful for your continued belief in our mission of creating a world free of MS.



Pam Mastrotta
President & CEO

In the past six months of our event season, the Chapter staff and I have been fortunate to meet many of you, and we continue to be motivated and energized by your stories.

One of the most recent opportunities we have had to meet individuals that have joined the movement was at our bikeMS® Twin Forks Ride on September 13 & 14. The event was a huge success, and the overnight stay allowed riders to share their stories of what motivates them to ride the 150 mile journey. I'm always amazed by the tremendous dedication, both in fundraising and cycling, of our bikeMS® participants. The sight of 300 cyclists riding toward the Montauk Lighthouse takes my breath away every year and reminds me of how powerful the movement is to create a world free of MS.

Funds raised through bikeMS® and all of our special events help provide crucial programs and services to the nearly 6,000 Long Islanders affected by MS. Fundraising dollars are also the driving force of the Society's funded research. Thank you for joining the movement toward a world free of MS. With your support, we are one step closer to a cure.

Sincerely,

Pamela J. Mastrotta

Learn how to make medical decisions

A diagnosis of MS brings with it a mountain of information, many decisions to make—and many questions to ask. How to sort through it all? A new Society program called **My Life, My MS, My Decisions** takes you step-by-step through the process of making decisions about your medical care. The program features a DVD and four online courses that cover the following topics:

- Teaming Up with Your Health-care Providers
- Navigating the Medication Maze
- Considering Clinical Trials
- Achieving Optimal Wellness

The courses can be accessed online wherever there is Internet access, whether at home, a community center, public library, or chapter. The DVD is also available separately if Internet access is unavailable.

Registering for better health

Three of the courses are now available and the fourth (“Achieving Optimal Wellness”) will be available in winter 2008. The DVD includes three separate segments, each featuring a different person journeying through medical decision-making:

- Annie is a recently diagnosed 20-something who is a bit reluctant to begin taking disease-modifying medication.
- Diagnosed 10 years ago, James, who is in his 30s, finds that his MS is affecting his walking and his physical relationship with his partner.

- Joann is in her 40s and uses a wheelchair to get around. She feels her MS is getting worse and would like to change doctors.

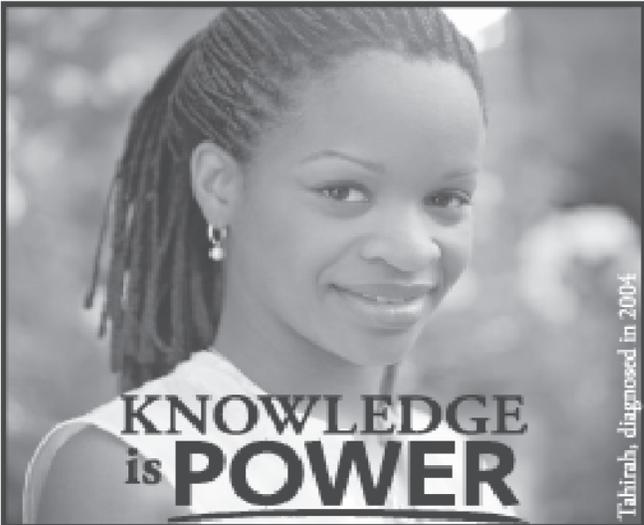
The DVD follows Annie, James and Joann through the decisions they make and how they arrive at them, including researching medications, communicating with their doctors, and exploring clinical trials.

For more information, visit

nationalMSSociety.org/mydecisions.

To register, call 1-800-344-4867, or e-mail **programsonline@nmss.org**.

My Life, My MS, My Decisions is partially funded by an unrestricted educational grant from Biogen Idec, Bayer HealthCare Pharmaceuticals, Genentech, EMD Serono/Pfizer Inc., and Novartis Pharmaceuticals Corporation.



KNOWLEDGE is POWER

Tabirrah, diagnosed in 2004

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.

MS
National Multiple Sclerosis Society

Society's National Conference

Every leader in the MS movement will find something of value at this year's National Conference.

Those of a scientific bent can ask about MS research at two open panel discussions. The first session features Marcia L. Finlayson, MSc, OTR, PhD, Stephen D. Miller, PhD, and Anthony T. Reder, MD; the second session features Howard Lipton, MD, David C. Mohr, PhD, and Betty C. Soliven, MD. At the MS Fellows Poster Session, people can



meet many of the "best and brightest" new MS researchers attending the first ever Research Fellows Conference, being held in conjunction with the National Conference. Those looking for inspiration will hear keynote speaker Malcolm Gladwell, author of **Blink, The Tipping Point**, and a new book, **Outliers: Why Some People Succeed and Some Don't**.

Many workshops address how to get our message out to a wider range of people with MS, reaching communities diverse in both culture and geography. Other workshops will discuss advocacy issues, including what the election's outcome may mean for the Society's Health Care Agenda.

To learn about advocacy on Long Island, please call Gene Veigl at (631) 864-8337 or (516) 740-7227 ext. 222 or email eveigl@nmssli.org

Bold Moves by our Hispanic/Latino Advisory Council

Under the leadership of noted neurologist Victor Rivera, MD, the Society's National Hispanic/Latino Advisory Council has established bold goals for the next three years. They include:

- Promoting more participation by Hispanics and Latinos in clinical trials
- Promoting studies on the experiences of Latinos and Hispanics with MS
- Developing more resources to educate health-care professionals about this community
- Increasing the number of Hispanic/Latino volunteers on chapter boards or as participants in Society fund raising, programs and events.
- Including Hispanic/Latino outreach dimensions in the proposed federal study of MS prevalence by the CDC.

The Council has already created the Spanish-language glossary of MS terms on our Web site and been instrumental in developing the national telephone support group, Café con Leche.

Currently, Dr. Ron Duran, a council member and a professor at the Alliant International University, is doing field work in collaboration with the Society to identify the unique challenges faced by Hispanic/Latino families living with MS. And Dr. Debbie Victor, an occupational therapist and recent graduate of the University of Illinois at Chicago, developed a set of action steps for outreach to Hispanics and Latinos to be distributed to all chapters in the new year.

