What Is It About MS That Makes It a ‘Family’ Disease?

By Rosalind C. Kallb, PhD,
Director, Professional Resource Center, National Multiple Sclerosis Society

The vast majority of people who have multiple sclerosis are diagnosed between the ages of 20 and 50 years. The disease thus affects people in their most productive years: young adults readying themselves to leave home in pursuit of academic, vocational, or social goals; men and women in the process of launching careers and families of their own; and those in middle age who are enjoying their productive years and planning for their retirement.

Since MS has little impact on life expectancy, it is likely the person diagnosed will be living and coping with its effects for many years. MS has often been compared to the “uninvited guest” that arrives at the door one day, complete with baggage, and never goes home. It moves into the household, using up space in every room of the house, and taking part in every family activity. Every person in the household needs to learn how to live and cope with this uninvited guest.

Living with MS poses an ongoing challenge to the emotional equilibrium of a family. The person with MS and family members experience feelings of loss and grief with every new symptom and each change in functional ability. Any progression in the illness requires family members to adjust to the loss, and to redefine themselves and the family accordingly. Anxiety and anger are commonly experienced by families as they try to cope with the uncertainty, change, and loss that accompany MS.

Challenges to family coping

Families’ efforts to cope with the intrusion of MS into their lives are challenged, not only by the complexities of the disease, but also by the complexities of the families themselves. What is it about families that complicates the coping process?

The family unit is made up of individuals, each with a unique personality and coping style, as well as age-appropriate needs and goals. Each person in the family will see the MS in a slightly different way, and respond to its demands in terms of the way it impacts on his or her particular situation. Therefore, the family’s efforts to deal with the disease cannot be seen as a unified, coherent process, but rather as the sum total of individual, sometimes conflicting, coping efforts.

The family’s response to the MS is not a simple one. At any given point in time, it is a reflection of the feelings, attitudes, needs, and priorities of each of the people involved.
Disruption of the family's rhythm

Over the years, families tend to develop a rhythm of their own – a reasonably smooth and predictable way of carrying out the routines of daily life, with each member having specific responsibilities within the family. If one person in the family becomes unable to carry out his or her particular role(s), the rhythm of the entire family is upset. Whether it is recognized at the time or not, this shift in roles begins to change the ways in which family members interact and communicate with one another.

Disruption in family communication

Talking about these kinds of changes within the family can be very difficult for a variety of reasons. First, since changes tend to happen slowly, families may not be sufficiently aware of their impact to discuss them as they begin to occur. Second, people often have difficulty talking about changes in family life that are caused by symptoms they cannot readily see or understand. MS-related fatigue, sensory symptoms, and cognitive changes are difficult to describe to others; they are easily misinterpreted by family members who cannot understand why family life is not proceeding as smoothly as it once did. Third, family members tend to be quite protective of one another, with the result that painful feelings, questions, and concerns are often left unexpressed. And fourth, people sometimes feel that “the less said, the better”, as though talking about problems will confirm that they actually exist, and not talking about them will make them magically go away.

Important resources and barriers to their use

Fortunately, a variety of resources exist to help families live well despite chronic illness. Healthcare teams, voluntary health organizations, educational materials, and various types of professional and self-help groups are some of the tools available to support families’ coping efforts. Unfortunately, there also seem to be significant barriers to the effective utilization of these resources. Some of the barriers are social and economic while others are much more personal and emotional. Access to quality healthcare is not universal, and access to professionals with expertise in MS is even more limited. In addition, many people do not make use of important resources even when they are readily available.

Many families may not want to acknowledge the potential impact of MS on their lives, or to think about MS more than is absolutely necessary; some are afraid that thinking about current or potential problems will somehow make the problems seem more real. Other families seem to feel that seeking outside help or support would be an indication of their own weakness or inadequacy. They do not recognize that these resources are the kinds of tools that might enable them to manage more effectively.

Becoming educated about the potential impact of MS on the family, and taking steps to protect the family’s financial, social, and emotional well-being, can help each person feel less vulnerable in the face of this unpredictable disease.
Greetings from your new Chapter President!

It is with great pleasure and excitement that I take on my new duties with the Greater North Jersey Chapter. I look forward to getting to know you, all of our volunteers and our wonderful staff, and just plain learning how best to serve our mission of ending the devastating effects of MS.

