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# msconnection

Volume 2004, Number 2

Long Island Chapter

*The National MS Society. . . One thing people with MS can count on.*

## **This is why we walk**

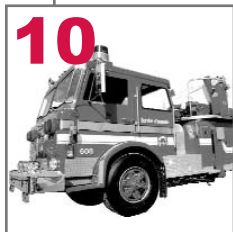
*Join us for a fun-filled day on April 18*



**S**tart stretching now—whether it’s your legs, your dialing fingers, or your vocal cords to cheer on more than 5,000 walkers, we’ll need your spirit and support on Sunday, April 18 during the **2004 Family Care & Family Aides MS Walk**.



You can choose from two relaxing walks through **Belmont Lake State Park** or **Jones Beach Boardwalk** to help end the devastating effects of multiple sclerosis.



“It is always exciting to see our walkers return.” said Pam Mastrotta, Chapter President, “We are thrilled to meet first-time walkers who are eager to help the

400,000 Americans living with MS.”

The MS Walk is one of the Society’s largest fundraising events. The \$281 million that has been raised since 1991 goes toward research and client programs

### **Let us entertain you!**

The 2004 MS Walk will feature more entertainment than ever! At press time, we’ve already confirmed:

- ◆ Jazz artist Matt Marshak
- ◆ Rabbi Gellman of the God Squad
- ◆ NY Yankee Joe Pepitone
- ◆ NY Mets Announcer Fran Healy
- ◆ The Puppet Company at Belmont

for people with MS.

Each spring nearly 700,000 people at

*story continues on page 6*



Register by calling (631) 864-8337 or visit [www.nmssli.org](http://www.nmssli.org)

**march/april 2004**

(631) 864-8337

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© 2003 National Multiple Sclerosis Society, Long Island Chapter

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

**FROM YOUR PRESIDENT**

*Take a walk with me  
(and 700,000 friends)*

Now that we're halfway through winter, we're ready to get outside and enjoy some early spring sunshine—and we know the perfect place for you to go.



On Sunday, April 18, why not join more than 700,000 people nationwide for the MS

*Pamela Jones Mastrota is President and CEO of the Long Island Chapter. You can reach her at (631) 864-8337 or at [pmastrota@nmssli.org](mailto:pmastrota@nmssli.org)*

Walk? You can

choose from two accessible locations on Long Island: Belmont Lake State Park or Jones Beach Boardwalk. Whether you walk, roll, or cheer, you're sure to have a wonderful time, all while raising money to fight MS.

To learn more about the MS Walk and how to register and form a team, visit the Long Island Chapter website at [www.nmssli.org](http://www.nmssli.org) or call (631) 864-8337 for a registration packet.

You can be part of the effort, and have an exciting day, all for the very small cost of registration. Join us. . . and show the world why we walk.

Toll-Free Number: 1 800 FIGHT MS

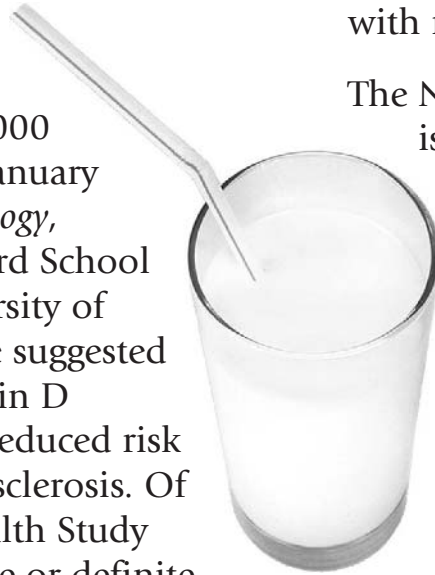
## Link between Vitamin D and MS?

*Study suggests higher intake may decrease risk*

**A**ccording to a new study of more than 187,000 nurses reported in the January 13, 2004 issue of *Neurology*, researchers at the Harvard School of Public Health, University of California at Irvine have suggested those with higher vitamin D intake may have had a reduced risk of developing multiple sclerosis. Of the original Nurses' Health Study group, 173 had probable or definite MS.

"The study showed that women whose intake of vitamin D was greater than or equal to about 400 IU/day from supplements and food, or from supplements alone, had a 40% lower risk of developing MS than women who did not take vitamin D supplements," noted Pamela Mastrotta, Long Island Chapter President. No reduced risks were found for vitamin D intake from food alone.

Because vitamin D intake was strongly associated with intake of other components of multivitamins, including vitamins A and E and folic acid, it was not possible for the group to analyze the effects of vitamin D intake independently from these other vitamins. The strongest evidence to date implicates vitamin D, and suggests it may be the most likely candidate for association



with reduced risk of MS.