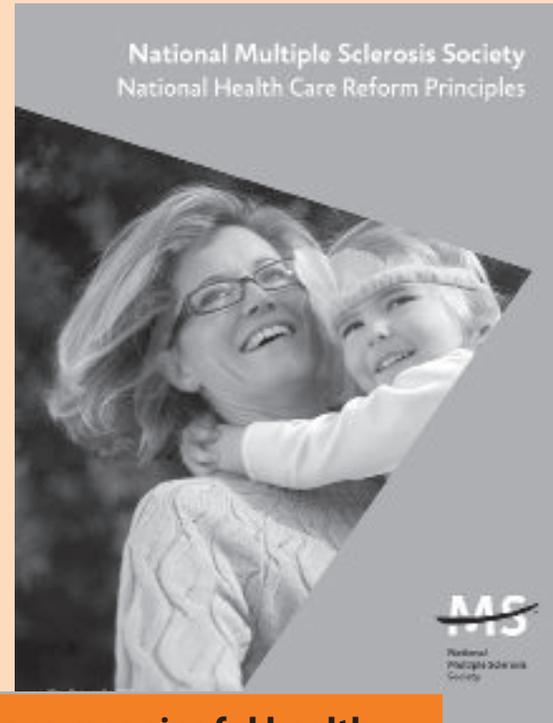
An invitation to join a national discussion by Weyman T. Johnson, Jr., Chair, National Board of Directors

This coming January a new federal administration will begin asking questions about how to address our national health-care crisis. The major presidential candidates may hold different views on how to fix the current system, but almost every voter in the country agrees without reservation that the status quo is unacceptable.

We at the National MS Society certainly agree. The impact of under-insurance, uninsurability, lack of coverage for maintenance or off-label therapies, disparities in quality and availability of care—especially of long-term services—and the consequences of inconsistent and expensive medical record-keeping are all harmful to those of us in the MS world. Last May, the National Board unanimously adopted a set of health-care reform principles to guide our active participation in the national discussion. Our board leads a movement that seeks a world in which we may live as powerfully and productively as possible, despite what MS may do. Based on that, we agreed on seven principles, listed in the box. The full principles are, like MS itself, complex. You can find the complete text at nationalMSSociety.org/healthcareprinciples or by calling us at 1-800-344-4867. I urge you to get it, read it, talk about it with family, friends and associates, and to send copies to your elected officials.

Fixing our health-care system will involve federal, state and local action. We will need all your voices to ensure that these priorities are taken seriously when reforms are in planning stages. Times are not easy, and the economy may take time to regain momentum. People with MS can and should contribute to a renewal. But we know that productivity of all kinds hinges on enabling people with chronic illness or disabilities to live their best lives. This in turn requires having access to high-quality medical care.

To learn more about the Society's health-care reform activities and to join in, call your chapter or go to nationalMSSociety.org/advocacy.



We believe meaningful health-care reform must involve these seven principles:

1. Accessible health-care coverage
2. Affordable health-care services and coverage
3. Standards for coverage of specific treatments
4. Elimination of disparity in health care
5. Comprehensive high-quality health care available to all.
6. Increased value of health care
7. Access to high-quality long-term supports and services

Chasing the blues away

Depression strikes an estimated 47% to 54% of people with MS—but a new study suggests that you can lift your mood by taking positive actions.

The study was an outgrowth of a longitudinal MS quality of life study conducted at the University of Texas at Austin, funded by the National Institutes of Health and conducted by Dr. Lorraine J. Phillips, PhD, APRN, BC, FNP, and Dr. Alexa Stuifbergen, PhD, RN, FAAN.

Stuifbergen started the study by surveying 443 people with MS yearly, asking how often they felt depressed, and to describe the symptoms they experienced. But one of the participants, Doris Varnell, a 57-year-old retiree, told Stuifbergen she found the questions “depressing.”

“I wanted to know what people were doing to make themselves feel better,” said Varnell.

Varnell wrote up a list of positive actions she engaged in to lighten her mood. She sent her list to Stuifbergen who, to Varnell’s surprise, began to ask study participants if they tried similar things. The results were dramatic. People who checked off the most items on Varnell’s list for a given week were the least depressed. Actions included:

- Saying “thank you” and meaning it
- Phoning a friend
- Visiting a friend

Bill Stanton



- Saying something pleasant to someone else who didn’t expect it
- Crossing off something on your to-do list because you finished it
- Learning something new
- Volunteering or agreeing to become a volunteer
- Going to the library and checking out a book to read
- Going shopping and buying something for yourself
- Taking a nap
- Pampering yourself with a manicure, massage or relaxing bath

Although the study does not prove that the actions alone were responsible for boosting the participants’ mental health—

Continued on page 7

Vote for your insurance!

There's another election looming: the annual coordinated election period. Every year, from November 15 to December 31, people eligible for a Medicare prescription drug plan can enroll or elect to switch plans. **Your current plan may change in 2009**

Carefully read the **Annual Notice of Change** that you received in October from your current prescription drug plan. (If you haven't yet received it, call and ask for it.) Any changes will take effect on January 1, 2009. Look for changes to your plan's:

- monthly premium
- annual deductible
- co-pays or co-insurance increases
- list of covered drugs (also known as the plan's "formulary").

If you are on an MS disease-modifying drug, pay special attention to the tier that this drug is on. The lower the tier, the lower

Chasing the blues away (cont.)

people who were happiest could have just been born that way—it does suggest that incorporating more positive actions into the day may improve quality of life even for a person with severe limitations.

"People who suffer from ongoing depression should always consult their doctor," Stuijbergen added.

"The Influence of Positive Experiences on Depression and Quality of Life in Persons with Multiple Sclerosis" is in **The Journal of Holistic Nursing**, V. 26, #1, March 2008, pp. 41-48.

your out-of-pocket expenses.

Special request?

If your doctor made a special request in 2008 to your plan, such as a preauthorization or exception request that allowed coverage for a specific drug, call and ask what you can do to maintain coverage for that drug.

Help!

Overwhelmed? Give us a call at 1-800-344-4867 and ask to speak to an MS Navigator® about your Medicare Part D coverage.

But don't wait too long—Medicare advises making any changes well before the December 31 deadline to allow for processing.

Treatment update— Betaseron only

Bayer HealthCare Pharmaceuticals will launch a very thin (30-gauge) needle and a new autoinjector (BETAJECT LITE) at the end of October. The new autoinjector will replace all previous autoinjectors for Betaseron. The use of any autoinjector other than this latest version may result in people not receiving their full dose of medication. Go to betaseron.com/thinner or call 800-788-1467 for more information and to request the new autoinjector.