First off, I would like to hear from you, our readers, supporters, and especially, anyone affected by MS. Please give me your suggestions and ideas on what I can and should be doing for you and our Chapter. I asked this same question of our staff, who quickly proposed some very good goals. In future issues of MS CONNECTIONS, we will publish some of your letters and ideas. My pledge to you is to be responsive to your suggestions, to implement those that we can, given existing resources, and to seek to increase those resources through enhanced fundraising efforts in the future.

Thank you all for your past support of our Chapter. I really look forward to working with you, and to supporting you, in the years to come.

Sincerely,

Frank

Contact me at: frank@njb.nmss.org

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**Email Requests**

If you would like to receive this newsletter or other information from the National Multiple Sclerosis Society via email, please submit your email address to chapter@njb.nmss.org
SELF-HELP Groups at your service

BERGEN COUNTY
BERGENFIELD — This “COPE” group meets at 11:00am on the last Thursday of the month at Cornell Surgical Supply. Contact Joan at 201 837-7790.

PARAMUS — This “TM” group meets at 7:00pm on the first and third Mondays of the month at the Trinity Presbyterian Church, 650 Pascack Road. Contact Joe at 201 797-3386.

TEANECK — This “Friends” group meets at 7:00pm on the first Thursday of each month at the Gimbel Center at Holy Name Hospital, 718 Teaneck Road. Contact Sister Mary Morris. Call the Chapter at 201 967-5599.

ESSEX COUNTY
LIVINGSTON — Meets at 7:00pm on the second Monday of the month at the Senior Community Center. Contact Marlene at 973 992-5313.

NEWARK — Meets at 11:30am on the third Thursday of the month at the University of Medicine and Dentistry (UMDNJ). Must RSVP. Contact Linda at 973 923-6912.

NUTLEY — This support group meets at 7:00pm on the third Thursday of the month at the Vincent United Methodist Church. Contact Gary at 973 667-5209.

HUDSON COUNTY
BAYONNE — Meets at 1:00pm on the fourth Monday of the month at the Jewish Community Center, Kennedy Boulevard and 44th Street. Contact Helen at 201 858-3999.

JERSEY CITY — Meets at 7:30pm on the first Wednesday of the month at the Franciscan Home and Rehabilitation Center. Contact Christine at 201 332-3417.

MORRIS COUNTY
MONTVILLE — Meets at 10:00am on the second Thursday of the month at the Montville Youth Center on Changebridge Road. Contact Bea at 973 263-2855 or Rosanne at 973 334-8434.

MORRIS COUNTY CONT’.
MORRISTOWN — Meets at 7:00pm on the first Tuesday of the month at the Presbyterian Parish House, 65 South Street. Contact Anita at 973 503-1141.

MORRISTOWN — This “But You Look So Good” group meets at 7:00pm on the second Tuesday of the month at the Presbyterian Parish House, 65 South Street. Contact Mary Ellen at 973 299-1778.

PASSAIC COUNTY
WAYNE — This “OUT” group meets at 7:00pm on the third Monday of the month at Packanack Lake Church. Contact Michael at 973 628-8991.

WEST MILFORD — This “Squeaky Wheels” group meets at 12:00pm on the fourth Wednesday of the month at the Hillcrest Center on Macopin Road. Contact Janice at 973 728-1282.

SUSSEX COUNTY
SUSSEX COUNTY — Meets at 12:00pm on the third Tuesday of the month at the the George Inn, Vernon, also 7:00pm on the first Wednesday of the month at the Lafayette House, Lafayette. Contact Dawn at 973 875-3461.

UNION COUNTY
CLARK — This “But You Look So Good” group meets at 7:00pm on the first Tuesday of the month at the Clark Municipal Building, 430 Westfield Avenue. Contact Julia at 908 298-9782, or Beth at 732 388-9407.

WARREN COUNTY
WARREN COUNTY — Meets at 7:30pm on the second Monday evening of the month at the Hackettstown Hospital. Contact Cynthia at 973 786-5382 or Helen at 908 979-0984.