The National Multiple Sclerosis Society is already conducting research on sunlight exposure, Vitamin D use, and the risk of MS, and the Nurses' study will add new information to that ongoing research. "Worldwide, MS occurs with much less frequency in lower latitudes closer to the equator," said Mastrotta. "There may be genetic, infectious, and environmental factors that increase or

decrease an individual's risk of developing MS. One of several possible "protective" factors at work in lower latitudes which are being explored is the increased sunlight exposure in these areas and the resulting increase in the body's production of vitamin D."

The U.S. government-issued "Adequate Intake" level of daily vitamin D for adults is 5-15 micrograms or 200-600 International Units, which includes the range of vitamin D intake that seemed beneficial in this study. Vitamin D helps the body use calcium. In addition, immune cells have been shown to be influenced by vitamin D, and preliminary research suggests that vitamin D can alter immune attacks in mice with MS-like disease.

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*story continues on page 11*

## *Want to recognize a community leader?*

### **Nominate him or her for the Class of 2004**

The Class of 2004 is a leadership recognition program established by the National MS Society, Long Island Chapter to honor executive-level professionals for their outstanding contributions to the business, civic and cultural enrichment of Long Island. Since 1995, the Long Island Chapter has recognized hundreds of leaders for promoting high ideals with a strong sense of purpose, for taking pride in a job well done, and for making the area a better place to live and work.

Class members demonstrate the ability to make a difference in the lives of others. They are invited to join the National Multiple Sclerosis Society in its mission to end the devastating effects of MS. Through participation in the Class cam-

paign, members have the opportunity to build a network with other professionals who are also committed to a vision of a better community and a better world. They are honored at the annual Class Recognition Cocktail Reception, and in the local media.

Class honorees make a commitment to raise a minimum of \$2,000 to support the work of the Society. Since its inception, Class has raised more than \$600,000 for MS research and programs.

To nominate someone for the Class of 2004, or for more information, please contact Christine Thomaidis at (631) 864-8337 or by email at [cthomaides@nmssli.org](mailto:cthomaides@nmssli.org).



Do your kids deserve a break? Bring 'em to

## **Kids Fun Day**

A day where kids can be kids!

Sunday, March 14, 2004

Sports Plus, Lake Grove

Call the National MS Society at (631) 864-8337 for info and registration forms. Open to kids with a parent, sibling, grandparent, or other close relative with MS.

Entertainment  
Games

Pizza Party Lunch

Characters

and lots more . . .

*I look fine on the outside. But on the inside. . .*

**Q** I've had relapsing and remitting MS for five years. Most of the time, I've been just fine. But a few recent falls convinced my doctor and me that it was time to get a special parking permit and to think about a cane.

The first day I used the permit, someone screamed at me in the parking lot.

"You're not handicapped! You're just lazy!" I was so upset, I left. What can I say next time?

**A** My mother used to say it best: "Mind your own beeswax."

But that doesn't begin to address the myriad of feelings that insensitive person brought up.

The safest and smartest thing you can do is to walk away from the accuser. In this era of road rage, you never know who you might be facing. Try not to take their anger personally. Maybe they've had an awful day. Or perhaps someone close to them needed a handicapped



*Susan Weber, C.S.W. is the Certified Social Worker for the Long Island Chapter. You can reach her at (631) 864-8337 or at sweber@nmssli.org*

parking spot and couldn't find one. No matter.

Instead, concentrate on your own feelings and your own day. It's perfectly normal to feel anxious about using an assistive device for the first time. . . and that's what a handicapped parking space is: an assistive device that helps someone maintain freedom, mobility, and quality of life.

It's important to think of the device as something that assists you, not as a badge that points out your

disability to the world. As human

*story continues on page 9*

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*story continued from page 1*

over 600 sites participate in the MS Walk. Last year, chapters in each of the 50 states contributed to the \$40 million raised to help the National MS Society continue its MS programs, research, and professional education.



*Mindy Alpert, 2004 Family Care and Family Aides MS Walk Chairperson*

“We were thrilled last year when the Long Island Chapter raised over \$660,000 to help the 38,000 people in Nassau and Suffolk Counties affected by MS,” said

Mastrota. “This is why we continue to provide innovative, life-affirming educational, recreational, and social programs for people with MS, their friends, families, and caregivers.”

For the third year, Mindy Alpert will serve as the MS Walk Chairperson. She says “It is important for those of us with multiple sclerosis to help ourselves by participating in activities that promote awareness of MS and raise funds for research on how to cure it.”

“As someone who lives with the challenges of having MS on a daily basis, I realize that one of the best ways of dealing with this illness is to do things to help myself create the best life I can in spite of the MS. One of the most fulfilling ways I have found is doing things to raise public awareness and money for the National MS Society.”

“If you haven’t had the chance to participate in this event, please join us this year. It is a great opportunity for you, your family, and friends to fight MS together. It is a lot of fun, great exercise and a very positive way to help yourself and others dealing with MS.”

