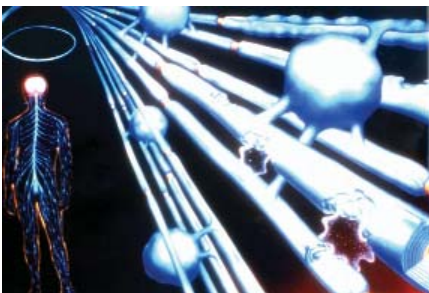


Long Island Chapter

annual *report*

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



our mission:

*to end the devastating effects of
multiple sclerosis*

2003 annual *report*

National Multiple Sclerosis Society Long Island Chapter

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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.



Gary Carpenter is Chairman of the Long Island Chapter.



Pamela Jones Mastrota is Chapter President and CEO of the Long Island Chapter.

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. 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.

what is multiple sclerosis?

There are more than 400,000 Americans with MS, and every week, 200 more are diagnosed—more than one per hour!

MS is not contagious and is not directly inherited.

MS is not considered a fatal disease.

MS strikes more women than men.

There is no cure for MS yet, but drugs can help slow the course and/or symptoms in some patients.

Multiple sclerosis is a chronic, often disabling disease of the central nervous system. Symptoms may be mild, such as numbness in the limbs, or severe—paralysis or loss of vision. Most people with MS are diagnosed between the ages of 20 and 50 but the unpredictable physical and emotional effects can be lifelong. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are giving hope to those affected by the disease.

In MS, myelin is lost in multiple areas, leaving scar tissue called sclerosis. These damaged areas are also known as plaques or lesions. Sometimes the nerve fiber itself is damaged or broken.

Myelin not only protects nerve fibers, but makes their job possible. When myelin or the nerve fiber is destroyed or damaged, the ability of the nerves to conduct electrical impulses to and from the brain is disrupted, and this produces the various symptoms of MS.

The Importance of Early Treatment

Thanks to significant advancements in research, the FDA has approved several treatments that may alter the underlying disease course of multiple sclerosis, and early treatment is critically important. People with MS should consult with their doctors about using one of these FDA-approved medications and other effective treatments for the symptoms of MS. If you or someone you know has MS, contact the National Multiple Sclerosis Society.



research

our commitment to

finding the cure and

new treatments

This year, the National Multiple Sclerosis Society gave its financial support to 52 new research projects by top scientists investigating many aspects of multiple sclerosis. Added to present commitments, the Society spent some \$30 million in 2003 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 projects hold incredible promise for advancing our understanding of MS,” said Pam Mastrotta, Chapter President. “We’ve invested \$380 million to find the cause and cure for MS—an investment into basic and clinical research that is responsible for the rapid progress we’re seeing now.”

\$16.1 million committed to 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.

Multiple sclerosis is the “prime of life” disease—striking people in their 20s to 50s. They have no idea how they’ll be affected—it’s so unpredictable. Imagine, at that age, wondering, “Will I become paralyzed, blind; have trouble walking? Will I be able to raise my family, continue my career?”

Hillary Rodham Clinton was named Senator of the Year at the annual National MS Society Public Policy Conference held this May in Washington, D.C. The five NY chapters nominated her for strong support of health care, disability policies and issues, and continued advocacy for programs and services for people with disabilities.

New York State will introduce the **National Multiple Sclerosis Society License Plate** in early 2004, thanks to the determination of the MSCan Committee and State Senator John J. Flanagan, who introduced the bill in the Senate. The \$25 annual service charge for the plate, which will bear the National MS Society logo, will be deposited in the state's "Multiple Sclerosis Research Fund." Governor Pataki signed the bill into law in late summer 2003, stating "(This) is a great way for New Yorkers to promote awareness of this disease, while also providing critical support for research."

I can hear it under their breaths and see it in their eyes as we pass. "Why is she walking that way?" "Why is her handwriting so sloppy?" For years, I have silently stood by and watched people judge my mom. It has been tough to handle, but her strength has made the difference.

My mom's multiple sclerosis has played a large role in all our lives. It has taught us to be patient and understanding. We have all been forced to learn that certain sacrifices and responsibilities come along with her illness and we must do what we can to ensure that she is well and comfortable. Obviously, my mom's life has been the life most affect-

ed. She has become a true emblem of courage and strength.