CHAPTER-WIDE
MS LEGS GAY/LESBIAN MS SUPPORT GROUP — Meets at 7:00pm on the second Thursday of the month at the Vincent United Methodist Church in Nutley. Contact Michele at 973 672-1855.

SINGLES WITH MS — This group meets at 1:00pm on various Sundays at Charlie Brown’s Restaurant in Denville. Contact Marcia at 973 625-8981.

*In case of inclement weather, please call your leader for status of meeting.

To learn more about Self-Help Groups, contact Pat Evertz at 1-800-FIGHT-MS or send e-mail to: pat@njb.nmss.org.

The information presented at Self-Help Groups does not necessarily reflect the views or official position of the Society nor carry the endorsement or support of the NMSS. For specific medical advice, contact your physician.

DON’T FORGET!

KNOWLEDGE IS POWER PROGRAM
Free at-home educational series.
Call Pat at 1-800-FIGHT MS
**PROGRAMS**

**FAMILY FUN AT THE CIRCUS!**
The Salaam Shrine Circus has graciously donated tickets for people with MS and their families to attend a fun-filled evening at the circus on Thursday, May 5, 2005, at 6:30 pm at the Mennen Sports Arena in Morristown, NJ. However, transportation is NOT provided. Please place your request for tickets by April 21st. At that time a lottery drawing will take place. If your name is drawn, you will be contacted, then tickets will be mailed to you along with directions. To enter, call Jennifer Healy at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 203, or e-mail jhealy@njb.nmss.org.

**MARDI GRAS IS BACK IN 2005!**
We are pleased to announce that we will once again be holding a Mardi Gras Festival. Join Chapter members, the MS Society staff, and family for great music and New Orleans-style food on Saturday, February 26, 2005, from 5:00 pm to 8:00 pm, at the Vincent United Methodist Church in Nutley. Space is limited and registration is required. To register, please call Jennifer Healy at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 203, or e-mail jhealy@njb.nmss.org.

**COUPLES & MS**
People often say that their relationships suffer as a result of multiple sclerosis. On Monday, April 11, 2005, from 7:00 pm to 9:00 pm, Dr. Fred Foley will present a talk on the unpredictability of MS. He will discuss the invisible symptoms, how emotional and cognitive issues can affect a couple’s relationship, and examine ways to counter these effects. The presentation will take place at the Richard Rodda Community Center in Teaneck, New Jersey. Dr. Frederick Foley received his Ph.D. in Clinical Psychology from Fordham University in 1986. He is the Director of Psychosocial Research at the Bernard Gimbel MS Center at Holy Name Hospital in Teaneck, New Jersey.

To register, call Jennifer Healy at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 203, or e-mail jhealy@njb.nmss.org.

**NAEC: THE PATH BACK FROM AN MS ATTACK**
On March 1, 2005, from 7:00 pm to 9:00 pm, Ms. Nancy Brewster, PT, will be presenting materials from the North American Educational Conference. The theme this year is “The Path Back from an MS Attack,” focusing on rehabilitation, research and maximizing quality of life during and after an exacerbation. The meeting will be held at the Presbyterian Parish House in Morristown, NJ. Ms. Brewster is a Physical Therapist who practices in New Jersey. She also is an active member of the Chapter’s Professional Advisory Committee. To register, please call Jennifer Healy at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 203, or e-mail jhealy@njb.nmss.org.

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**SWIM-IN PROGRAM**
September–May, Wednesdays, 1:00-3:00 pm
JCC on the Palisades, 411 East Clinton Avenue, Tenafly, NJ
The Chapter helps to support Swim-In, which is an aquatics exercise program for people with MS. Volunteers are needed to provide assistance by walking in the water with swimmers, assisting with recreational swimming movements, and assisting with entrance and exit of the pool. Training will be provided. Volunteers must be at least 18 years of age and do not need to know how to swim. For more information, please call Patti Pasquino 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 206, or e-mail patti@njb.nmss.org.
2005 CAMPSERSHIP PROGRAM

The Chapter has applied for grant funding to sponsor a Campership Program to assist Chapter clients in sending their children and/or themselves to camp. Assuming that the Chapter is the recipient of such funding, financial assistance will be available for qualified individuals. For more information and an application, call Patti Pasquino at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 206, or e-mail patti@njb.nmss.org. To qualify for consideration, all completed applications must be received at the office by Friday, June 3, 2005.