## Talk, Walk, and Win!

Raise money for the MS Walk and you’ll win wonderful prizes. It’s easy and fun. Here are just a few of the prizes available:

- Vacation getaways
- LL Bean Gift Certificates
- Stadium Blankets
- Beach Towels
- Baseball Caps
- T-shirts!

Raise just \$100 and you can win. . . and help people with MS.

For your convenience, prizes will be distributed the day of the Walk.

"If you have participated in the past, thank you and congratulations for doing something positive for yourself and all the others affected by MS. Remember—together we can and will make a difference. . .see you at the walk!"

## Why the \$20 fee?

Because the MS Walk is primarily a fundraising event, all involved contribute to the financial fight against MS. We recognize that thousands of our walkers raise amazing sums for the National MS Society, and their support makes a huge difference.

It's expensive to produce the Walk event because the Long Island Chapter must pay for things like parking, permits, and insurance.

We're asking participants to add the registration fee to their fundraising total in 2004, so that together, we can do even more to fight the devastating effects of MS.

## Walked before? Get ready for something new!

Thanks to the support of dozens of local entertainers, businesses, and individuals who are generously donating their time, talents, and products, the 2004 Family Care and Family Aides MS Walk will be a invigorating and fun-filled day for the whole family. We're working to bring a selection of nationally-known celebrities to kick-off the event. A partial list of our confirmed guests is on the front of this issue—and we hope to bring you a few surprises.

This year we are proud to welcome the Lions of Nassau County and Bermuda, who are joining our volunteer efforts and providing some of the food for the Jones Beach Walk. Please be sure to stop by their table and learn more about the good work they do for people with vision-related difficulties. In fact, if you have an old pair of eye-glasses that you don't use anymore, please bring them to the Lions table and donate them to their Recycle for Sight Program. It's an easy way to make a profound change in the life of someone who simply wants to see.



**Please contact the peer facilitator before attending a meeting. Specialty groups are noted in *red italics***

**Amityville**

2nd Thurs, 7pm.  
Mo (516) 795-7142

*Professionally-run at a nursing facility*

3rd Thurs, 3-4 pm.  
Robin Moeller, CSW  
(631) 264-0222, ext. 4132

**Bayshore**

4th Mon, 7pm.  
Rich (631) 745-0478

*Professionally Run Caregivers Support*

2nd Tues, 7:30 pm.  
Joanne (631) 630-3811

**East Hampton**

*Well Spouse*  
2nd Weds, 7 pm.  
Joan (631) 324-7828

**East Williston**

*Free Ceramics, Hobby Group*  
Thurs, 1pm.  
Rosemary (516) 593-2247

**Hampton Bays**

1st Mon, 7pm.  
Pam (631) 765-3765 or  
Diane (631) 653-5537

**Hauppauge**

*Free Spirits*  
1st Tues, 11 am.  
Tamar (631) 754-8366 or  
Millie (631) 821-0634

**Lake Ronkonkoma**

*Newly Diagnosed*  
2nd Weds, 7-8:30 pm  
March-weather permitting  
Arlene (631) 580-2729  
Jamie (631) 472-5045

**Lindenhurst**

*Sharing Our Cares Away*  
1st Mon, 11am.  
Louise (631) 421-0846 or  
Zaida (631) 243-3174

**Lynbrook**

1st and 3rd Tues, 11 am.  
Jane (516) 378-9706 or  
Michael (516) 593-2487

**Manhasset**

*Singles*  
1st and 3rd Tues, 7 pm.  
Karen (516) 546-0480

**Melville**

*But You Look So Good*  
3rd Tues, 6:30 pm.  
Vic (631) 531-5637 (day)  
or (631) 351-3645 (night)

**Patchogue**

*Avonex Group*  
Weds, 2pm.  
Ginger (631) 289-5270

**Port Jefferson**

*Handicapped Support, All Disabilities*  
Last Tues, 1:30-3:30 pm.  
Barbara (631) 474-6365

**Salisbury**

*Long Island MS Support*  
1st Thurs, 11 am-12:30pm  
3rd Weds, 7-8:30 pm  
Ann (516) 679-8298  
Barbara 718-843-3020

**Seaford**

Alternate Weds, 11:30 am.  
Jim (516) 826-8514 or  
Rachel (516) 867-4864

**Syosset**

*Couples Concerns*  
Thurs, 6:30-8pm.  
Call for dates.  
Jodi (917) 592-1376

**Valley Stream**

1st & 3rd Tues, 7:30 pm.  
Tracy (516) 791-7440

**Wantagh**

*Family/Friends of Someone with MS*  
2nd Tues, 7-8:30 pm.  
Lori (516) 826-4351

## Phone Support

Have MS for more than 10 years and have trouble coping? Call Sal (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 about your invisible chronic illness? Leave messages until 8:30 pm for Lisa at (516) 294-4278.