Prior to her diagnosis, my mom was an art educator. She held an extreme passion for art. MS caused her practice of art to become nearly impossible and she was left to find a solution. It may have been easier for my mom to sit back and let her diagnosis define her, but she refused. Since she could no longer comfortably practice art, she decided to go back to college. My mom graduated from C.W. Post in May 2002 and is now a librarian. She truly is a hero to me and I am so incredibly proud of her motivation and accomplishment.

**is that
woman
drunk?**



our impact

We believe we can make a difference in the lives of young people affected by multiple sclerosis. In 2003, the Society launched a scholarship program for high school seniors who have, or live with someone with, MS. One of the national winners, **Maeve Gavagan** of Huntington (above, right, with her mother Diana), is now a freshman at the University of Notre Dame. Her winning essay is excerpted below.

richard blanck, md

is a Long Island based neurologist who specializes in multiple sclerosis. His patients describe him as humanistic, knowledgeable, and "someone who gives his all for people with MS."

For the past quarter-century, I have seen a great number of patients with multiple sclerosis. Every so often, I marvel at the technological breakthroughs in that time—and greater advances are inevitable. It is this belief that constantly recharges my emotional batteries.

Nothing is quite so onerous than meeting a young person on the threshold of his/her most productive years, and delivering the news that multiple sclerosis has just rendered their future uncertain. The prospect of neurological impairment and disability evokes a wide spectrum of feelings that range from mild concern to sheer terror.

When I first began seeing patients with MS in the early 1970s, treatment was aimed at managing symptoms and trying to expedite recovery from acute attacks. By the late 1970s, CT scanning (computer axial tomography) gave clinicians our first chance to look at the brain using x-ray techniques. The earliest CT scans produced Polaroid pictures that looked more like checkerboards than white or grey brain matter. But we were able to gain useful information.

The technology improved. In the late 1980s, MRI (magnetic resonance imaging) was born—and I was blown away by the

fact that brain images could be produced using powerful magnets and radio frequency pulses—electromagnetic energy that could disturb protons so that signals were emitted, recorded, and reconstructed using computer technology to more accurately represent brain structures.

The past decade has brought even more exciting breakthroughs. We are now able to detect changes on MRI studies in patients with early MS—patients who have not yet developed clinical evidence to establish a definite diagnosis. Abnormal MR findings predict a high probability for developing clinically definite MS. If trends continue, we will soon be able to image brains and inspect normal-appearing white matter and find people who may be at risk for developing multiple sclerosis long before there are MR changes that we see today and long before clinical symptoms and signs of MS ever develop. MRI findings reveal the physical appearance of brain tissue. MR spectroscopy reveals information about the actual chemical make-up of brain tissue.

There is still more to come. New MR technology called functional MR is being developed. Not only can we image the physical and chemical structure of the brain, we can now “look” at brain function. It is conceivable and probable, in my



view, that we will be able to determine changes in brain function that predict subsequent development of MS long before structural or biochemical changes ever take place. The benefit from these kinds of technological advances will allow for “hyper-early” diagnosis and treatment. We already know that MS patients who begin treatment early have the best prognosis.

Early detection and early treatment is our aim. Ultimately, I believe we will be able to look at the genotype (the genetic make-up of individuals). If we are able to determine which genes are necessary and sufficient for the development of MS, even earlier detection will be possible—perhaps as early as *in utero*. We know that genetic predisposition is an important factor, and a requirement for the development of MS. Some populations never develop MS. It may be possible to alter the gene makeup so that multiple sclerosis can never develop. This would, of course, be “the cure.”

I believe that “the cure” or total eradication is the final goal—the ideal. Until that ideal is actualized, we will have to settle for other treatment options better-termed control measures. No Cure is not equivalent to No Treatment.

For example, if we could completely shut down MS attacks, and patients could fully

recover, MS attacks might be like a bad flu

that happens every year or two. Patients could live perfectly healthfully and happily between episodes. Currently, the gold standard for expediting recovery from attacks is corticosteroid treatment (Solu-Medrol). The treatment does little more than “give nature a boost” because after six months or so the outcome is pretty much the same whether patients take steroids or whether they take nothing at all.

Another kind of control that would be wholly satisfactory would be to manage symptoms optimally. In other words, if a person with MS had walking difficulty and technology would allow him/her to walk with a normal gait in spite of MS, this would be another example of excellent control. The same could be said for managing other symptoms such as numbness, fatigue, incontinence and even cognitive problems. We are getting better in terms of symptomatic treatment, which has been a great boon for helping people with MS to achieve better quality of life.