“LESS COMMONLY KNOWN MS THERAPIES”

On May 25, Dr. Joseph Herbert will speak about less commonly known therapies for people with MS. The event will take place from 7:00 pm to 9:00 pm at Saint Barnabas Ambulatory Care Center in Livingston, NJ. Call Jennifer Healy at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 203, or e-mail jhealy@njb.nmss.org.

ADULT GETAWAY WEEKEND

Join other adults for a weekend of support, renewal and fun! The Society is pleased to extend an invitation to its members who are single and couples (21+) who would like to join other members for a wonderful weekend in the Poconos. We are planning to relax and enjoy all the comforts and recreational opportunities of the resort as well as spend time together sharing ideas and concerns through the facilitation of professional staff. Informal and formal time has been scheduled to explore and educate. The weekend begins on Friday, April 1, 2005, and concludes on Sunday morning, April 3, 2005. Please call Pat Evertz at 1-800-FIGHT MS (1-800-344-4867) or 201 967-5599, or e-mail pat.evertz@njb.nmss.org to request a registration form.

A UNIQUE OPPORTUNITY – BECOME A PART OF THE MONDAY AFTERNOON CONFERENCE CALL!

The Chapter, in conjunction with Hackensack Medical Center, provides a weekly conference call for individuals with multiple sclerosis who are confined to their homes. According to Pat Evertz, Manager, Client Programs Department, “Conversations are supportive and social. The calls lessen feelings of isolation and offer an exchange of ideas and concerns among people with MS who cannot attend support groups in the community.” If you would like to join this call, please call Pat Evertz at 1-800-FIGHT MS (1-800-344-4867) or 201 967-5599, or e-mail pat.evertz@njb.nmss.org.

MS LEARN ONLINE

The National MS Society has an exciting menu of MS Learn Online webcasts currently available on its website (www.nationalmssociety.org/mslearnonline). Each webcast features experts presenting on various topics relevant to people affected by multiple sclerosis. MS Learn Online webcasts are usually 10 minutes in length, and educate people about MS from the convenience of their own computers. Program topics cover: the Basic Facts of MS, Symptom Management, Progressive MS, Research, Healthy Living and Family Life, Life Planning and Independence, and En Español. In addition to the existing menu of programs, new webcasts debut the first and third Thursday of each month throughout the year. The upcoming months topics are:

Series Three: Medicare
March 3 - Home Therapy Services
March 17 - Addressing Your Concerns on Medicare
April 7 - Ask the Expert

Series Four: The Path Back from an MS Attack
April 21 - Relapse Management and the Role of Rehabilitation
May 5 - Benefits of a Rehabilitation Program

Series Five: Getting a Grip on Exacerbations
May 19 - Is it an MS Attack - or Not?

To access programs and written transcripts, please log on to: www.nationalmssociety.org/mslearnonline

Continued on p. 7
WELLNESS PROGRAMS

Generously sponsored by Berlex

It is the Chapter’s pleasure to announce 16 weeks of wellness programs taking place this spring and summer for people with MS. There is one program available in each of the eight counties we serve. Classes start at the end of March. Please look for dates, times, and locations in the upcoming program calendar mailing and on our Chapter website (www.njbnmss.org).

Below are descriptions of the programs offered. Tai Chi classes will be held in Bergen, Morris, Passaic, Sussex and Warren counties; Yoga in Hudson and Union counties; and Aquatics in Essex County. The Tai Chi and Yoga classes are instructed so that individuals may perform the movements in either seated or standing positions. Participants may bring a companion or aide to any of the classes for assistance. There is a $30 fee for 16 weeks of classes.

Aquatics – Water prevents overheating and its natural buoyancy gives support, making movement easier and enhancing endurance. Aquatic exercise lets people with MS move in a way that their disability might not otherwise allow.

Tai Chi – An ancient Chinese system of movement, Tai Chi’s primary goals are balance and integration of the whole person: all bodily functions including the mind and the spirit. Because the movements of Tai Chi are soft and gentle, it is one of the few forms of exercise that anyone, regardless of physical ability or age, can do safely. The mind and body are calmed and strengthened by the regulation of breathing and slow, deliberate movements.