I've had MS for 13 years. Need to talk? Call Bob at (631) 471-4559 until 6 pm.

Want to talk about your spiritual journey as you live with MS? Call Sister Mary Jo at (631) 928-2975 and leave a message until 8 pm.

*story continued from page 5*

beings, we're all bound to need a little help now and then. It's nothing to be embarrassed about and there's no reason to justify it to anyone else.

Of course, if you want to say something to those who speak up, or if someone asks why you're using a device or special parking space, you can always offer the following answers:

*Thanks for your concern. Have a great day!*

*Not all disabilities are visible.*

*Please don't make assumptions about me or my health.*

*I may look terrific, but walking is difficult for me.*

*More than 400,000 people in this country have MS, and I'm one of them. Want me to tell you about it?*

All of these answers allow you and the other person to maintain dignity and walk away without confrontation.

Also remember that making the transition to using an assistive device can be difficult or uncomfortable for many people. These feelings are natural and normal. As our bodies age, we all feel frustrated when we can't do what we could—whether we have MS or not! Don't let those negative thoughts overwhelm your thinking. Concentrate instead on what you *can* do.

If you need help dealing with this or other related issues, please call the Long Island Chapter and talk with a member of our Programs staff. This is why we're here!

## *She fights fires with words and wisdom*



For more than ten years, Jay Backes tried to join her local volunteer fire department, but

the answer was always the same: "Oh, no. We don't have any women here! This is a men's-only department."

Undaunted, she joined the ambulance corps in the next town. "They were also a men's-only company," she remembers, "But they needed help in the day and I was available, so they decided to give me a chance. It was great to finally be able to help people in need."

Backes did well, moving up through the ranks and eventually becoming the ambulance company chairman. But her dream to become a firefighter was still alive. "After ten years, I sent a registered letter to my local fire department again, making an offer they couldn't ignore."

It was the right move. After years of trying, Backes was now an official member of the fire department. Once she'd been through training, she donned her helmets and boots and took on the grueling job of saving property and lives. "They took me into the fire department *and* the ambulance company. Things were great: I was working on two ambulance companies, a fire department, and the fire department's Ladies Auxiliary."



Three years later, she started having intermittent trouble with her vision. "Then the following year, my left leg was acting up, so I went to a neurologist."

The neurologist diag-

nosed MS, and once again her career path changed direction. "I was a life member of the first ambulance corps, so that was okay, but without five years at the fire department, I could no longer be a member there."

"But I still wanted to do more," she explains. "The year I joined the department, a newsletter was started, and I joined that staff. Now, 22 years later, the original people are long gone, but I'm still there, getting the pictures, schedules, and news stories. Even though I now use a wheelchair, I still help my fire department, and I'm glad to do it."



Wheelchair in for repairs?

Don't sit home waiting! Borrow one of ours.

Call Barbara at (631) 864-8337 for details.

*story continued from page 3*

Vitamin D intake was determined through the Nurses' Health Study questionnaire and four one-week diet records, which included queries about diet and use of dietary supplements. Blood levels of vitamin D were examined, and analyses were performed to determine other factors that might affect the results, such as latitude of the subject's birthplace and smoking.

**To learn more about the National MS Society's latest research, please call the Long Island Chapter and request a copy of Research Highlights, our bulletin on the important work being done to end the devastating effects of MS.**

## Fast Forward to reading material

If your MS affects your vision, you may benefit from the services offered by the Long Island Talking Book Library (LIBTL). They offer a large-print newsletter, website, and dozens of other resources for people who enjoy good books. To receive a copy of their Fast Forward newsletter, call (631) 286-1600. Audicassette and large-print versions are available.

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## New Target for MS Treatment

*This article is reprinted from the January 2004 issue, where the last line was inadvertently deleted.*

Scientists have found a striking difference in the patterns of ion channels—tiny pores—on immune T-cells from people with MS and people without MS. According to Heike Wulff, PhD (University of California, Davis) and colleagues, they have also shown that a protein that blocks these pores can prevent MS-like disease in rats. In a new study using T-cells that react to myelin, taken from people with MS, the group reported that one particular

ion channel may be repeatedly stimulated throughout the course of disease.

Dr. Wulff presented these findings during the eighth annual meeting of the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS), held October 2003 in San Francisco. The meeting was jointly sponsored by the National Multiple Sclerosis Society and the University of Maryland School of Medicine, in collaboration with the MS Society of Canada. MS experts presented findings to an audience of 270 MS-specialist physicians, basic scientists and clinical investigators, who met following the American Neurological Association's Annual Meeting. The meeting was chaired by Dr. Kenneth P. Johnson and jointly sponsored by the National Multiple Sclerosis Society and the University of Maryland School of Medicine, in collaboration with the MS Society of Canada.