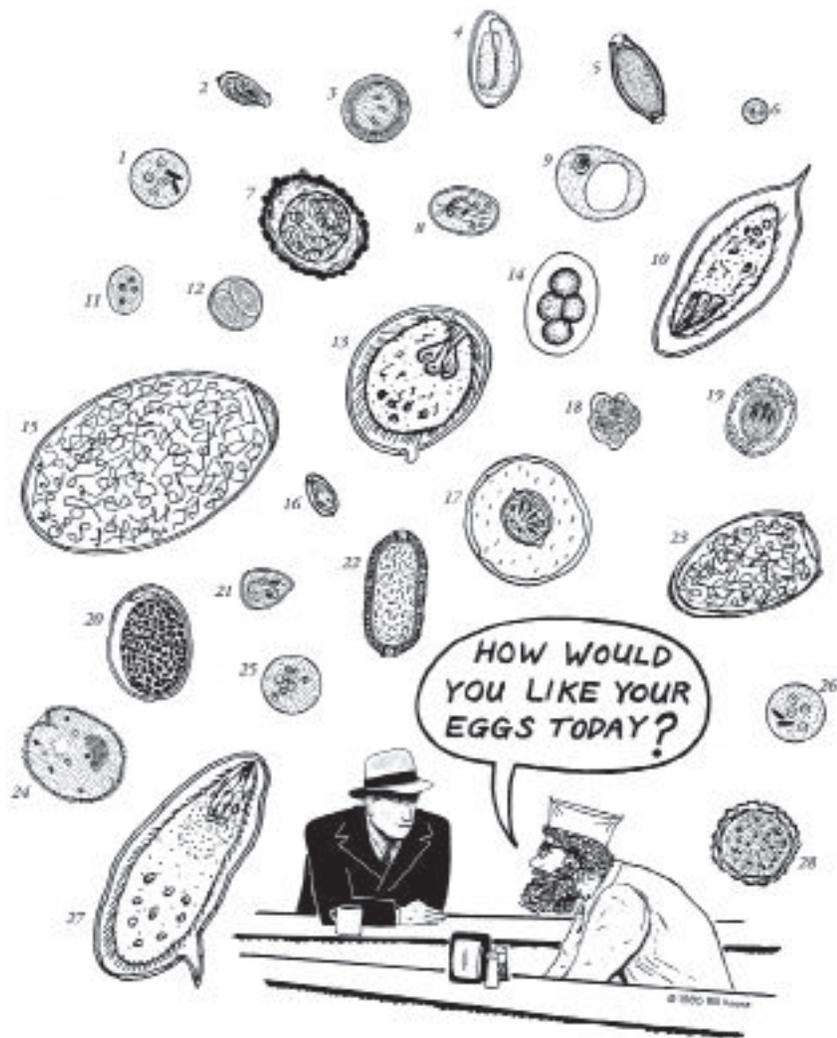
The “Yuck” Factor

John Fleming, MD, calls it the “yuck factor.” But people with MS might happily drink parasitic worm eggs if it meant a reduction in disease activity. In a study run by Dr. Fleming, five people with MS will ingest the eggs of the whipworm, or *Trichuris suis*, a virtually harmless organism, to see if they will divert the immune system from attacking myelin. If the experiment shows promise, Dr. Fleming hopes to enroll 15 more people with MS and follow them for a year.

The study is based on the “hygiene hypothesis,” which theorizes the low incidence in MS in developing countries may be due to early exposure to infectious agents.

“Modern sanitation is of course an important advance for public health,” explained Dr. Fleming, a professor of neurology at University of Wisconsin, Madison, “but it is possible that autoimmune diseases may be an unanticipated consequence of extremely hygienic environments.”

A recently published study involving a small number of people with MS underscores the potential of the worm egg approach: Investigators from the Raúl Carrea Institute for Neurological



O & P Designs, bugshirts.com

Researchers need you! ←

Scientists are testing new medications for MS in clinical trials across the country. Some will result in groundbreaking new treatments for the disease. Clinical trials depend on volunteers—people like you—who want to participate. For information on clinical trials taking place in your area, visit nationalmssociety.org/clinicaltrials.

Research in Argentina found that helminth-infected people with MS showed evidence of anti-inflammatory immune activity, compared to uninfected people with MS and those with a different infection. The investigators also

found that immune cells isolated from the helminth-infected individuals produced nerve growth factors, which may translate into beneficial nerve protection.

What's Your Financial I.Q.?

by Natalie Karlin

Can medical expenses reduce my taxes?

- **Specific rules must be met** on what percentage of income went to medical expenses for tax deductible status. See IRS publication 502 or visit www.irs.gov/publications/p502/index.html.
- An **air-conditioner** can be a medical expense according to the IRS!
- Before purchasing a **wheelchair**, check with a tax adviser about your medical plan's specific restrictions and deduction status.

Answer: Yes, if you meet requirements.

Does it make sense to transfer medical debt to a credit card?

- It only eliminates the debt to the **medical provider**.
- The **debt still exists** to the credit card company but isn't considered "medical."
- **Medical expenses can be used to offset income** in many states which could make you eligible for Medicaid or other assistance programs based on a "medically needy" status.

Answer: The best option is to negotiate a payment plan with the medical provider.

Is it wise to take a loan from a 401k to pay off debt?

Some 401k plans do allow loans against funds already contributed to the plan.

Factors to consider

- How much is in the 401k?
- How enormous is the debt?
- Can it be paid off without the loan?
- What is the person's cash flow?

Answer: Once that money is taken out, it is not growing for future benefits.

Is it possible to reduce education loan payments?

- **Contact the agency or organization** that provided the loan. Qualifications exist for some forms of payment relief. Take action before late fees are charged.
- Under the U.S. Department of Education, a **completely disabled individual can qualify for a loan to be forgiven**. But strict rules apply. Visit <http://www.ed.gov/index.jhtml>.

Answer: It's worth trying.

Where to turn for help: The Society has enlisted 600 volunteer financial advisers nationwide to give free advice through The Financial Education Partners Program. Call us, toll free at 1-800-344-4867.

Guidestar.com verifies a nonprofit's legitimacy regarding credit counseling services.

Bankrate.com can figure how much of a monthly credit card payment goes to pay down the original debt.

Natalie Karlin is a freelance reporter who was diagnosed with MS in 2005.

Join the Movement—without leaving your office

Designate the National MS Society in your employee giving campaign

Every year, over 1.5 million employees support important non-profit organizations nationwide through employee giving campaigns. If you are a federal government employee or your private employer offers a charitable giving campaign, you can help move us closer to a world free of MS by designating a contribution to the National MS Society.

Most charitable giving programs offer employees the opportunity to make an annual pledge, which means a portion of their donation is automatically deducted

from each paycheck. Donations can also be made as a one-time contribution by writing a personal check. When you choose the National MS Society your donation comes directly to our chapter.

