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# msconnection

Southern New York Chapter

## Women Against MS Luncheon Standing Room Only

**T**he Chapter's first annual *Women Against MS (WAMS)* Luncheon - with actress Teri Garr entertaining a packed house of 350 guests - was held June 20<sup>th</sup>, 2006 at the Doral Arrowwood in Rye Brook, and raised over \$60,000 for MS research and local services. Ms. Garr opened by saying, "I'm proud to be a member of a group that is focusing on MS research and the care of MS patients. And yes, I might have a touch of it [MS] myself." She added with a grin, "I like to say it that way; it keeps out the riff raff."

WAMS is a national program with a specific aim: "To raise awareness of multiple scler-

osis and the work of the Society in bringing hope and help to people with MS, the majority of whom are women". Nancy Holland, National MS Society Vice President of Clinical Programs, provided an overview of the National Strategic Response Plan.

"In initiating the first WAMS luncheon in Westchester County, we wanted to raise awareness of the disease in this region and create a spirit of philanthropy in women" said Committee Chair, Tobi Rogowsky. Ms. Rogowsky was ably assisted by her fellow committee members: Rita Bangser, Lisa Brettschneider, Barbara Essick,

Mary Foster, Andrea Glenn, Camille Failla Murphy, Susan Pouch, Jane Silverstein, Marjorie Shapiro, Leslie Synder, Susan



*Actress Teri Garr with Rayna and Tobi Rogowsky*

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## President's Letter

In case you have missed it in recent publications, the Board of Directors of the National MS Society in June of this year approved a five year plan with a number of bold initiatives that all local Chapters are taking as a renewed call to action. The Southern New York Chapter is no exception.

The essential components of this plan state that the Society will:

- Be a driving force for MS research for prevention, treatment and a cure.
- Address the challenges of every person whose life is affected by MS.
- Mobilize the talents and resources of the millions of people who want to do something about MS
- Be activists.
- Double income by the end of 2010.

They are all pretty bold statements. Especially that last one. But that is what we need to do. We want to double our income, but we also want it to go to the real root cause: preventing, treating and curing multiple sclerosis.

In my first President's letter in the previous issue of *MS Connections*, I told you about some of the results from our Client Survey. Based upon what you told us, in the coming year we will be putting a lot more emphasis on direct care services, including the Adult Day program, financial assistance for those who need it, home health care, individual counseling and advocacy.

*continued on page 3*

## TYSABRI AVAILABLE AGAIN

Tysabri (natalizumab)—the latest disease-modifying drug for controlling MS—returned to market this summer following its second approval by the FDA. Biogen Idec and Elan Pharmaceuticals anticipate some delays over the next few weeks while infusion professionals receive special training and new infusion sites are set up.

The drug, given monthly by IV, is only available to patients and physicians who have registered in the TOUCH prescribing program at authorized infusion sites where medical personnel have been trained to minimize the risk of PML. PML (progressive multifocal leukoencephalopathy) is a brain disease that occurred in three people who had been in Tysabri clinical trials. Two of them died.

Under new FDA guidelines, Tysabri is generally recommended for people who are unable to tolerate or have had a poor response to the other approved disease-

modifying MS therapies. It is not to be combined with the chronic use of any other immune-modifying agents and it is not recommended for anyone with a weakened immune system.

Complete information, including frequently asked questions, is available on our national Web site at [nationalmssociety.org/tysabri.asp](http://nationalmssociety.org/tysabri.asp), or by calling us, or Biogen Idec (1-800-456-2255).

## EXPERTS ONLINE

The Rocky Mountain MS Center has an online Forum where anyone with a computer can get answers to questions from MS professionals as well as tap into the collective wisdom of experts—people who live with MS.

To participate, register at [www.mscenter.org/forum](http://www.mscenter.org/forum). The Forum is moderated by the professional staff of the Center who will do their best to answer all questions.