## SOCIAL SECURITY DISABILITY

Long Term Disability

- ◆
- Accidents
- ◆
- Disability
- ◆

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

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Need help grocery shopping?

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Call Barbara at (631) 864-8337 for details.

## Had it with winter?

### Come join us for a spring program (or two!)

If you're like most Long Island residents, you've had it with winter for a while. If that's the case, put away your mittens and join us for our growing list of spring programs.

You can call the Long Island Chapter's Programs staff for a complete list of options and registration materials, but here are just a few highlights to pique your interest:

#### Managing MS Teleconference Tuesday, March 16

Neurologist Dr. Mark Gudesblatt will discuss the treatment of MS, symptom management, new research being performed, pain management and more. Open to people with MS, their friends and families.

#### Newly Diagnosed Seminar Wednesday, April 14

Are you or a loved one new to the world of multiple sclerosis? Come to this informative and relaxed session and learn the basics about life (and

living) with MS. We'll have a team of experts and lots of information to take home.

#### Meet the Lawyers Thursday, April 29

The National MS Society, Long Island Chapter invites you to meet with an attorney one-on-one. This program is designed to answer your specific legal questions and concerns. The attorneys participating specialize in Elder Law, Social Security/Disability Law, and Matrimonial/Family Law.

#### Just for Fun Luncheon Friday, May 21

If you reside in a nursing home in Nassau County, mark your calendar for this annual event. We're busy booking the entertainment and planning the menu for a delightful day out. Details to be announced!

#### Tools for Success: A Job Search Skills Workshop Wednesday, May 26

Ready to change direction? Deanna Rieber, Employment Specialist at UCP of Greater Suffolk will help. For info, call Edith Cowan at (631) 864-8337.



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## You CAN DO

### The Heuga Center program arrives on Long Island October 13-17, 2004

The Heuga Center's renowned CAN DO program teaches people with MS how to focus on what they can do instead of what they cannot by emphasizing general health, physical fitness, and psychological wellbeing. It takes a whole person approach to managing MS and teaches individualized lifestyle strategies that include exercise, nutrition, self-management, social interaction and support. The CAN DO Program also offers an extensive component for support partners, addressing their individual needs and concerns and educating them about the disease.

This October, The Heuga Center will bring its CAN DO Program to Long



*Heuga Center representatives share a laugh with Long Island resident Millie Cinquemano at last spring's CAN DO program in Colorado*

## THE HEUGA CENTER

PROMOTING HEALTH, CREATING HOPE

Island. The five-day program, to be offered at The Garden City Hotel, includes 45 hours of individ-

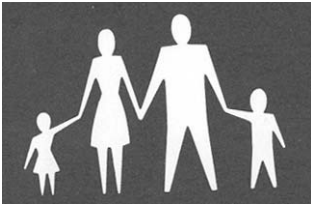
ual and group workshops, seminars, and evaluations. It is served by 45 MS specialists.

The Program is limited to 25 participants and their support partners. The fee is \$2,000 per participant, which includes all meals and program components. Transportation and lodging are not included. There is no extra charge for support partners. Need-based scholarships are available for all or part of the fee. Visit [www.heuga.org](http://www.heuga.org) to download a scholarship application, or call (800) 367-3101.

### How to Apply

Please visit [www.heuga.com](http://www.heuga.com) to download a CAN DO Program application, or call the Heuga Center directly at (800) 367-3101 to get more information and have an application mailed to you.

To read a Long Island Chapter member's personal account of her experiences at the CAN DO Program, see the September, 2003 issue of MSConnection, or call (631) 864-8337 and we will mail you a copy.



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Home Health Aides/Pediatric Nurses/Pediatric Therapists, Special Educators–516-681-2300

Home Health Aides . . . Social Workers . . . Nurses . . . Therapists . . . Home Health Aides

As a leading provider of home health care services on Long Island, and proud signature sponsor of this year's MS Walk, we wish to congratulate and support the hard work and dedication of the Long Island Chapter of the National Multiple Sclerosis Society.

**120 West John Street  
Hicksville, New York 11801**



**Joint Commission**

*on Accreditation of Healthcare Organizations*

## *How to take control of your legacy*

You've heard (probably more times than you can count!) about how important it is to have a last will and testament—and maybe you already have one. But think for a moment about why.

Perhaps what's most important to you is the fact that having a will ensures your property will pass to those you care about. If you don't leave a will, state law determines how your assets will be divided. It's highly doubtful you would agree to this arbitrary method of choosing your heirs and determining their shares.

An old will can be almost as bad as none at all. Your wishes today for the division of your estate may be quite different from those you had when you made your will. Life events, tax law changes, a move to another state or changes in the nature and value of your assets can also affect your will. To make sure your wishes are followed, you need an up-to-date will.

### **The form of your bequest**

Remembering the National Multiple Sclerosis Society in your will is a fitting testimony of your belief in our mission. When you name us as a beneficiary, you have many choices.