Combined Federal Campaign (CFC)

If you work in the public sector or you are in the military, contributions can be made through the CFC by selecting the designation number 11409. If you work in the private sector, look for us listed under Community Health Charities or ask your campaign coordinator about designating a gift to the Society.

Your company doesn't offer an employee giving program? Talk to your benefits administrator about starting one. And call us. We can give you the resources you need.

Participating in a charitable giving program is an easy way to help provide vital services, spark public policy advocacy, and fund cutting-edge research.

Real Talk, Real Answers



living with ms in your 20s and 30s

Wondering how to balance your career and your MS? Is fatigue interfering with your social life? Considering telling the person you are dating you have MS? At **Real Talk. Real Answers. Living with MS in your 20s and 30s** you'll find discussions on these topics and more—and get some answers to the questions that matter. Go to **realtalkrealanswers.com** for live webcasts, virtual journals, tips from others living with MS, and other features.

Real Talk. Real Answers. is made possible through a collaboration of the National MS Society and MS LifeLines.

Save the Date: Saturday, November 22, 2008

Please join us at 7:30 pm at

Carnegie Hall
Isaac Stern Auditorium



Concert for a Cure:

**A night at the Symphony with
16-year-old Violin Virtuoso
Jourdan Urbach and the Park Avenue
Chamber Symphony conducted by
David Bernard, performing the
Tchaikovsky Violin Concerto and an
electric violin World Premier that will
ROCK the house... by Grammy Award
nominated composer Chris Caswell.**

**To benefit the
National Multiple Sclerosis Society's
Promise 2010 Research Campaign**

Hosted by Dr. Max Gomez
Emmy Award Winning CBS-TV Medical Journalist

With Special Guests
Film and TV Star Teri Garr and
Country Music Star Clay Walker

For Concert Information:
www.SavingLivesWithMusic.org

Tickets: \$100, \$60, \$45 (Students \$25)
Please call Barbara Travis at (631) 864-8337 or (516) 740-7227
ext. 224 or email btravis@nmssli.org for tickets

Giving in their own ways...

Many times individuals cannot participate in the Chapter's annual fundraising events but want to raise money to stop MS now. The Long Island Chapter gratefully acknowledges these individuals for creating their own fundraising events. If you would like to hold your own fundraiser, please call Barbara Travis, VP of Donor Development at (631) 864-8337 or (516) 740-7227 ext. 224 or email btravis@nmssli.org.

Congratulations and thanks to the following who held their own event to raise important funds to benefit the Long Island Chapter membership:

7th Annual Southside Hotel Golf Tournament

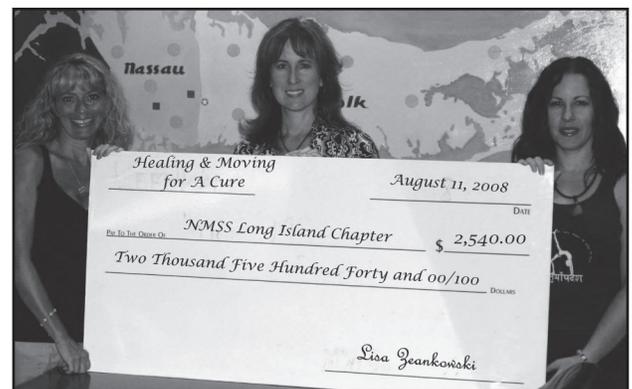
The Southside Hotel in Bay Shore held it's 7th Annual Golf Tournament generating \$4,250 for the Long Island Chapter. Owner of the restaurant, Ned Baker, hosted this golf event to support the Long Island non-profit community.

In selecting the Long Island Chapter as a beneficiary this year, Ned indicated that he feels "like he is doing good while having fun." David Treanor of Baycrest Auto Services, Brightwaters, helped with the logistics of the day. They relied heavily on local area businesses to contribute products and services to the raffle in an effort to increase fundraising.



Pictured l to r: Ned Baker, owner Southside Hotel, Bay Shore, Barbara Travis, V.P. Donor Development, David Treanor, Baycrest Auto Services, Brightwaters

Moving for a Cure



Pictured l to r: Lisa Zeankowski, Pamela J. Mastrota, Chapter President and CEO, and Laurie Ahlemann

This summer, Long Island Chapter member Lisa Zeankowski organized a fundraiser "Healing & Moving for a Cure." Along with the help of Laurie Ahlemann, of Prana Shakti Yoga, they hosted a day of health and healing raising \$2,450 for Long Island Chapter Programs. "Because of its success, I am committed to making this an annual event. This is how I am joining the movement," said Lisa. A special thanks goes to the Town of Hempstead, who donated the use of Levittown Hall for the event.

Congratulations to Lisa and all of her supporters who came out and made a difference!

Generous Grantmakers

Grants help us address the challenges of each person who is affected by MS through funding the Chapter's vital programs and services. The Long Island Chapter extends its sincerest gratitude to the following:

- **The Winston Foundation, Inc.** donated \$25,000 for Respite and Advocacy Programs.
 - **The Roslyn Savings Foundation** gave \$10,000 for Respite Programs.
- **The Bank of America Charitable Foundation, Inc.** donated \$5,000 for Medical Equipment Subsidy Program for Low Income Families.

A Grant was made to support critical MS research to help move us closer to a cure:

- **The David & Minnie Berk Foundation, Inc.** provided \$44,000 for a pilot research project, researcher Dr. Paula Dore-Duffy, *Pericytes in Cell Replacement Therapy in MS*.

To learn more about Long Island Chapter programs or scientific research call Barbara Travis at (631) 864-8337 or (516) 740-7227 ext. 224 or email btravis@nmsli.org.

