

# essential news

*Exclusively for major donors to the Long Island Chapter's efforts to end the devastating effects of multiple sclerosis*

## \$16.1 million to local research

The National MS Society has just committed \$16.1 million to support 52 new research projects by top scientists investigating many aspects of multiple sclerosis. Added to present commitments, the Society will spend some \$30 million this year to fund over 300 new and ongoing MS investigations—more MS research than any voluntary health organization in the world—to cure, treat, and better understand this disease.

“The new research projects hold incredible promise for advancing our understanding of MS,” says Pam Mastrota, Chapter President. “We’ve invested \$380 million to find the cause and cure for MS since our founding 56 years ago—an investment into basic and clinical research that is responsible for the rapid progress we’re seeing now.”

## Three studies on Long Island

The newly committed projects include two MS investigations in Stony Brook and Brookhaven, representing a total funding of more than \$1.4 million. These include investigations at SUNY Stony Brook conducted by Pamela Block, Ph.D., who will investigate Attitudinal and Structural Barriers to Physical and Recreational Activity, including factors that facilitate or discourage physical and recreational activity among people with multiple sclerosis who use wheelchairs and walkers; and by Lauren B. Krupp, MD, who will study mild cognitive impairment in multiple sclerosis, and whether it worsens over time. At Brookhaven National Laboratory, William Rooney, Ph.D. will use magnetic resonance imaging to track and measure MS lesion development in early stages of the disease.

## Annual Meeting Slated

The National Multiple Sclerosis Society, Long Island Chapter, will host its Annual Meeting on Monday, December 1, 2003 from 2-4 pm at the Huntington Hilton in Melville. To register, call (631) 864-8337 or send a message to [sgerardi@nmssli.org](mailto:sgerardi@nmssli.org).



This year's keynote speaker will be neurologist Dr. Richard Blanck, who will discuss the latest updates in multiple sclerosis research, as well as important information for people with MS, their friends and families, physicians and other health care providers.

## Create a Legacy

Did you know you could help end the devastating effects of multiple sclerosis and retain payments for yourself and your loved ones? You can donate cash or securities and receive payments for life through a National Multiple Sclerosis Society Charitable Gift Annuity.

Gift Annuities help you to:

- ◆ Support the mission of the National MS Society.
- ◆ Obtain a charitable income tax deduction.
- ◆ Receive fixed, lifetime payments, a portion of which may be tax-free.
- ◆ Increase cash flow from an investment with a lower rate of return.
- ◆ Convert low-yield appreciated assets while reducing long-term capital gains taxes.

To learn more about benefits available through a charitable gift annuity, please contact us at (631) 864-8337.

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

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## executive update

Thanks to the generous support of so many on Long Island, we are proud to promote a better quality of living for the 38,000 Long Island residents affected by multiple sclerosis.

We do so with the full support of a dedicated board, a community of excellent care providers, and a devoted staff.

In our roles as Chairman and President of the Long Island Chapter, we've met hundreds of people who

have amazed us with their knowledge, compassion, and ability to embrace life. . . and many have made a difference in *our* lives. In Pam's first month as President, she met Sal and his wife Lenora at a self-help group luncheon. Sal's a captivating man whose progressive MS has advanced to the point that he is quadriplegic. For most of us, that alone would be devastating.

Not Sal, who calls Pam on a monthly basis to ask what he can do to help the Chapter and people with MS. Sal plays a tremendous role in our crisis support program by answering calls from people in need. He demonstrates compassion and understanding in everything he does, and he makes us want to do everything possible for the Chapter's clients.

We can improve their lives by finding a cure for multiple sclerosis, as well as new treatments. The Long Island Chapter is proud to sponsor cutting-edge national research, and to be associated with some of the world's most brilliant scientific and medical minds. Their determination to discover the cause and cure for multiple sclerosis is without limits. Their commitment to finding new treatments is just as strong.

Please join us in saluting those who have joined us in our fight to end the devastating effects of multiple sclerosis. And whether your gift is one of financial support, time, or spirit, please know that we, and all who are affected by MS on Long Island, are truly grateful for your generosity.

**Happy Holidays and best wishes for a healthy, prosperous 2004!**



Gary Carpenter is Chairman of the Long Island Chapter. You can reach him at (631) 752-7400 x283 or at [gcarpenter@hrcpa.com](mailto:gcarpenter@hrcpa.com)



Pamela Jones Mastrota is Chapter 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)

## 2004 National MS Society Scholarship info now available

Do you know a bright high school senior who has MS, or whose parent has MS? If so, encourage him/her to apply for a National MS Society Scholarship. The program is also open to high school graduates who have never attended a post-secondary school. Details and eligibility requirements are available on the National MS Society website at <http://www.nationalmssociety.org/scholarship.asp>. Applications will be accepted between January 1, 2004 and February 16, 2004. Winners will be notified in June, 2004.