One possibility is a bequest of a fixed dollar amount. Another is to give us a

percentage of the estate, which allows you to keep the division of the estate residue in desired portions, regardless of its size.

Your gift can be contingent. That is, the funds would go to some individual if that person survives you. If not, they would be paid to the Society. Often a better alternative is to create a trust, which would pay an income to the individual for life, with the remaining principal to be given to us after.

### **Get sound legal advice**

When the time comes for your will to be probated, you won't be here to correct any misunderstandings. To avoid trouble for your heirs, be sure to seek the counsel of an attorney who specializes in probate and estate planning. We would be happy to work with your attorney and financial advisors to make sure that your wishes are met.

Feel free to call us at 1-800-923-7727, or e-mail us at [giftplanning@nmss.org](mailto:giftplanning@nmss.org), for more information.

## Access to adequate health care

Do all individuals with multiple sclerosis have access to adequate health care? If not, what factors impede this access? Answering these questions is one goal of investigators funded by the National MS Society's Health Care Delivery and Policy (HCDPR) Program. Here we report progress from several such efforts.



well-being programs, pharmaceutical services, nutrition programs, and exercise, wellness and physical well-being services.

"People with MS and their family members viewed health services very broadly and included health promotion services (physical and social), community accessibility, and support to remain at home among their concerns," notes Finlayson.

"Health care professionals tended to focus more on medically related services and coordinating components of health care. These differences highlight the importance of using a client-centered approach to ensure that our interventions are addressing what people with MS identify as critical."

### Aging With MS

Aging can be especially challenging for individuals with MS, but until now little research had been done to examine the special health-related needs of this population, and how those needs are or are not met. Marcia Finlayson, PhD, OTR/L, is exploring this issue in a large region around the Great Lakes. She is collecting information using focus groups with people with MS, caregivers and medical professionals.



To date, the study team has completed seven of these focus groups, which have identified the following as critical needs of people growing older with MS: transportation, housing, professional home care, social

Finlayson's team used this baseline information to develop a telephone interview guide, and is now interviewing 1200 people with MS who are 45 years of age and older about their usage and satisfaction with health care services. Of 950 individuals interviewed, many have reported using a wide range of services to manage MS and general health and well-being.

"With the exception of health insurance services, so far, the majority of respondents have reported being satisfied with the services that they are receiving,"

*story continues on page 18*

*story continued from page 17*

notes Finlayson. "Nevertheless, unmet needs seem to be emerging with differences between men and women, and older and younger people with MS (within the 45-and-up range). The study team will be monitoring these emerging trends, and exploring them in detail once all of the interviews are completed." The team hopes to complete interviews with people with MS soon and then proceed with care partner interviews.

### Seeking Equality in Quality of Care

There is evidence from other disease populations that members of minority

groups do not always receive care of the same quality as that received by non-minorities. In a project just begun, Janet P. Sutton, MSPH, PhD (National Opinion Research Center, Bethesda, MD) is investigating whether Hispanics and African Americans – who are affected by MS less frequently than Caucasians – have access to the same types and amounts of health services and how they perceive the quality of this health care.

To address these questions, Sutton and colleagues are conducting surveys of about 2300 individuals who are Hispanic, African American or Caucasian. The survey focuses on the use of preventive and specialty care, insurance coverage of prescription drugs, and use of durable medical equipment and assistive devices.

The results of this and other projects supported through the Society's Health Care Delivery and Policy Research Program will provide the solid evidence needed to advocate for quality health care for all of those who live with multiple sclerosis.

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# Stretch your body and your mind with our spring recreation programs

## ADAPTED AQUATICS

A low-impact form of exercise to improve strength, balance & coordination. May be joined after start date.

*This program is funded by the Dee Kaplan Memorial Fund.*

### Bay Shore

**Mondays 1-1:45 pm**

March 1-June 14

**Thursdays 9:30-10:15 am**

March 4-June 17

Great South Bay YMCA

200 West Main Street

### Commack

**Wednesdays 10-11:00 am**

April 14-June 23

Suffolk Y JCC

74 Hauppauge Rd

### East Hills

**Tuesdays 9:30-10:30 am**

April 20-June 22

**Thursdays 10:45-11:45 am**

April 15-June 24

Sid Jacobson JCC

300 Forest Drive

### Freeport

**Mondays 11:30 -12:30 pm**

Jan 5-April 26

Freeport Rec Center

130 East Merrick Rd

### Oceanside

**Mondays 7-8:00 pm**

April 19-June 28

**Thursdays 10-11:00 am**

April 22-June 25

South Shore Y-JCC

15 Neil Court

### Plainview

**Mondays 10:15-11:15 am**

April 19-June 21

**Tuesdays 7-8:00 pm**

April 20-June 22

**Thursdays 7-8:00 pm**

April 16-June 25

**Fridays 10:15-11:15 am**

April 16-June 25

Mid-Island Y JCC

45 Manetto Hill Rd

## HORTICULTURAL THERAPY

Gardening as a healing process to improve body, mind and spirit for increased concentration and dexterity. Six two-hour workshops over 12 weeks.