STAIRLIFTS



- Straight Lifts
- Custom Turn Lifts
- Multiple Options & Features Available
- Interior & Exterior

ALSO Vertical Porch Wheelchair Lifts

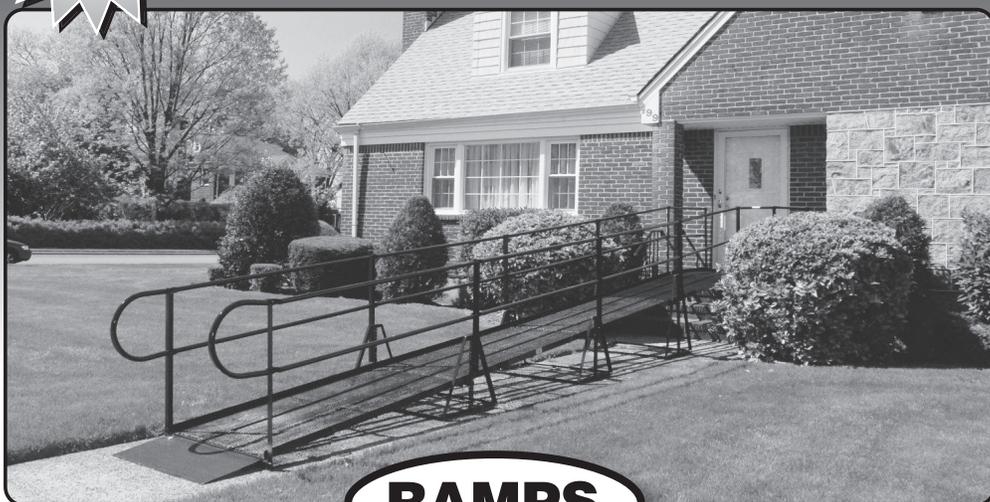
OWN or RENT We Install

ALPHA RAMPS & LIFTS

Division of Alpha Care Supply LLC

Serving Long Island's MS Community for 16-years

1-866-291-7039 • 1-516-561-5566



RAMPS

of every type . . . for every application

Portable • Modular • Temporary • Singlefold • Multifold • Solid • Threshold

Use a Local Reliable Dealer • Licensed and Insured

426 Rockaway Avenue
Valley Stream, New York 11581

Self Help Groups *Please contact the peer facilitator before attending a meeting.*

Amityville

Sharing Our Cares Away

1st & 3rd Friday, 11:00 am
Carolyn (631) 608-5639

Bayshore

4th Monday, 7:00 pm
Rich (631) 745-0478

Bayshore

Let's Be Positive

Southside Hospital
2nd Tuesday, 6:30 pm – 8:30 pm
Marie (631) 277-6552 or
(516) 297-9331

**This is group for people with a diagnosis of MS and their current caregiver (if interested)*

Hampton Bays

First Monday of the month, 7:00 pm
Theresa (631) 288-2161

Hauppauge

Free Spirits

1st & 3rd Tuesday, 12:00 pm
Tom (516) 220-4869

Huntington

Professionally Speaking

This Self Help Group is *for professionals only*, who are dealing with MS and its effects on their lives in the workplace. Please join us for this unique networking opportunity where we will share common concerns as well as coping strategies.

Legal Seafood

Walt Whitman Mall, Route 110,
First Tuesday of every month, 7:00 pm
(starting December 2nd)
Donna - (516) 643-2155
dmanvich@ipellic.com

Huntington

Reaching for that Silver Lining

Huntington Library
2nd Tuesday, 11:00 am
Louise (631) 470-5565
Dennis (631) 495-0512

Long Beach

Parents, Caregivers and Friends

Sharon (516) 448-0928
** if interested in group, please call*

Melville

Caregivers (spouses or partners)

Andrea (516) 466-4955
**If interested in group, please call*

Melville

Social Group

Bertucci's Restaurant
881 Walt Whitman Road
2nd Tuesday, 6:00 pm – 8:00 pm
Anthony (516) 609-9708

Melville

You Look So Good

Bank of America, Morgan Stanley
290 BroadHollow Road - Suite 400
3rd Tuesday, 6:30 pm
Vic - (631) 425-5650

Nesconset

Moms with MS

Tuesday evenings, call or email for details
Patty (631) 656-9019
pattycakerose@optonline.net

Port Jefferson

Handicapped Support

Last Tuesday of the month, 1:30 pm
Barbara (631) 474-6365

Seaford

Seaford Challengers

Alternate Wednesdays, 11:30 am
Jim (516) 826-8514 or Nancy (516) 489-9163

Self Help Groups Continued

Shirley

Looking Good

Mastic, Moriches, Shirley Library
2nd Thursday, 7:00 pm- 8:00 pm
Karen (631) 255-4744
mshopefuls@yahoo.com

Syosset

Couples Concerns

3rd or last Thursday, 6:30 pm – 8:00 pm
Jodi (917) 592-1376

Valley Stream

People with MS, Caregivers and Friends

1st & 3rd Tuesday , 7:00 pm
Tracy (516) 792-1567

Wantagh

MS Support Group

St. Francis de Chantel Parish
3rd Tuesday, 10:30 am – 12:00 pm
Anastasia (516) 808-6784
Christine (516) 851- 0947
Donna (516) 242-2132

Teen Talk* – (ages 12 – 17)

EAST

Call for details, Alex (516) 541-0909

Teen Talk*– (ages 12-17)

WEST

Call or email for details
Allie (516) 621-6645
Akolb109@gmail.com

**these groups are for teens with a relative with MS.*

CARING FOR CAREGIVERS

A program for caregivers

Saturday November 15, 2008

10:00 am – 2:00 pm

40 Marcus Drive, Suite 100, Melville N.Y.

Featured Presenter

Peg Rinaldi, LC, certified Co-Active Coach and founder of Coaching for Caregivers

Come discuss issues including:

- Parent/child issues
- Spouse issues
 - Respite
- How to care for yourself

Please call Gene Veigl at 631-864-8337 or 516-740-7227 ext. 222 or eveigl@nmssli.org to register.
Please RSVP by November 7, 2008

SOCIAL SECURITY DISABILITY

Long Term Disability

◆
Accidents

◆
Disability

◆
Lectured at MS conferences and support groups; active on Long Island Chapter's MS Committees

◆
27 YEARS EXPERIENCE

◆
OFFICES

200 Broadhollow Road, Melville, NY
225 Broadway, New York, NY

FREE CONSULTATION
LAW OFFICES OF GARY GLENN
(516) 829-5551
(631) 423-0182

Available Resources. You are not alone.

Phone Support

- Pregnancy and Post Partum Issues? Call Jodi at (917) 592-1376 in the afternoon.
- Have MS for more than 10 years and have trouble coping? Call Sal at (516) 752-1116
- Trouble leaving your home? Call Eileen at (516) 579-5097
- Newly Diagnosed? Call Karleen, RN at (516) 873-9220 between 6-8 pm
- Need to talk? Call Bob at (631) 648-0570 until 6 pm
- Want to talk about your spiritual journey as you live with MS? Call Sister Mary Jo at (631) 928-2975 leave message until 8 pm
- Living, Coping and Understanding MS? Call Rosemarie at (516) 937-9069 anytime.

BE AN ADVOCATE FOR PEOPLE WITH MS Join the Action Alert Network

For many people living with MS, the disease is just one challenge. We must work together to break down barriers to care, improve access to quality health services, and make MS therapies more affordable. We must pursue funding for more MS research and fight for disability rights.