In 2003, the Society awarded more than \$68,500 in scholarships to 36 children of people with MS. The awards each year depend on funding available and quality of the applications.

## Women Against Multiple Sclerosis (WAMS) luncheon crosses the million dollar mark

The National MS Society, Long Island Chapter hosted its Women Against Multiple Sclerosis (WAMS) *Spotlight 2003 Luncheon* on September 18 at Leonard's of Great Neck. Now in its fourth year, WAMS is held annually to raise funds and awareness for multiple sclerosis.

"This year's luncheon was marvelous," said Long Island Chapter President Pamela Jones Mastrotta. "Our committee created an absolutely stunning event that thrilled our 550 guests."

Dr. Lauren Krupp, Co-Director of the MS Comprehensive Care Center at SUNY Stony Brook, was the keynote speaker.

The 2003 WAMS luncheon raised more than \$413,000 for MS research and local programming, bringing the event's cumulative total to more than \$1 million.

The WAMS luncheon featured a Chicago theme with a dazzling fashion show by Georgina, catering by Lawrence



The 2003 WAMS Committee Chairwomen, from left to right: Amy Paston, Madeline Modolo Raylman, Merry Slone, Linda Goodstein, Terry Elias (Committee Co-Chairs), with Long Island Chapter President Pamela Mastrotta. Photo Credit: Pace

Scott, and a raffle with dozens of fabulous prizes, including diamond jewelry, a fur, original artwork, and several vacations.

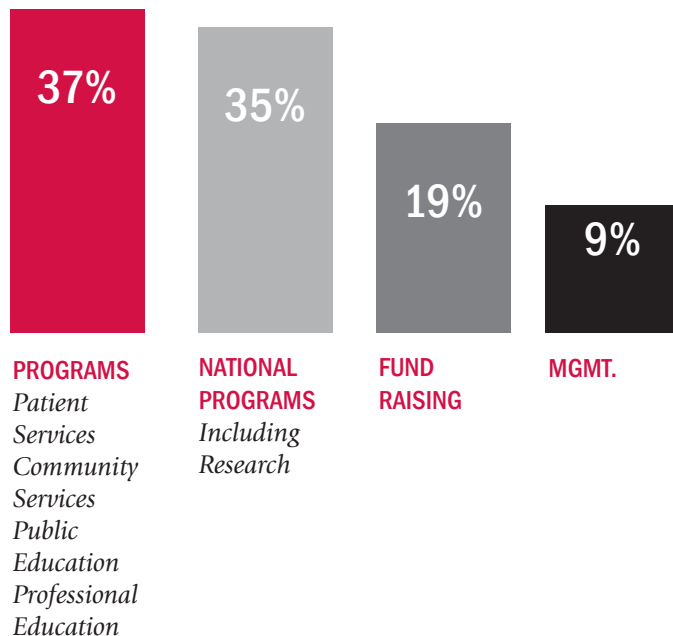
## National MS Society, Long Island Chapter Revenue and Expenses for the Year Ended September 30, 2003

### General Revenues:

Direct Mail, Membership, etc.	\$763,831
Events: Walk, Bike, Golf, etc.	\$1,586,134
Other: Interest	\$6,886
<b>Total</b>	<b>\$2,356,851</b>

### Expenses:

National Programs, including Research	\$694,645
Programs and Services	\$722,950
Fundraising	\$383,476
Benefit to Donor	\$217,026
Administration	\$175,196
<b>Total</b>	<b>\$2,193,293</b>
<b>Excess Revenue over Expenses</b>	<b>\$163,558</b>



This is a preliminary financial statement. Final statements, together with the auditor's report, are available from the Chapter or by calling (631) 864-8337.

# MS research offers hope to Long Island residents

## Novel technology tested for making “DNA vaccine cocktail” to fight MS in mice

Researchers are using advanced technology to design vaccines to treat EAE, an MS-like disease in mice. William H. Robinson, MD, Ph.D., Lawrence Steinman, MD (Stanford University), and colleagues report the results of a novel study in *Nature Biotechnology*.

Research has indicated that “epitope spreading” may play a role in the immune attack on nerve-insulating myelin in MS. This means that although one protein in myelin may trigger the attack, the resulting immune response may spread to additional segments of that protein or other proteins. Understanding how epitope spreading occurs will be important in developing possible vaccines for use in treating MS.