In the past decade, the FDA has approved a number of drugs that modify the course of MS. We are seeing a reduction of the frequency, duration, and severity of MS

attacks, slowing of disease progression and accrual of disability. I look forward to better treatments and perhaps combination therapies that would result in even greater control, and ideally complete cessation of disease progression. These advances will be especially significant when combined with early detection and treatment.

For me, the greatest challenge—and the greatest frustration—is the inability to reverse existing neurological deficits. I hope that genetic engineering and stem cell research will allow researchers to find ways to help the body remyelinate demyelinated nerves, repair broken axons, and remove the scar (gliotic tissue) in MS plaques. We know the body has the raw materials and means for injury repair: we see it every day when a person has a cut or bruise. We need technological advances that will allow for the healing of central nervous system injuries, too.

We are learning more and more about the pathophysiology, or mechanisms that are responsible for the development of MS. But the cause of the illness is still unknown.

Developing relationships with people who become patients and friends and watching them deteriorate clinically is both gut-wrenching and heartbreaking. I always

believed I could emphasize with patients and their families fairly well, until 1992 when my father was dying of pancreatic cancer, and the emotional maelstrom became more palpable for me. Nothing is more painful—and educational—than going through this kind of ordeal. The only solace I could take was the fact I was a human being and not a god, and I was trying the best I could to help.

Fortunately with multiple sclerosis, we are not dealing with the loss of life. But we are dealing with the loss of quality of life, which many would consider just as important.

My colleagues and I will continue to do our very best to stop the devastating effects of MS and improve quality of life for our patients. As clinicians, we believe in research and technology and are ready to try any new treatments that may be helpful and safe. We want to work with you, and frankly, we need your strength as much as you need ours.

Together, we will prevail, and the day will come when multiple sclerosis is completely controllable or curable—and we are out of the MS business. Nothing would make me happier. I salute all of you for helping us to fight MS, and am honored and proud to be on your team.

programs

for people with MS, their friends and families

Knowledge of MS

information and referrals
programs & seminars
in-services
teleconferences
internet programs
MSConnection newsletter
educational literature
Inside MS magazine
lending library
school outreach program

Physical Health

MS Care Centers
treatment programs
wellness programs
referrals to local neurologists
and health care professionals

Emotional Health

professional group counseling
peer-facilitated self-help &
support groups
short-term counseling
telephone support
mental health referrals
programs for people unable to
leave their homes

Family Support

case management services
family outings
individual and family support
groups
respite care services
social and recreation programs

The National MS Society, Long Island Chapter invests in innovative programs for people with MS, and the family members, friends, and caregivers who are affected by this lifelong disease.

With more than 60 programs offered in 2003, we're proud to showcase just a few of our members' favorites:

Take Me Out to the Ballgame

This summer, 300 participants enjoyed a pre-game picnic, followed by an evening of baseball cheering the Long Island Ducks. "Gracious thanks for giving me the opportunity to take my children on this outing," said one participant. "They had a great time—it was something we could all do together!"

Equipment Subsidy Programs

MS can rob people of their mobility—but the cost to purchase assistive devices can be even more daunting. The hand controls or lifts that allow a person to keep driving to work every day, or the cost of a ramp, air conditioner, incontinence supplies, transportation to the doctor's office, or grocery shopping service can all be difficult when your income is already stretched to the limit.

In 2003, the Long Island Chapter continued its financial help to members who could not afford these items. Subsidies were based on financial need. We also provided a list of community resources to help members defray the expenses of larger installation projects.

our programs

help thousands of people to celebrate life, assert their independence, and cope with the devastating effects of this disease.

Independence

referrals for:
durable medical equipment
home and auto modification
legal advice
estate planning

Long Term Services

referrals to:
home health agencies
long-term care and rehabilitation facilities
programs on legal issues and entitlements

Employment

employment & career counseling
computer training & workshops
referrals to government and community agencies
support of ADA guidelines

Wellness Programs

Yoga, t'ai chi, golf, tennis, adapted aquatics, group physical therapy, horticultural therapy, reiki workshop: these are just a few wellness programs the Chapter offered throughout Long Island. Most were held at community centers, or outpatient recreational facilities that donated space.

Homebound Recreation

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

Kids Fun Day

When a parent or a close relative has multiple sclerosis, a child may take on a caregiving role at a very early age. Kids need time to be kids—free of additional responsibilities. That's why we hosted Kids Fun Day.