You can help shape the policies and programs that impact people living with multiple sclerosis.

The **Action Alert Network** is a group of dedicated volunteers who contact local, state, and federal legislatures to support or oppose laws that will impact individuals who have multiple sclerosis.

The Chapter is looking for interested people to expand this group committed to **advocating for people with MS**. There are no meetings to attend. Interested individuals only need to be ready to call or write their elected officials.

If you are interested in joining the **Action Alert Network**, please contact Gene Veigl at (631) 864-8337 or (516) 740-7227 ext. 222 or at eveigl@nmssli.org

We welcome your participation.

• Member Bulletin Board

- **95 Dodge Grand Caravan**
80,000 miles
Braun remote lower floor, six-way seat
hand controls, auto start, and more
Asking \$35,000
Contact Laurise @ (516) 432-2659 or
(516) 432-3688
- **Quickie Electric Wheelchair**
4 years old - Never used, needs battery
Asking \$100 or best offer!
Contact Barbara @ (516) 822-8430
- **1999 Plymouth Voyager SE**
Accessible Mini Van, 73,000 miles
Brand new tires, starter, battery and brakes
Contact Stanley Gutin @ (516) 799-5432
- **Mr. Mobility Electric Wheelchair**
5 years old
Asking \$2000 negotiable
Contact Lorene @ (646) 330-3015
- **Invacare Power Wheelchair**
Needs new battery
Contact Lane Seidman @ (516) 509-8187
- **Various Equipment**
i.e. walker, wheelchair
Contact Bob @ (631) 666-3245
- **Twin Hospital Bed**
Wood frame, massages!
Contact Myrna @ (631) 864-8929
- **Portable Washing Machine, Brand New!**
Contact Myrna @ (631) 864-8929
- **Invacare Electric Wheelchair**
2 years old, needs replacement battery
Call Jan @ (516) 561-0824
- **Two Electric Mobility Scooters**
Both in excellent condition
Front and rear basket and elevating
seat option
Asking \$800 negotiable
Call Frank @ (516) 766-4369
- **Invacare Power Chair**
Never used
Asking \$2,500
Call Kathy @ (631) 821-9711
- **Quickie P200**
Four years old
Battery charger included
Very good condition- used once
Asking \$100
Call Barbara @ (516) 822-8430
- **Pride LL660 Infinite Position Lift Chair**
Asking \$700
Call Kathleen @ (631) 368-0980
- **Jazzy Electric Wheelchair**
2 years old – Excellent condition
Contact Rich @ (212) 539-3264
- **Vehicle Hand Controls**
5 years old
Contact Barbara @ (516) 822-8430
- **Amigo Scooter**
6 years old
Excellent condition!
Contact Tony @ (631) 692-7234
- **American Metal Products Bed**
No cost
Motorized
Contact Hank @ (631) 909-3618
kobi@optonline.net

To place an ad, please call **Gene Veigl** at **(631) 864-8337** or **(516) 740-7227**
ext. 222 or email eveigl@nmssli.org

Home Modification Project

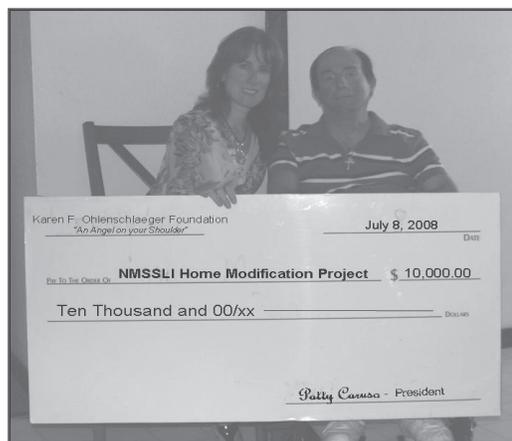
Funded by The Karen F. Ohlenschlaeger Foundation

Sal Capanzano is the happy recipient of a \$10,000 remodeling grant from the Long Island Chapter's Home Modification Project. This Project is an initiative to improve the lives of those living with multiple sclerosis with limited mobility by updating their home to accommodate their needs.

The Home Modification Project was sponsored by the Karen F. Ohlenschlaeger Foundation. When Karen lost her battle with MS, her sister, Patty Caruso, decided to do something to honor Karen's memory in a positive and meaningful way. With the love and support of Karen's family, the Karen F. Ohlenschlaeger (KFO) Foundation was born. When Karen's husband, Bill, first read about the project in the MS Connection, he knew that it was a perfect fit for the foundation. He explained, "our mission is to help individuals who are living with MS with things that hospitalization doesn't cover. All of us at the Foundation knew this was a perfect way to affect the life of an individual – and their family – which is very important to us."

The Foundation sponsors numerous fundraising events, including their Annual Golf Classic/Texas Hold 'Em Tournament, held for the second time this past July. This event raised funds for the Home Modification Project. The family reviewed the applications and work has begun to benefit the Capanzano family. The Foundation hopes to award a second grant next year.

To learn more about the Home Modification Project, please call Gene Veigl at (631) 864-8337 or (516) 740-7227 or email eveigl@nmssli.org.



Pictured (l to r) Pam Mastrotta, President & CEO, Long Island Chapter and recipient Sal Capanzano

Recreation and Socialization

These programs provide an outlet for fun in a social arena. They include a variety of craft projects as well as refreshments. You may join at any time. These programs are funded by the Wolfson family.

Bay Shore

Southside Hospital, Neuroscience Institute, North Shore LIJ Health Systems
Montauk Highway
Alternating Fridays 10:30 am - 1:30 pm
Lorrie Prescott, CTRS
November 14; December 5, 19; January 5

Freeport

Freeport Recreation Center
130 East Merrick Road
Saturdays 12:00 pm - 3:00 pm
Gerry Albers, CTRS
November 8, 15, 22; December 6, 13
January 10, 24, 31

*Please call for start dates and schedule. For more information, please contact Jane Reilly (631) 864-8337 or (516) 740-7227 ext. 218 or email jreilly@nmssli.org

Fall 2008 Wellness Programs

To register for the following programs, please contact the facility or instructor listed. Instructors will provide registration forms and waivers.

* Please note: Due to fundraising challenges presented by the current economic climate, the Long Island Chapter will offer limited winter programs.

AQUATICS:

A low-impact form of exercise to improve strength, balance and coordination.