In this study, the investigators have used a large-scale study of proteins—known as proteomics—to track the evolution of B-cell responses in mice with EAE. B-cell responses to triggering proteins have been implicated in autoimmune diseases such as diabetes and lupus, and there is evidence they play a role at some point in the course of MS. Using advanced technology called microarrays, they were able to study B-cell responses to more than 2,000 myelin protein molecules at once.

The results showed that mice with the most diverse B-cell responses—meaning that the B cells reacted to many protein molecules—experienced the largest number of relapses. These relapses were also associated with epitope spreading. Using this information, the investigators designed customized DNA vaccines containing “cocktails” of the genetic material that instructs several myelin proteins, which would induce maximal immune system

“tolerance.” The vaccines succeeded in reducing relapse rates in the mice, as well as epitope spreading.

In an accompanying editorial, Eli Sercarz, PhD (Torrey Pines Institute for Molecular Studies, San Diego) suggests that further studies are needed to establish the usefulness of these exciting results in devising therapies for people with MS. Bayhill Therapeutics, a company that has licensed therapeutic compounds from the Stanford team, notes in an August 2003 press release that it plans to enter clinical studies in 2004 with a therapy for MS.

## FDA approves Betaseron® pre-filled syringe

The U.S. Food and Drug Administration (FDA) has approved a new pre-filled syringe for Betaseron(R) (interferon beta-1b) for subcutaneous injection. All four of the injectable immunomodulatory medications that have been approved for use in MS—Avonex®, Betaseron®, Copaxone®, and Rebif®—are now available in pre-filled syringes that require no mixing. Of these, Betaseron® requires no refrigeration; Copaxone® can remain at room temperature for up to one week without harm to the product, but should otherwise be refrigerated; Avonex® and Rebif® require refrigeration.

## Association between smoking and MS

Researchers report that in a study of more than 20,000 Norwegians, the risk of developing MS was higher among smokers than in people who never smoked (Trond Riise, Ph.D., University of Bergen, Norway) and colleagues from Bergen University College and Harvard University, report their efforts in the October 28, 2003 issue of *Neurology*.

The investigators administered questionnaires that covered current and previous smoking habits, including the age at which smoking started, as well as if and when MS symptoms first started. The risk of developing MS was nearly twice as high in people who were current or former smokers compared to people who had never smoked. The average duration from start of smoking to MS symptom onset was 15.2 years.

This was the second large, population-based study to find an association between smoking and risk of developing MS. Further study is necessary to confirm this association and to explain the underlying mechanisms for a possible link between smoking and developing MS. However, there is increasing evidence for a link between smoking and MS.

Several studies have examined the association between smoking and the risk of developing MS, with mixed results. Some smaller, hospital-based studies were negative, but a recent larger population-based study to address this question did find a statistically significant association between smoking and risk of developing MS.

**What will your \$1000 gift to the National MS Society do for someone with MS?**

**It will provide 20 hours of computer training so the person can begin a new career at an accessible workplace.**

# How to help people with MS to live full, satisfying lives

In addition to funding critical research that seeks improved treatments and a cure, the National Multiple Sclerosis Society, Long Island Chapter also invests in innovative programs for people with MS, and the family members, friends, and caregivers who are affected by this lifelong disease.

Our Programs department has access to a wealth of information and resources that can make life less challenging for people affected by MS. Throughout the year, we offer a continuing series of seminars, workshops, support groups, social activities and publications, as well as access to the outside world via our Ramp Assistance Program and durable medical equipment loan closet.

A complete list of our current and future programs is available by contacting the Long Island Chapter at (631) 864-8337. For many donors, program sponsorship is a fulfilling way to give—and to give hope.

Some of our programs, and our costs to produce them, include:

## Take Me Out to the Ballgame \$7500

Each summer, 300 participants enjoy a pre-game picnic buffet, followed by an evening of semi-pro baseball cheering the Long Island Ducks in Central Islip. For some, this is the first positive introduction to a large group of people who are using wheelchairs, scooters, and other assistive mobility devices *and* having fun.

The ballpark is “disability-friendly” with wheelchair and companion seating as well as stadium seating, ramped entrances and a large handicapped-parking area.

