

About MS

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, including paralysis or loss of vision. Most people with MS are diagnosed between the ages of 20 and 50. The unpredictable physical and emotional effects can be lifelong. The progress, severity, and symptoms cannot be predicted, but advances in research and treatment are giving hope to those affected by the disease.

For more information about Multiple Sclerosis, contact the National MS Society at 1 800 FIGHT MS or the Long Island Chapter at (631) 864-8337. **Website:** www.nmssli.org



Long Island Chapter
200 Parkway Dr. South
Hauppauge, NY 11788
(631) 864-8337
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Long Island Chapter

2003-2004

Programs and Services

Provided by the National Multiple Sclerosis Society, Long Island Chapter

The National MS Society, Long Island Chapter is dedicated to ending the devastating effects of multiple sclerosis. We do so in two ways: by funding critical research that seeks improved treatments and a cure, and by providing innovative programs and services to 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 multiple sclerosis. 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.

Inside, you'll find information about nine of our most important programs: Case Management, Homebound Conference Calls, Kids Fun Day, Take Me Out to the Ballgame, Equipment Subsidy, Wellness, Homebound Recreation, Respite Care, and a popular Social Recreation Program. We invite you to learn more about how we serve the more than 38,500 people affected by multiple sclerosis on Long Island. With your help, we can continue to make a significant difference in improving their quality of life.

For more information:

Call us at
(631) 864-8337

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Case Management

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 for people with MS. 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.

Projected budget: \$24,120

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. Three times a year, we offer a supportive counseling group via telephone 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.

Projected budget (45 minute sessions): \$6,090

Projected budget (90 minute sessions): \$12,000

Respite Program

Caring for someone with multiple sclerosis can be a fulltime commitment. When a medical emergency, health problem, or burnout prevents caregiver from providing the necessary 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 of 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 up to \$15/hour of care for 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.

Projected budget \$9,180 will serve 15 families

**Projected budget (increase number of participants to 20 and number of care hours to 60)
\$18,000**

Social Recreation Program in Ronkonkoma

"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, four-hour 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 woodworking, holiday crafts, scrapbooks, and much more.

Projected budget: \$11,100

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Take Me Out to the Ballgame

Attending a summer baseball game is a traditional American pastime, but not so easy if you're mobility challenged. The MS Family Baseball Outing offers our members the opportunity to enjoy a pre-game picnic buffet, followed by an evening of semi-pro baseball cheering the Long Island Ducks in Central Islip. For some families, 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 cost per person, including the picnic, is \$25, but the Chapter underwrites the picnic so members are asked to pay just \$10 per person. The ballpark is "disability-friendly" with wheelchair and companion seating as well as stadium seating, ramped entrances and a large handicapped-parking area.

Other than cost, our biggest problem is obtaining enough tickets for everyone who wants to attend. The maximum we can reserve is 300 and our tickets sell out within a few days of the announcement.

Projected budget: \$7,500

Equipment Subsidy Programs including Ramps

Coping with a chronic disease can take a big bite out of your budget. You may be out of work on disability. Medications can cost over \$1000/month. Power wheelchairs are more expensive than some used cars! Maybe you're considering installing hand controls in your vehicle, or a lift so you can get a wheelchair or scooter into your van. Maybe it's time for a ramp instead of those three steps to the front door. Maybe you need just a little help stretching your dollars to cover purchasing an air conditioner, incontinence supplies, emergency response service, transportation to your doctor's office, or a grocery shopping service.

The Long Island Chapter offers financial help to our members upon request. We understand it can be difficult to ask for monetary help so we publicize our programs as a Chapter service. 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.

Projected transportation budget: \$1,000

**Projected grocery shopping budget: \$5,000
(\$50/month—47 members used this during FY 2003)**

Projected medical equipment budget: \$5,000

Projected ramps budget: \$10,000

Wellness Programs

Yoga, tai chi, golf, tennis, adapted aquatics, group physical therapy, horticultural therapy, reiki workshop: these are the current seasonal wellness programs the Long Island Chapter offers at one-hour classes held at accessible sites throughout Long Island. Most programs are held at community centers or and hospital or sports-affiliated sites that donate the 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 (per season, not per class!) and a no-questions-asked policy for scholarship requests.

Projected budget:

Yoga: \$9,000

Tai Chi: \$2,200

Tennis: \$1,000

Group physical therapy: \$2970

Horticultural therapy: \$900

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Homebound Recreation Program

Jim demonstrates zero active movement in upper and lower body extremities requiring total assistance for manipulation. Jim will experience enjoyment and contentment by participating in social/leisure activities of choice. All activities will be adapted to verbal. Jim is physically unable to engage.

Karen sits in a recliner in living room all day. Can only sit in wheelchair for an hour at a time. Doesn't like to impose on spouse to transfer. Uses chair lift to return to bedroom. Can only use non-dominant hand and only minimally. Poor sight. Speech and hearing remain good. Karen will respond to weekly socialization and achieve success during cognitively stimulating games, will be able to assert personal choices, and will experience increase in self-esteem.

Mario is very physically compromised. Movement is very limited. Gastric tube-fed. Speech is minimal and slurred. Legally blind. Mario will maintain his leisure enjoyment by participating in therapeutic recreational activities—social, intellectual, music and humor. He will continue to maintain present listening skills.

These assessments were submitted by three of Certified Therapeutic Recreational Therapists who create recreational programs for our homebound members who live with progressive forms of multiple sclerosis. The therapists make one-hour weekly visits and activities are chosen based on interest and physical ability. They 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. For many, it is the highlight of the week! Our recreational therapists (working as independent contractors) now visit 27 participants. The cost per ten-week session is approximately \$450. The number requesting this service increases every year.

Projected budget: \$26,200

**Cost per person for year round (50) weekly visits:
\$2,250**

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. 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, an exciting excursion for children in families where a parent, grandparent, sibling, or other close family member has multiple sclerosis.

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. Costumed characters and a clown visit and pose for photographs, and kids enjoy a magic show, balloon sculpting, 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 National MS Society 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.

Projected budget : \$7,000