Yoga – A gentle form of exercise designed to relax the mind and body. Yoga combines breathing techniques with postures to improve physical and mental well-being. Meditation techniques used at the end of each session will help to release tension and calm the mind. Feel free to contact Patti Pasquino with any questions at 1-800-FIGHT MS (1-800-344-4867) or 201 967-5599, ext. 206.

KEEP S’MYELIN

Keep S’Myelin, a newsletter for children about MS, is available through chapters as well as on the National MS Society’s website. Designed for children 5-12 years old, who have a parent or loved one with multiple sclerosis, Keep S’Myelin includes regular articles about different aspects of MS, puzzles and games, photos, book reviews, tips, and more.

“MANAGING PROGRESSIVE MS”

We are pleased to announce the availability of a new booklet, “Managing Progressive MS.” It provides an overview of symptom management and coping strategies when progressive MS makes the road rougher. Please call Jennifer Healy at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 203, or e-mail jhealy@njbnmss.org if you would like to receive a copy of this booklet.

EARLY MEDICARE COVERAGE FOR MS Rx STILL AVAILABLE

About 5,000 people with MS are taking advantage of the nationwide Medicare demonstration project covering certain therapies for patients who have multiple sclerosis, cancer, rheumatoid arthritis and pulmonary hypertension. Funding is still available for people with MS – in fact, more than half of the 50,000 slots are still available! Applications will be accepted until the patient slots or funds for this project run out. For additional information please visit: http://www.nationalmssociety.org/medicare_demo.asp. Interested individuals may also call the National Organization for Rare Disorders (NORD) for help with the application process and financial assistance at 1-800-634-7207 or Trailblazer Health Enterprises at 1-866-563-5386, TTY Number: 1-866-563-5387.

Visit our Website at: njbnmss.org
The National MS Society launched a new initiative to speed research on nervous system repair and protection in MS. The Society has invited proposals from research teams to compete for grants of up to $5.5 million each to pave the way for clinical testing of therapies to restore function in people with MS.

The U.S. FDA approved Tysabri® (natalizumab, Biogen Idec and Elan Corporation) to reduce the frequency of clinical relapses in relapsing forms of MS. Tysabri (formerly Antegren) is a monoclonal antibody given by monthly infusion into a vein. Results from the first year of ongoing clinical trials showed that Tysabri reduced the relapse rate up to 66%, reduced the development of new MRI-detected lesions, and showed other benefits. This approach was first explored in laboratory animal research in part with funds provided by the National MS Society to Stanford investigators.

A Harvard-led study, supported in part by the National MS Society, involving 187,563 women enrolled in the Nurses’ Health Study, suggested that those with higher intake of vitamin D (in multivitamin supplements) may have had a reduced risk of developing MS. The study did not determine whether vitamin D affects the course of MS once it has begun. Further research is necessary to clarify these findings.

A paper published from the Society-supported Sonya Slifka Longitudinal MS Study, following over 2,000 individuals with MS over a long period of time, reported on the first-ever national study of aging and MS. Results pointed to challenges facing persons who are aging with MS. For example, older participants tended to be more severely disabled, more likely to need help with daily activities, and less likely to have used MS disease-modifying therapies. Despite their disability and care needs, many viewed their health status and quality of life positively. Over time, this study will allow investigators to tease out factors in individuals’ lives that may influence disease course and quality of life.

Researchers from Australia, supported in part by the National MS Society, found evidence in brain samples suggesting that the primary pathology in some people with MS involves a killing-off of myelin-making cells with little or no evidence of immune attack. If confirmed, these findings raise intriguing questions about the MS disease process and how it begins, about how and when the immune attack becomes involved, and about the potential for different forms and different underlying brain-damage categories for MS.

Results from a study of the oral immune-modulating drug laquinimod indicated that in 209 persons with relapsing forms of MS, the drug was well tolerated. Those on a higher dose had significantly fewer new active MS brain lesions during 24 weeks of testing. Larger studies, needed to explore the drug’s potential in MS, are beginning now.