## Equipment Subsidy Programs \$21,000

It’s bad enough that MS can rob people of their mobility—but the cost to purchase assistive devices can be even more daunting. Some power wheelchairs are more expensive than used cars! The hand controls or van lifts that allow a person with MS to keep driving to work every day can be too expensive on a tight budget. Even the cost of a ramp, an air conditioner, incontinence supplies, emergency response service, transportation to the doctor’s office, or grocery shopping service can all be difficult when your income is already stretched to the limit.



The Long Island Chapter offers financial help to members who cannot afford these necessary items. While subsidies are based on financial need, we fund up to \$500 per fiscal year per member for medical equipment, up to \$150 towards the purchase of an air conditioner, and provide unlimited help for any member requesting the grocery-shopping program—until our budget runs dry.

Our Ramp Program subsidizes 1/3 of the cost of installing a ramp or lift, up to \$1,500.00. When possible, we underwrite the total \$300 - \$400 cost of threshold tri-fold suitcase ramps for members who cannot leave their homes. We also provide a list of community resources that can help members obtain funds to defray the expenses of larger installation projects.

## Wellness Programs \$16,070

*Yoga, tai chi, golf, tennis, adapted aquatics, group physical therapy, horticultural therapy, reiki workshop:* these are the current seasonal wellness programs the Chapter offers at accessible sites throughout Long Island. Most programs are held at community centers or hospitals or sports-affiliated sites that donate space to us.

Thanks to the generous funding from the Dee Kaplan Memorial Fund, our aquatics program is free for our members. Throughout the year more than 100 members attend these water exercise classes. Registration for all of our other programs has a suggested fee of \$25 and a no-questions-asked policy for scholarship requests.

## Homebound Recreation \$26,200

For our homebound members who live with progressive forms of multiple sclerosis, the weekly visits from our Certified Recreational Therapists are a lifesaver. Activities are chosen based on interest and physical ability, and can include reading aloud, listening to music, discussing politics, playing scrabble, teaching computer skills, or engaging in craft and cooking projects.

We currently offer this ten-week program twice a year, although most of our homebound members would appreciate weekly visits year-round. The cost per ten-week session is approximately \$450. The number requesting this service increases every year.

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## **Kids Fun Day** **\$ 7,000**

When a parent or a close relative has multiple sclerosis, a child may take on a caregiving role at a very early age. The National MS Society, Long Island Chapter recognizes that kids need time to be kids-free of additional responsibilities. That's why we host Kids Fun Day.

At Kids Fun Day, children have the opportunity to meet and interact with others who are coping with the effects of MS, all while enjoying games, unlimited rides, and a pizza and ice cream lunch. They can choose between an Iwerks Motion Movie or a game of LaserTron. Kids enjoy a magic show, balloon sculpting, costumed characters, contests and door prize drawings.

Parents and chaperones are required to attend, and they can enjoy adult camaraderie while the children play (although many prefer to play the games!). A selection of materials on multiple sclerosis for children and adults is available for adults to browse and take home.

Kids Fun Day is held at Sports Plus Event Center in Lake Grove, which is accessible by elevator and escalator. The Long Island Chapter subsidizes the majority of the \$25/person cost, and charges just \$10/person, with a \$50/household maximum. Scholarships are available on request.

## **Case Management** **\$24,120**

People with multiple sclerosis and their family members often find themselves in crisis: an elderly parent may agonize over the need to place an adult child in an assisted living facility. Or a person with MS might be frustrated and depressed by the inability to manage daily tasks that once were easy.

There are vital community services available to help, but people in crisis often don't know how to get the assistance they need. Our case management program offers families the guidance of a Social Worker or a Registered Nurse so families can obtain required services in the community. There is an application process overseen by the Chapter Social Worker, including a client history, current needs and possible goals, and a maximum financial range for all participants. The case manager makes up to three home visits with the client and/or family members and follows up by phone as necessary.

## **Homebound Conference Calls** **\$12,000**

Imagine being unable to leave your home—the social isolation you'd feel. For some people with multiple sclerosis, this is a sad reality. But the National MS Society, Long Island Chapter can help. Three times a year, we offer a supportive counseling group via tele-

phone conference call. This gives people with MS who cannot leave their homes the opportunity to socialize, provide peer support, and connect with the help they need. Ten to 13 people participate during each 45 minute conference call over the course of eight weeks. The group is facilitated by a mental health provider.

Conference call participants are consistently positive in their evaluations, but have one request: they wish the calls could be longer than 45 minutes. We wish to extend calls to 90 minutes, same as the time allotted for face-to-face counseling groups.