This program is funded by the Dee Kaplan Memorial Fund

Oceanside – Barry & Florence Friedberg JCC

12 Neil Court
(516) 766-4341

Instructors, Helene Hines and Barbara Vitale

MONDAYS – 7:00 pm - 8:00 pm
November 3, 10, 17, 24

THURSDAYS – 10:00 am - 11:00 am
November 6, 13, 20

Bay Shore – Great South Bay YMCA

200 West Main Street
(631) 665-4255 – Maureen Kiernan



(Continued)

MONDAYS – 1:00 pm – 1:45 pm
November 3, 10, 17, 24

THURSDAYS – 9:30 am – 10:15 am
& 6:00 – 6:45 pm
November 6, 13, 20

Commack – Suffolk Y JCC

74 Hauppauge Road
(631) 462-9800 – Nancy Briel

Instructor, Ann Meisen

WEDNESDAYS – 10:00 am – 11:00 am
November 5, 12, 19, 26

Plainview – Mid-Island Y JCC

45 Manetto Hill Road
(631) 822-3535

Instructor, Lisa Klobus

PROPOSED DATES:

MONDAYS – 10:15 am – 11:15 am
November 3, 10, 17, 24

WEDNESDAYS – 11:00 am – 12:00 pm
November 5, 12, 19, 26

FRIDAYS – 11:00 am – 12:00 pm
November 7, 14, 21

East Hills – Sid Jacobson JCC

300 Forest Drive
(516) 484-1545 – Audrey Kurland

TUESDAYS – 9:45 am – 10:30 am
November 4, 11, 18, 25

GROUP PHYSICAL THERAPY:

These programs are offered to members who are unable to continue physical therapy due to lack of private health insurance or maximization of their health benefits welcome to participate.

East Meadow**STARS Rehabilitation**

801 Merrick Ave., Suite 170-S

Instructor, Doug Griffin, PT-
(516) 393-8900

Monday 1:30 pm - 2:30 pm
November 3, 10, 17, 24;
December 1

Greenlawn**Progressive Physical Therapy & Rehabilitation**

266 East Pulaski Road - Suite 3

Instructor, Mike Rosati, PT
(631) 673-4600

Tuesday 1:30 pm - 2:30 pm
November 4, 11, 18, 25;
December 2

Smithtown**St. Charles Rehab Network**

240 Middle Country Rd. Suite 208

Instructor, Brian Quinn, PTA
(631) 382-4550

CHANGE IN DATE & TIME!!

Wednesday 1:00 pm - 2:00 pm
November 5, 12

Thursday 1:00 pm - 2:00 pm
November 6, 13

HORTICULTURE:

Gardening is a healing process for the body, mind and spirit. Benefits include increased concentration and dexterity.

Holtsville – Holtsville Ecology Center

249 Buckley Road (meeting room behind the greenhouses)
(631) 758-9664 ext. 10

Instructor, April Perry

CLASSES ARE EVERY OTHER WEEK

THURSDAYS - 10:00 am - 12:00 pm
November 13;
December 4

TENNIS:

Group tennis instruction held at an indoor racquet club. No experience necessary. Includes Wheelchair Tennis.

Oceanside – Point Set Indoor Racquet Club

3065 New Street
(516) 536-2323

Instructor, Dan Dwyer

TUESDAYS – 12:00 pm – 1:00 pm
November 4, 11, 18, 25;
December 2, 9, 16



THERAPEUTIC EQUESTRIAN:

Please contact either Horseability or Pal-O-Mine directly to request information on dates and times for these programs.

Islandia – Pal-O-Mine

829 Old Nichols Road
(631) 348-1389

September - November 2008

Please contact Pal-O-Mine for riding time

Melville – Horseability

238 Round Swamp Road
(631) 367-1646

September - November 2008

Please contact Horseability for riding time

YOGA:

Stretching and breathing exercises to promote whole body relaxation and wellness.

East Meadow –

1400 Prospect Avenue

Instructor, Shelley Sidelman
(516) 802-3786

Wednesday 1:00 pm - 2:00 pm
November 5, 12, 19



Freeport – Freeport Rec Center

130 E. Merrick Road

Instructor, Shelley Sidelman - (516) 802-3876

THURSDAYS – 12:00 pm - 1:00 pm

November 6, 20

PLEASE NOTE:

The following classes will be held at Hendrickson Park, Valley Stream (123 S. Central Ave).
November 13

Hauppauge – Paradise Diner

579 Veterans Memorial Highway

Instructor, Shelley Sidelman – (516) 802-3876

FRIDAYS – 10:00 am – 11:00 am

November 7, 14, 21

Plainview – Mid Island Y JCC

45 Manetto Hill Road
(631) 822-3535

Instructor, Anthony Guerino

MONDAYS – 7:00 pm - 8:00 pm

November 3, 10, 24

Wantagh – St. Frances De Chantal Church

1309 Wantagh Avenue

Instructor, Shelley Sidelman – (516) 802-3876

FRIDAYS – 1:00 pm - 2:00 pm

November 7, 14, 21

***Please continue to consult our website www.nmssli.org for new classes, last minute changes in dates or class cancellations.**

Counseling Series Fall '08

Adult Family Members

Carle Place

1 Old Country Road, Suite 295
Vicki Kulberg, ACSW
Saturdays, 12:00 pm – 1:30 pm
In progress through December 6th
(No session November 29th)

Adult Family Members

Melville

Long Island Chapter Office
Michael Greenberg, ACSW
Thursdays, 7:00 pm – 8:30 pm
In progress through December 4th
(No session November 27th)

But You Look So Good

Syosset Hospital

Michael Greenberg, ACSW
Saturdays, 10:00 am – 11:30 am
In progress through November 22nd

Home Bound Conference Call

Karen Tuminello, MSW
Thursdays, 1:00 pm – 2:00 pm
In progress through December 18th
(No session November 27th)

Parenting Conference Call

Karen Tuminello, MSW
Wednesdays, 1:00 pm – 2:00 pm
In progress through December 10th

Living With MS

Lake Ronkonkoma, Senior Center

Karen Tuminello, MSW
Wednesdays, 7:00 pm – 8:30 pm
In progress through December 10th
(No session November 26th)

Living With MS

Mather Memorial Hospital

Karen Tuminello, MSW
Thursdays, 7:00 pm – 8:30 pm
In progress through December 11th
(No session November 27th)

East End Support Group

Riverhead

Peconic Bay Hospital
Karen Tuminello, MSW
Mondays, 7:00 pm – 8:30 pm
In progress through December 8th

Must be registered to be notified of any schedule changes.