Four new Collaborative MS Research Centers were established by the National MS Society to speed the search for the cause and cure of MS by teaming up investigators from diverse fields focusing on promising avenues of research. Each is focusing on the exciting area of nerve tissue repair. These awards add $3.3 million to the Society’s long-term research commitments.

An international team of investigators from Australia and the U.S., partially funded by the National MS Society, successfully reduced the severity and duration of MS-like disease in mice by vaccinating them with "Nogo,” a protein normally found in the brain that is known to inhibit nerve regeneration. They determined that the vaccinations caused the mice’s immune systems to produce their own antibodies that neutralized Nogo’s inhibitory activity in the nervous system.

Avanir Pharmaceuticals announced positive results from a Phase III clinical trial evaluating the oral drug Neurodex™ for treating the symptom of "pseudobulbar affect,” a condition involving uncontrolled laughing and/or crying affecting a small proportion of persons with MS and some other neurological disorders. The company announced intentions to apply to the FDA for approval to market the drug for pseudobulbar affect.

Acorda Therapeutics announced preliminary results of a Phase II clinical trial of Fampridine-SR, an oral, sustained-release formula of 4-aminopyridine, to treat MS symptoms. According to the company, the drug showed a trend toward improved walking speed and significantly improved leg muscle strength. Fampridine-SR blocks tiny pores on the surface of nerve fibers, to improve nerve impulse conduction. The first studies of this ion channel-blocking approach in people with MS were supported by the National MS Society.

These and other leaps forward have made 2004 a momentous year in the fight against MS.

— Research Programs Department
MEMORY AND MULTIPLE SCLEROSIS

If you:
• are diagnosed with multiple sclerosis
• are between the ages of 30-59
• are experiencing significant memory problems
• have no other neurological illness

**You CAN receive $300**

For your participation in a new study examining the effect of a memory-retraining technique for individuals with multiple sclerosis.

What does it require?
• eight months of participation
• completing some paper-and-pencil memory tests and questionnaires at three different times within the eight-month time span
  ■ Week one: 1-3 hour visit to Kessler Medical Rehabilitation Research and Education Corp. in West Orange, NJ
  ■ Weeks 2-6: two 1-hour sessions per week at Kessler in West Orange, during which time you will either undergo an experimental treatment for memory problems or participate in memory exercises
  ■ Week 7: 1-3 hour visit to Kessler
  ■ Months 3-7: depending on what group you are assigned to, either (1) nothing or (2) one 1-hour session per month at Kessler
  ■ Month 8: 1-3 hour visit to Kessler

Confidentiality is guaranteed. For more information, please contact:
Nancy B. Moore, M.A.
Kessler Medical Rehabilitation Research & Education Corp.
(973) 330-3660

2005 RESEARCH SYMPOSIUM

Together with the MS Society’s Southern New York Chapter, the Greater North Jersey Chapter will hold its 2005 Research Symposium on Saturday, March 5, 2005, from 1:00 pm – 4:00 pm at the Sheraton Crossroads Hotel in Mahwah, New Jersey. Speakers are Nicholas G. LaRocca, PhD. and Dr. Jeffrey Greenstein.

Dr. LaRocca will speak about recent findings from the Sonya Silfka Longitudinal Multiple Sclerosis Study. In conjunction with the Promise 2010 Campaign, this study is designed to answer dozens of important questions about the day-to-day impact of multiple sclerosis. MS Society medical experts determine that the data captured in the study will provide promising information for future program, advocacy and research efforts.

Dr. Larocca is the Director of Health Care Delivery and Policy Research for the National MS Society.

Dr. Greenstein will speak about Monoclonal Antibodies as an effective form of treatment for MS. Research has demonstrated that monoclonal antibodies directed against specific t-lymphocytes can regulate activity of these cells. Dr. Greenstein is the Director of the Multiple Sclerosis Institute at Graduate Hospital in Philadelphia, Pennsylvania.

To register, call Joy Robinson at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, ext. 215, or e-mail joy.robinson@njbmnss.org.