## **Respite Program** **\$18,000**

When a medical emergency, health problem, or burnout prevents a caregiver from providing assistance, The National MS Society, Long Island Chapter's Respite Program provides a solution. This subsidy program reimburses families for the cost of 40 hours of hands-on home healthcare assistance to a person with MS. The MS Respite Program also offers the same subsidy to people with MS to offset the yearly cost for home healthcare assistance.

The program currently will pay for up to 40 hours of care per year. By increasing the number of participants to 20 and the number of care hours to 60/year, we can provide this critical assistance to many more Long Island families who desperately need it.

## **Social Recreation Program** **\$15,000**

"We love this program. When will it begin again?" That's the unanimous reaction to the National MS Society's Social Recreation Program, a 10 week program dedicated to people with multiple sclerosis who wish to enhance their lives, enjoy the company of their peers, and stimulate their minds. The Long Island Chapter offers this program at the Community Programs Center of Long Island in Ronkonkoma. Limited transportation is provided for members who have no means of attending the program. The group meets in the spring and fall. Participants enjoy a meal together, play board games, and then get busy on creative projects including wood-working, holiday crafts, scrapbooks, and much more.

A similar program is also offered in Freeport.

# How you can make a bigger difference against MS

The National Multiple Sclerosis Society, Long Island Chapter wants to make your giving experience as easy as possible, and so we offer **Ring of Friends**, a program that allows you to electronically transfer regular contributions to us. When you use **Ring of Friends**, the administrative costs of fundraising are greatly reduced, and more of your gift goes directly to helping people with multiple sclerosis.

**Ring of Friends** is simple and completely safe. Upon your authorization, your bank transfers a specified gift to us each

month. *You can increase, decrease, or end your participation at any time.* You determine the amount you want to give.

The rewards are wide-reaching, and some of the benefits to you include:

- ◆ You can join **Ring of Friends** with a gift as little as \$2/month
- ◆ The satisfaction of knowing **your gift is helping** people with MS
- ◆ Making smaller monthly gifts allows you to give more over the course of a year

Complete this form and return it to us by mail with a voided, blank personal check. We'll keep your information private and secure. If you have questions, please call us at (631) 864-8337.

**Thank you for your generosity.**

## Rather make a one-time gift now?

We'd welcome that, too.

Please make your check payable to National Multiple Sclerosis Society, Long Island Chapter, and mail to us at:

National MS Society  
Long Island Chapter  
200 Parkway Drive South  
Suite 101  
Hauppauge, New York 11788

To give via credit card (we welcome MasterCard, Visa, and American Express, just call us at (631) 864-8337.

All gifts are tax deductible. Thank you for your support.

## National Multiple Sclerosis Society Long Island Chapter

I authorize my bank to debit my account each month and pay the National Multiple Sclerosis Society, Long Island Chapter the amount shown below, according to the terms and conditions on this form.

I would like to make a monthly contribution of:

\$25    \$50    \$100    \$200    \$500    \$1000    Other \_\_\_\_\_

I request these monthly payments start on the 1st or the 15th of \_\_\_\_\_.

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

**Terms and Conditions:** My authorization to debit my account at my bank shall be the same as if I had personally signed a check to the National MS Society, Long Island Chapter. This authorization shall remain in effect until I notify my bank or the Long Island Chapter in writing that I wish to end this arrangement. I will give my bank and the Long Island Chapter a reasonable amount of time to act on it. A record of each debit will be included in my regular bank statement and will serve as my receipt. In the event of an error, I have the right to tell my bank to reverse any charge. I understand this must be done within 15 days of the date of the bank statement or within 45 days after the charge was made.

## Has it been a while since your last gift to the MS Society?

The Conrad Hilton Foundation has awarded the National Multiple Sclerosis Society a matching challenge grant of \$100,000. The grant is restricted for research and concludes on June 30, 2004. The Hilton Foundation has a long history of support to the National MS Society, with grants totaling more than \$4 million since 1989.

All gifts restricted to research from new donors qualify for the matching challenge grant, and in addition, gifts from those who have not given to the National MS Society in more than 18 months are also eligible.

To learn more about this special giving opportunity, please contact the Long Island Chapter at (631) 864-8337, or the National MS Society's Vice President of Major Gifts, Mary Milgrom at (303) 813-6619.

**For more on other ways to give to the National Multiple Sclerosis Society, please look inside!**

## 2004 Events Schedule

4/18/04	MS WALK
5/18/04	Renaissance Ball
6/9/04	CLASS
7/26/04	MS Golf Classic
8/9/04	MS Ladies Golf
9/16/04	WAMS Luncheon
9/19/04	MS Pooch Parade
TBA	MS Bike Tour
TBA	Research Dinner



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