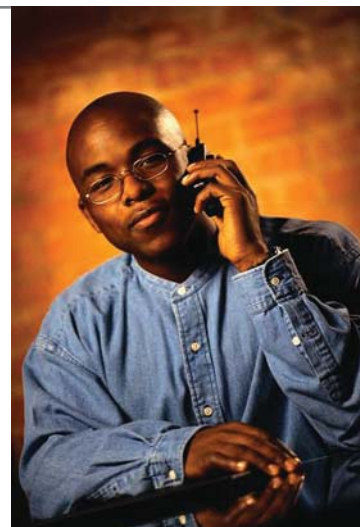
At Kids Fun Day, children met and interacted with others coping with the effects of MS, all while enjoying games, rides, a magic show, balloon sculpting, contests, and a pizza and ice cream lunch.

Parents and chaperones enjoyed adult camaraderie while the children played (although many prefer to play the games). An educational component is built into the event. In 2003, children completed a puzzle that used MS words as clues. A selection of materials on MS for children and



“Thank you so much for thinking about us. You know what we face every day. You really care if we are happy, or trying to enjoy life with our families. Thank you, with sincere appreciation.”

Take Me Out to the Ballgame participant



adults was available for adults to browse and take home.

Case Management

When daily tasks became overwhelming, people with multiple sclerosis and their family members often found themselves in crisis. Our case management program offered families the guidance of a Social Worker or a Registered Nurse so families can obtain services in the community.

Homebound Conference Calls

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. In 2003, we offered several supportive counseling groups via a series of telephone conference calls. This gave people with MS who could not leave their homes the opportunity to socialize, provide peer support, and connect with the help they needed. The group was facilitated by a mental health provider.

Respite Program

When a medical emergency, health problem, or a much-needed break prevented a caregiver from providing assistance, the Long Island Chapter’s Respite Program provided a solution. This subsidy pro-

gram reimbursed families for the cost of 40 hours of hands-on home healthcare assistance to a person with MS. The MS Respite Program also offered the same subsidy to people with MS to offset the yearly cost for home healthcare assistance.

Social Recreation Program

“We love this program. When will it begin again?” was the unanimous reaction to our Social Recreation Program, a program dedicated to people with multiple sclerosis who wish to enhance their lives, enjoy their peers, and stimulate their minds. The Long Island Chapter offered this program at the Community Programs Center of Long Island Inc. in Ronkonkoma. The group met in the spring and fall. Participants prepared a meal, played board games, and enjoyed creative projects including woodworking, holiday crafts, scrapbooks, and much more.

A similar program was also offered in Freeport.

development and fundraising

We stand in awe of the thousands of Long Island residents who joined us in the fight against MS. Thanks to their energy, spirit, sweat, and commitment, the Chapter was able to provide more than 60 programs and fund critical research.



Team MS Kick-Off Rally



WAMS Luncheon



MS WALK



MS Walk

Each year, the MS Walk is the Chapter's most popular and profitable fundraising event, bringing together thousands of people who demonstrate their support with every single step. In 2003, MS Walk events were held in Belmont Lake and Long Beach, raising a total of \$612,405.

WAMS Luncheon

The Women Against Multiple Sclerosis (WAMS) Luncheon is one of the highlights of the social season, thanks to event founder Merry Slone and her amazing team of Co-Chairs and Committee Members. The 2003 Luncheon was a smashing

"It was such a good feeling inside to know all of our friends and family were being so supportive. We made a graph to show what amount we were up to. Everyday we thought that we reached our goal and they kept coming in!"

Sammie, Jake and Charley Paston, who raised \$10,000 in the MS Walk.

success, bringing in more than \$413,000—which means that in its fourth year, WAMS has already exceeded the \$1 million mark in raising funds for research and programs. Distinction Magazine was the media sponsor. Luncheon guests enjoyed fashion and art shows, luxurious raffles, and a fabulous luncheon catered by Lawrence Scott.

Renaissance Ball

The 2003 Renaissance Ball brought together some of Long Island's most prominent citizens for a glittering evening of elegance. The Renaissance Ball raised \$95,386.



CLASS

Business leaders were selected to join the CLASS of 2003 and generate awareness and support of multiple sclerosis and the National MS Society. This year's CLASS raised nearly \$104,000 to end the devastating effects of multiple sclerosis.