FDA APPROVES TYSABRI® (NATALIZUMAB, FORMERLY KNOWN AS ANTEGREN) FOR RELAPSING FORMS OF MS

(Excerpted from the Research Programs and Clinical Programs Department statement. For a complete statement, please contact the Chapter Programs Department at 1-800-FIGHT MS)

After one year of an ongoing clinical trial, the FDA has approved Tysabri® (Natalizumab, formerly known as Antegren) to reduce the frequency of clinical relapses in relapsing forms of MS, creating another new treatment option for those with this disease.

The approval was based on results from the first year of two ongoing clinical trials of the drug alone or added to Avonex®. According to the FDA, as part of this approval, the manufacturer has made a commitment to continue the trials of Tysabri for another year.

Tysabri reduced the rate of clinical relapses by up to 66% and reduced the development of new or newly enlarging MRI-detected brain lesions. Tysabri appears to be safe and well tolerated. The most common side effects included headache, fatigue, urinary tract infection, depression, lower respiratory tract infection, joint pain, and abdominal discomfort. There is no information available about long-term safety.

The drug is given by intravenous (into the vein) infusions every 4 weeks in a doctor's office. It is designed to interfere with movement of potentially damaging immune cells from the bloodstream, across the “blood-brain barrier,” and into the brain and spinal cord. Tysabri blocks this movement by attaching to alpha 4-integrin, a protein on the surface of immune T cells that normally enables them to pass through the blood-brain barrier.

For more information about Tysabri, individuals with MS are encouraged to consult their neurologists. In addition, Biogen Idec and Elan Corporation have established a toll-free number that individuals can call for further information: 1-800-456-2255.

The National MS Society is proud to be a source of information about MS. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.
FROM THE ADVOCATE’S DESK:
Parting Is Such Sweet Sorrow
For the last two and a half years, it has been a distinct honor to be part of the Greater North Jersey Chapter of the National MS Society. In this capacity, I have had the pleasure of working with staff, volunteers, chapter members and the larger New Jersey disability community to fight for the rights of people with disabilities in our state. And though advocacy is a difficult road to travel, and successes often take years to realize, I am proud to say that together with your help we certainly did achieve some goals. And rest assured that many of the issues we have fought to improve—in areas such as transportation, accessibility, community services and parking—will live on with the help of the Government Relations Committee and with each of you as individual advocates.

When the Chapter began to fight for the rights of people with disabilities through advocacy, they made a commitment to raising their voice here in our eight counties and throughout the state. And their commitment will continue with the appointment of a new advocacy liaison, Stephanie Hunsinger. On January 1st, Stephanie assumed the advocate’s role and is now there working with the members of the Government Relations Committee and with each of you to improve the lives of people with disabilities living in our communities. I encourage you to get to know her if you do not already and tell her any issues you may have that require an advocate’s attention.

In closing, I would like to say thank you for allowing me into your lives, and for sharing with me the issues that are most important to you. I hope that together we were able to make improvements and I hope you continue to voice your concern in the areas that still need work. Always remember – only the squeaky wheel gets the grease – and that well-known adage is never more true than in advocacy.

Best Wishes,
Autumn Strier

GETTING INVOLVED:
ADVOCACY PROGRAMS & COMMITTEES
Action Alert: Action Alert is the grassroots program of the MS Society and is used as a tactic to address priority advocacy issues. Team members can voice their position on an Action Alert issue in a variety of ways, including: writing letters, e-mailing, calling or visiting elected officials or executive agency staff.

Government Relations Committee: The Government Relations Committee focuses its efforts on monitoring and influencing public policy at the State and local levels. The all-volunteer committee consists of people with MS, community leaders, politicians and others, all with an active interest in achieving change within their communities.

P.A.V.E: Through the Chapter's new Project Access: Visibility & Education (P.A.V.E.) Program, clients and volunteers will be able to work in the community to encourage establishments to be accessible and sensitive to all persons with disabilities. This is accomplished in a non-confrontational approach designed to educate the business community about accessibility.

For more information, or to volunteer, please contact the Chapter office at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599.

ACROSS THE NATION: ADVOCACY SUCCESSES IN 2004
ACCESSIBILITY: EXECUTIVE BRANCH REPRESENTATION
The New Jersey CAN (Chapter Advocacy Network), Maryland and National Capital Chapter, and Northwestern Ohio Chapter supported legislation establishing a Maryland State Department of Disabilities headed by a new cabinet-level Secretary of Disability Services.