For more information, please contact Jane Reilly at (631) 864-8337 or
(516) 740-7227 ext. 218 or jreilly@nmssli.org



\$10 for Each Program. Please make checks payable and mail this form to:

**National MS Society, Long Island Chapter
40 Marcus Drive, Suite 100 Melville, NY 11747**

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Series: _____ Amount: \$ _____

The Long Island Multiple Sclerosis Nurse's Society
in collaboration with the
Department of Nursing at Good Samaritan Hospital Medical Center
is proud to present its Fourth Annual Patient Education Program

LIVING WITH MULTIPLE SCLEROSIS

Saturday, November 15, 2008

The Guild Conference Center
Good Samaritan Hospital Medical Center
1000 Montauk Highway, West Islip, New York
9:00 am for check-in, continental breakfast and exhibitors
Program: 10:00 am – 3:00 pm
Complimentary brown bag lunch and refreshments
Please call to register: (631) 758-1910 ext. 2115

***Thank you to all that attended the
Dinner of Champions
Thursday, September 25th***

A Special Thanks to our Honorees:

***Comprehensive Multiple Sclerosis Care Center at
South Shore Neurologic Associates, PC***



The Kolb Family

David Leviton

***Your committment and dedication to create a
world free of MS made the event a huge success!
Thanks for all of your hard work!***

Thank you for your support at the 2008 bikeMS® Twin Forks Ride!



This year, nearly 300 riders participated in the bikeMS® Ride on September 13 and 14, and have helped us aim to reach our goal of \$325,000. Each rider is truly an inspiration to everyone at the Long Island Chapter. Your spirit & determination, along with your dedication to ride 150 miles has touched each of us. Thank you for all that you do! We look forward to seeing you next year at the 2009 bikeMS® Ride.

The Fat Frogs



Cyclists at the Goldrush Farms reststop



The Long G'Island Express



Riders, ready to go



Please help us reach our goal of \$325,000! Please visit www.nmssli.org to donate.



The Long Island Way

Special thanks to Donna Cariello from The Long Island Way - Connecting Community Partners and Non-Profits for all of her hard work and dedication! Donna held an event to create awareness of bikeMS® and the Chapter on September 10, 2008. Donna also initiated a new team, LI Way.

L-R - Richard Palese, Finance Director, Debi Pisano of Island Group, Nicole Chamblin of Organized Vision, David Chamblin, Dr. Katz of Massapequa Wellness Center, Donna Cariello of The Long Island Way, & Derek Martin of Pre-Paid Legal Services



Volunteers Make a Difference!

Thank you to the hundreds of amazing volunteers that spent the bikeMS[®] weekend making the ride fun, safe, & enjoyable! It is due to outstanding individuals such as our Fed Ex team, SAG drivers, HAM radio operators, riding marshals, rest stop volunteers, bike mechanics, bus drivers, truck drivers, EMS, Camp Quinipet crew, check-in crew, Elks Lodge members, and Lisa & the Leftovers that made bikeMS[®] a success.

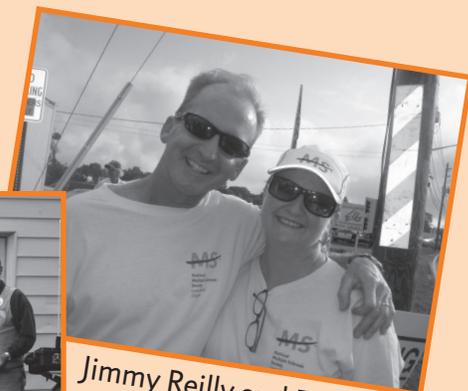
Thank you!



Volunteers at a rest stop



The Blue Knights



Jimmy Reilly and Dawn Balvin

Thank you to our 2008 bikeMS[®] Sponsors!





Capell Vishnick LLP

*Compassionate Attorneys
Vigorous Advocates*

Our areas of practice:

- Estate, Probate and Trusts
- Estate Litigation
- Elder Law
- Disability Planning
- Matrimonial and Family Law
- Real Estate and Business
- Litigation
- Taxation



OUR TEAM

More than 100 members of Team CV walked the length of Jones Beach boardwalk together with more than 7,000 other walkers, on a beautiful Sunday morning. Team CV was one of the top Long Island fundraising teams, having raised in excess of \$65,000.00 towards the walk event.

Capell Vishnick LLP

Contact: Joseph G. Milizio, Esq.
3000 Marcus Avenue, Suite 1E9, Lake Success, NY 11042
t 516.437.4385 f 516.437.4395
www.CapellVishnick.com

TEAM CV: WE DON'T FIGHT ALL OUR BATTLES IN COURT!

Save the Date!

2009 walkMS® & Pooch Parade*

May 3rd, 2009



**Jones Beach State Park
Belmont Lake State Park**

*** Pooch Parade (at Belmont Lake State Park Only)**

To register, visit www.nmssli.org

Olivia Visconti - Team Captain of Liv Life



"As a newly diagnosed pediatric MS patient I decided to turn the tables and deal with this disease with a positive twist. What's a better way than fundraising? In May 2008, I decided to get involved in walkMS®. I became Team Captain for LIV LIFE and began fundraising with a goal of \$2,500. In no time, we surpassed that goal and raised more than \$17,000. What a great feeling it was for me to see people being so supportive and coming together as a whole to help raise awareness for this debilitating disease. I will continue to fundraise until there is a cure for multiple sclerosis."

Volunteers Wanted!

Volunteers are critical to the 2009 Walk MS. Please consider "joining the movement" and ask your friends, colleagues and family members to do the same. We welcome volunteers with a wide range of talents and skills.

To register, please contact Stefanie Taylor, Volunteer Coordinator at (631) 864-8337 or (516) 740-7224 ext. 215, or by sending an email to staylor@nmssli.org

Newly Diagnosed Teleconference

Wednesday, January 14, 2009
7:00 pm – 8:30 pm

This program is designed to provide support and guidance to those individuals diagnosed with MS within the last 12 months.

- ✓ Hear up-to-date information from a neurologist specializing in the treatment and management of MS
- ✓ Speak to individuals who have MS and who can provide a personal perspective on the impact of MS on their lives
- ✓ Learn about services and programs the Chapter provides
- ✓ Seek advice from an employment counselor
- ✓ Ask questions of the Long Island Chapter staff

To register, please make sure to contact Michelle Lenox at (631) 864-8337 or (516) 740-7227 ext. 206 or email mlenox@nmssli.org by Monday, January 12.



Long Island Chapter
40 Marcus Drive, Suite 100
Melville, NY 11747

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
New York, NY
Permit No. 7131