MS Golf Classic, Founded by Fred Weingarten

On a sunny day in July, more than 130 golfers (and many more supporters) spent an exciting day at the Muttontown Club for the 2003 MS Golf Classic. The day's highlights included an enjoyable and challenging round of golf, three sumptuous meals, the Jet Blue Challenge, and dozens of raffles. Karen Meyer of RCA was the honoree, and the Classic brought in \$157,960.

MS Ladies Golf Tournament

Just one week later, the lady golfers hit the links at the Creek Club in Locust Valley, where their early morning tournament included breakfast, 18 holes, and a delicious luncheon buffet.

Beatrix McKane of Holtz Rubenstein was the honoree. The 2003 Ladies Golf Tournament raised \$79,025.

CLASS of 2003



MS Bike Tour for a Cure

More than 300 cyclists donned helmets and set out on one of four scenic tours, ranging from 10-100 miles. This year's new 100-mile route with challenging twists and hills near Stony Brook was the brainchild of Paul Langer, pictured at right. Riders and guests celebrated with a picnic in Oakdale. The MS Bike Tour for a Cure raised \$71,000.



Pooch Parade

The Long Island Chapter doesn't limit its fundraising efforts to humans. This year, more than 300 canine friends did their part to fight MS, walking with their owners and friends in the MS Pooch Parade. A big "Woof" to all of those best friends, who collected \$46,903.



community support

In addition to our official events, the National MS Society is grateful for the support of dozens of Long Island residents who created and ran their own "third party" events to benefit the Chapter.

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
TBA	WAMS Luncheon
9/19/04	MS Pooch Parade
TBA	MS Bike Tour
TBA	Research Dinner



Potato Hampton



Nightsong: Huntington Cabaret Singers



Jazz at Sunset

Though it's impossible to list all of the wonderful third-party events here, we offer our resounding thanks for making a difference.

volunteers

are our partners and heroes in the fight against the devastating effects of MS. Whether they lend their hands at the Long Island Chapter Office, cheer participants at our events, or represent us at community health fairs, they are an integral component of our success.

2003 Volunteers of the Year

Thomas Acker

Gery Albers

Sarina Eastlund

Maria & John Fausone

Loretta Gray

Rich Kareckas

Joseph Licari

Rocky & Norma Perillo

Patricia Sedlick

Mary Alice Strang

Helga Walter



Maria and John Fausone



MS Walk volunteers help participants complete certificates



Magic tricks and more at Kids Fun Day

we are proud to honor

the following individuals and companies who truly stand out in the fight against multiple sclerosis. Their vision inspires and empowers us.

2003 Program Awards

Gerry Albers, Recreation Therapist
Dana Waite Esposito, MS, CRC, MA
Senator John J. Flanagan
Toby Hobish
The Kaplan Family
The Luongo Family
Vincent Restituto
Barbara and Richard Roaman
Michael and Linda Wolfson

2003 Media Awards

Anton Community Newspapers
Distinction Magazine
Latin Long Island Magazine
News 12 Long Island

2003 Development Awards

Martin Bernard
Tracie Castiglione
Nancy Douglas and Kathy Spanos
Terry Elias
Marj and Sid Goldberg
Linda Goodstein
Paul Langer
Lincoln Computer Services
Lucille Lufrano
Joseph Milizio
Madeline Modolo Raylman
Allan Newman
JoAnn O'Hagen
Jimmy Papadopoulos
Amy Paston
Sammie, Charley, and Jake Paston
Michael Rabinowitz
Cheryl Schack
Neal Schack
Merry Slone
Lawrence Scott
Gail Warrack

Long Island Chapter Honored at National Conference

The Long Island Chapter took three awards during the National Multiple Sclerosis Society's National Leadership Conference in November, 2003. The first recognized our Men's Night Out program, subtitled Drugs, Sex, Rock and Roll. The second honored our work in getting the Governor and state legislature to approve the National MS Society license plate bill. We also received the highest award, Diamond Level, for supporting MS research.