DISABILITY RIGHTS: REMOVING BARRIERS
In advocating for disability rights, chapters hope to remove barriers that prevent people with MS from leading full lives and participating in community activities. Chapters often become aware of the need for advocacy in this area from clients reporting difficulties they face or from chapter staff encountering problems when planning chapter events. Accessible housing and transportation, Medicaid buy-in programs, and accessibility to public places and private businesses are just some of the issues chapters supported this year. Disability rights advocates also focused on voting rights in 2004. In addition to get-out-the-vote efforts, chapters tackled 46 statewide disability issues with 18 successes and 30 local disability rights issues with 10 successes.

To read more about chapter advocacy successes during 2004, log on to www.nmss.org/advocacy.asp.

Save the Date:
The National MS Society’s Family Weekend at Pocmont Resort is back! The weekend is scheduled to take place June 3rd-June 5th. More details will follow.
ANNUAL MS WALK
Sunday, April 17, 2005

The Greater North Jersey Chapter will host the 17th annual MS Walk on Sunday, April 17, 2005, in seven locations throughout the chapter area. These locations include Cranford, Jersey City, Mt. Olive, Parsippany, Ridgewood, Ringwood and Roseland. All routes are approximately five miles and are accessible or offer accessible route options. Check-in at all locations will begin at 9:00 am and the walks will begin at 10:00 am. There will be live entertainment and fun festivities at the finish lines.

Last year, over 4,000 people participated in the last MS Walk and raised $1,100,000 toward our mission to end the devastating effects of MS. Participants included individual walkers, friends and family teams, corporate teams, and teams formed through organizations. In addition, 250 people volunteered their time to the event.

To learn more about participating or volunteering for the MS Walk, please call Jennifer Parisi at 201 967-5599 x222.

SPONSORSHIP OPPORTUNITIES AVAILABLE

You can get involved in the Annual MS Walk by becoming a sponsor. Different levels of sponsorship include: a Checkpoint Sponsor for $500, a Start or Finish Line Sponsor for $1,000, a Site Sponsor for $2,500, a Major Sponsor for $5,000, a Presenting Sponsor for $10,000, or become a Title Sponsor for $25,000. Based on level, your sponsorship may include a banner at the walk site, your logo on route cards and newsletters, name recognition in day of announcements, and opportunities for product sampling.

For details, please contact Jennifer Parisi at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, or via e-mail jennifer.parisi@njb.nmss.org.

DINNER OF CHAMPIONS
Thursday, March 31, 2005

The Chapter’s Dinner of Champions fundraiser will be held on Thursday, March 31, at the Hanover Marriot in Whippany, NJ.

The black-tie optional gala will include a silent auction and orchestral entertainment. Honorees include Anthony R. Coscia of Windels Marx Lane & Mittendorf, LLP, and Chairman of the Port Authority of New York and New Jersey, New York Giants player Michael Strahan and “2005 MS Champion,” Ronni Lieberman.

The cost to attend Dinner of Champions is $300 per ticket. Sponsorship opportunities are also available. All proceeds will support local programs and services of the National Multiple Sclerosis Society Greater North Jersey Chapter and the national research effort to find the cause and a cure for MS. For more information, please contact Stephanie Karlo at 1-800-FIGHT-MS (1-800-344-4867) or 201 967-5599, or e-mail stephanie@njb.nmss.org.
SPREAD THE WORD ABOUT NEW WAYS TO FIGHT MS!

Thanks to significant advances 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 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 at 1-800-FIGHT-MS (1-800-344-4867) or log onto www.nationalmssociety.org. To contact the Greater North Jersey Chapter directly, please call 201 967-5599 or visit www.nationalmssociety.org/NJB.

CLASSIFIEDS

Rascal 245 Scooter. Needs batteries, aluminum ramp for van, Rack & Roll for trailer hitch and trunk mount lift for sedan. All for $1250. Call Annie at 201 438-5133.


Custom-made Pronto Electric Wheelchair with double motor and double battery. Excellent condition. Also includes manual ramp. Asking $1500. Call Anna at 973 726-6144 or 973 534-2840.

Free Elevator. Call Amparo at 201 641-0135.
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