### Holtsville

**Thursdays 10-12 noon**

April 8, 22

May 6, 20

June 3, 17

Ecology Center

Buckley Road

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## MEDITATION WORKSHOP

Shari Davidson, RYT, will lead a 4 hour workshop exploring different types of meditation, readings, times of silence, and methods of relaxation. Wear loose comfortable clothes and bring a pillow or blanket to sit on. Time includes 30 min. for brown bag lunch. (Bring your own!)

Lake Success  
Saturday 10 am-2pm  
April 3  
B.E.T.A. Center  
2001 Marcus Ave.  
Suite 170-S

## THERAPEUTIC EQUESTRIAN PROGRAM

The LI Chapter is pleased to provide a referral to the following independent equestrian programs and to provide partial scholarship for our members upon request:

Pal-O-Mine classes start at Caumsett State Historic Park on Thursday, April 15 for eight weeks. Weight limit of 175

pounds. Evaluations for riders new to the program cost \$75. Lesson cost \$40/class. To register, please submit the medical form from Pal-O-Mine's website ([www.pal-o-mine.org](http://www.pal-o-mine.org)) directly to Pal-O-Mine indicating you're a member of the National MS Society. If you do not have internet access, or for additional information about this program, please contact Pal-O-Mine directly at (631) 423-7183. Class size is limited.

HorseAbility classes start at The Thomas School of Horsemanship, 238 Round Swamp Rd, Melville, the week of April 15 for eight weeks. Evaluations for riders new to the program cost \$50. Lessons cost \$45/class. To register and for all information about this program, please contact HorseAbility directly at 631-367-1646 ([www.horseability.org](http://www.horseability.org)) indicating you're a member of the National MS Society. Class size is limited.



## PHYSICAL THERAPY

Long Island Chapter members unable to obtain or continue physical therapy due to lack of health insurance or maximization of their health benefits can participate.

East Meadow  
Mondays 1-2pm  
March 1-April 5  
STARS Rehabilitation  
801 Merrick Ave.  
Suite 170-S

Holbrook  
Tuesday, 11-12 noon  
March 2-April 6  
PRN Physical Therapy  
20 Peachtree Ct. #105

Smithtown  
Thursdays 11am-12noon  
March 3-April 7  
St. Charles Rehab Network  
260 Middle Country Rd  
Suite 208

## TAI CHI

Gentle turning and stretching movements for increased coordination

**Brookhaven**

Tuesdays 6:30-7:30pm

April 13-June 29

Post Morrow Foundation

16 Bay Road

**TAI CHI/YOGA  
COMBINATION**

Gentle breathing, turning and stretching movements for increased coordination and total body relaxation

**Freeport**

Thursdays 12-1:00pm

April 8-29

June 3-24

Freeport Rec Center

130 East Merrick Rd.

**YOGA**

Stretching and breathing exercises to promote total body relaxation

**East Meadow**

Wednesdays 12-1:00pm

Dates TBA

Fridays 12-1:00 pm

Dates TBA

East Meadow Jewish Center

1400 Prospect Ave

**Hauppauge**

Fridays 10-11:00am

April 16-June 25

St Thomas More Church

**Lake Success**

Thursdays 12-1:00pm

April 29-June 24

B.E.T.A. Center

2001 Marcus Ave.

Suite 170-S

2 hour format, 4 sessions

**Lake Success**

Saturdays 10am-12noon

April 10, 24

May 1, 8

B.E.T.A. Center

2001 Marcus Ave. #170S

**Mineola**

Date, Time, Location TBA

**Plainview**

Mondays 7-8:00pm

April 19, 26

May 3, 10

June 7, 14

Mid-Island Y JCC

46 Manetto Hill Road

**MS RECREATION &  
SOCIALIZATION  
PROGRAM -  
FREEPORT**

This ten-week Saturday afternoon socialization and recreational therapy program is run by a certified recreational therapist. It is held at the Freeport Recreation Center from noon until 3:00 p.m. and includes a variety of craft

projects as well as refreshments. There is no fee to participate and new members are welcome to join at any time. The Spring 2004 dates are March 6, 13, 20, April 3, 17 & 24.

**How to Register**

If you have already participated in a specific program, you will receive a registration form by mail. If you are new to a program, please call the Chapter office at (631) 864-8337 for a registration form.

**Fees**

There is no fee to Chapter members for the aquatics exercise program. The suggested fee for any other entire single program is \$25.00.

Fee waivers are available upon request—we are here to help!