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

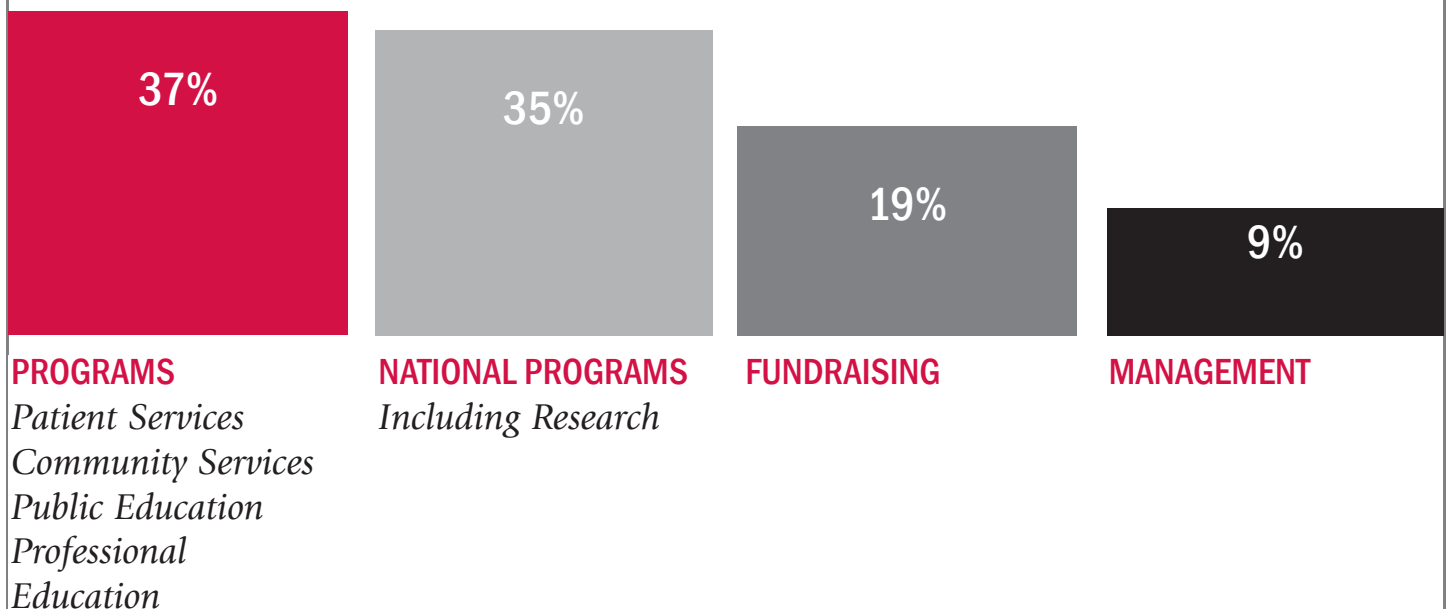
General Revenues:

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

Expenses:

National Programs, including Research Programs and Services	\$694,645
Fundraising	\$722,950
Benefit to Donor	\$383,476
Administration	\$217,026
Total	\$2,193,293

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.



long island chapter *staff*

President & CEO
Pamela Jones Mastrota

Director, Chapter Programs
Edith Cowan

Social Worker
Susan Weber, CSW

Programs Manager
Catherine Silverstein

Programs Manager
Barbara Reyling

Director, Development
Christine Thomaides

Development Manager
Erin Cleary

Development Manager
Candace Stabile

Editor/Communications Manager
Pamela Yaeger

Grantwriter
Sally Jones

Director, Finance
Rosemary Newbeck

Director, Information Technology
Edward Newbeck

Volunteer Coordinator
Stefanie Taylor

Office Manager
Sarina Eastlund

Support Staff
Arlene Aspromgos
Odette Lipari

executive committee

Gary P. Carpenter, Chairman

Eugene DeMark, Vice Chairman

Bill Goff, Vice Chairman

Neil Hamburger, Vice Chairman

David Leviton, Vice Chairman

Alphonsus Monahan, Treasurer

Loretta Power, Secretary

board of trustees

Theresa Ahlstrom

Mindy Alpert

Richard H. Blanck, MD

Patricia K. Coyle, MD

Robert Gershowitz

Sidney Goldberg

Stanley M. Heller

Michael Lewis

Steven Luongo

Allan Newman

Joseph O'Connell

Vincent Restituto

Richard Roaman

Ray Sikorski

Steven Stern

Gail Warrack

The National Multiple Sclerosis Society is a not-for-profit organization serving people with MS in every state. Founded in 1946, the Society supports more MS research and serves more people with MS than any national voluntary MS organization in the world. The Long Island Chapter serves 38,000 people affected by MS in the area.

The mission of the National Multiple Sclerosis Society is to end the devastating effects of multiple sclerosis.



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY



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