**Accessibility**

All of our programs welcome ambulatory and non-ambulatory participants. All of our sites are accessible. Please check with each site separately for scheduled holiday and other closings.

## Update: the Betaseron® diluent syringe

The National Multiple Sclerosis Society recently updated information on its website about the Betaseron® pre-filled diluent syringe. Here is the revised statement:

The FDA has approved a new delivery system from interferon beta-1b (Betaseron®), called a Pre-filled Diluent Syringe. The new system, which reduces the number of steps involved in reconstituting the medication,

includes a syringe that is pre-filled with the diluent (mixing solution). Previously, the diluent was stored in a vial and had to be drawn up into the syringe in order to be mixed with the Betaseron®. There have been no changes to the formulation—the medication is exactly the same—so that it remains non-acidic and able to be stored at room temperature. The new delivery system was expected to be available by late January, 2004.

## Young adults with MS telephone support group

Share and compare your experiences with other young adults with MS ages 17-21 through monthly conference calls. Discuss the challenges of being a young person with MS and help others cope with situations that may be difficult, empowering or even hard to imagine.

Meet young adults from all over the Northeast with MS while sharing your knowledge and helping others.

The program is offered by Young Persons with MS: A Network for Families with a Child or Teen with MS, in collaboration with the National MS Society's Central New England Chapter.

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Brooklyn  
1861 86th St.  
Brooklyn, NY 11214  
(718) 621-5300

The call is offered from 7:00 - 8:30 pm (EST) 3rd Wednesday of each month, including March 17, April 21, May 19 and June 16. The dial in number will be provided upon registration. Sandy Marshall, MSN will facilitate. To register please contact Elana MacGilpin at (800) 493-9255, ext. 115 or [elana.macgilpin@mam.nmss.org](mailto:elana.macgilpin@mam.nmss.org).

## Have something to buy or sell?

### Wheelchairs, scooters for sale

Electric wheelchair, hardly used. \$900 negotiable. Call Dan at (631) 698-0201, or cell (631) 897-0695.

Manual wheelchair brand new, never used. Original cost \$350 selling for \$200. Call Tom at (516) 735-8165.

### Vans/Autos for sale

2003 Chrysler Town and Country Limited with every option. Rear kneeling and in floor ramp. Equipped with E-Z lock behind front seat for a passenger in wheelchair. White with gray interior,

6000 miles. Asking \$39,500. Call David Angelo (631) 249 8300 during business hours or (516) 448 2372.

1998 Ford Econoline Van 350, 40,000 miles. Fully handicapped. Asking \$4,750. Call Ed (516) 796-3345.

### Misc. for sale

EZ Stand 5000 Hydraulic Stander. Like New. \$1,000 negotiable. Call Jim at (631) 957-0987

*Placing your ad is easy: just call Barbara at (631) 864-8337, or email us at [breyling@nmssli.org](mailto:breyling@nmssli.org).*

## Families with multiple auto-immune diseases needed

The Multiple Autoimmune Disease Genetics Consortium (MADGC) is a group of genetic researchers who have joined efforts to identify and understand the genes that autoimmune diseases have in common. If at least two members of your family are affected with different autoimmune diseases from the list below, your family may qualify to participate in this important research study.

Multiple Sclerosis

Systemic Lupus

Crohn's Disease

Sjogren's Syndrome

Rheumatoid Arthritis

Type 1 Diabetes

Psoriasis

Juvenile Rheumatoid Arthritis

Ulcerative Colitis

Autoimmune Thyroid Disease

Participation includes a brief telephone interview and providing a blood sample, which can be drawn at your local clinic or physician's office.

To learn more about this NIH funded study, visit [www.madgc.org](http://www.madgc.org) or call North Shore University Hospital, Manhasset at (877) 698-9467.

## *Unlocking the mysteries of MS*

### **Video to be shown at two Long Island sites in April**

Mark your calendars—there are two opportunities to see the 2004 North American Education Conference Video, “Unlocking the Mysteries of MS.”

On Thursday, April 1, it will be shown as part of a Research Seminar at Winthrop University Hospital’s Community Outreach Center in Mineola. Malcolm Gottesman MD of the MS Treatment Center at Winthrop will host the presentation from 6:30-7:30 pm.

On Tuesday, April 27, it will be shown at Central Suffolk Hospital in Riverhead, at a Research Seminar under the direction of

Barbara Bumstead, NP of South Shore Neurologic Associates PC. This seminar also is scheduled for 6:30-7:30 pm.

In the video, internationally known experts make presentations on their fields of MS research, and information on alternative and complementary therapies is presented. Speakers include John H. Noseworthy, MD, Claudia Lucchinetti, MD, Moses Rodriguez MS, and Brian Weinshenker, MD, all from the Department of Neurology, Mayo Clinic and Foundation.

To register for either seminar, or to learn more about the video, contact the Long Island Chapter at (631) 864-8337.



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