## ■ President's Letter

— *continued from page 2*

We are a Chapter that is blessed with a great group of volunteers at our events and in our programs. And each day we receive offers from people who want to do more. Some great ideas come from those who raise money through what we call “third-party” events. They come with ideas we would never have thought of ourselves, but they are among the millions of people who want to do something about MS. There is more on these “third-party” events elsewhere in this issue.

In a recent video from the National MS

Society, I am haunted by the words of a woman who was obviously interviewed while participating in a part of an MS Walk. I have no idea where she was, or who she was, but that does not matter. What I remember is what she said and the way she said it. She walked slowly and with obvious effort, away from the camera, but looking back to say “I just want answers...that’s all I want...no one yet has the answers”.

We all want her to have those answers.

## DEATH OF SENATE BILL 1955

When Society activists converged on Washington last spring they hoped to stop S. 1955, the Health Insurance Marketplace Modernization and Affordability Act of 2005.

Despite the appeal of words like modernize, affordability, and marketplace, our policy analysts quickly saw the pitfalls for people with MS. The bill would have allowed small businesses to opt for inadequate health coverage and it would have required them to pay higher insurance rates for their employees with chronic health problems. The MS community was deeply concerned about the impact this would have on getting or keeping a job with a small firm.

MS activists visited 80 senators and made their concerns known. So did members of the Society's Action Network, who along with other advocacy groups, flooded Senate offices with calls and emails. On May 11th the Senate failed to invoke cloture on S. 1955 (meaning a motion to bring the bill to a vote). The maneuver means the bill is dead.

An alternative bill, S. 2510, has been introduced that may make insurance more affordable for small business without jeopardizing state health care protections. To keep abreast of federal insurance legislation and more, join the MS Action



Joshua Roberts

*MS activists at work during the 2006 Public Policy Conference.*

Network. Go to [nationalmssociety.org/ActionNetwork](http://nationalmssociety.org/ActionNetwork). Or call us.

## MILESTONES IN MS CARE: 20, 9, AND 6 YEARS OF SERVICE

MS professional organizations are flourishing—with success that brings benefits to everyone contending with this disease.

**20 YEARS:** The Consortium of MS Centers, or CMSC, pioneered the concept that people with MS need medical care plus rehabilitation, psychological, and social supports by a team of specialists. Today, CMSC connects 4,000 MS professionals in the U.S., Canada, and Europe.

Go to [www.ms-care.com](http://www.ms-care.com) for an alphabetical list of the U.S. comprehensive MS care centers that are CMSC members.

**9 YEARS:** International Organization of MS Nurses, or IOMSN, was formed to share the knowledge nurses need to best care for people with MS. It encourages nurse-led research and offers certification examinations. In just 9 years, IOMSN has certified 11,000 MS nurses in 29 countries.

If you see a nurse name tag with “MSCN” on it, you have met an MS specialist. Visit [www.iomsn.org](http://www.iomsn.org).

**6 YEARS:** Latin Americas' Committee for Treatment and Research in Multiple Sclerosis, or LACTRIMS, includes 500 professionals in 17 North, Central, and South American countries. Once considered rare among people of Hispanic backgrounds, MS is now reported at rates matching the U.S. in areas where MRI is readily available.

LACTRIMS helps establish clinical care centers, stimulates research, and promotes the best MS treatment. Go to [www.lactrims.org](http://www.lactrims.org) for more information.

## Positive Results Reported For Oral Teriflunomide For Relapsing MS

**A**n experimental oral drug being tested for multiple sclerosis, called teriflunomide (Sanofi-Aventis), significantly reduced MRI-detected disease activity in a 36-week, Phase II clinical trial involving 179 people with relapsing MS. Teriflunomide is an agent that may modulate T cells, which drive the immune attack in MS. Paul O'Connor, MD (University of Toronto) and colleagues originally reported these results at the 2004 Congress of the European Committee for Treatment and Research in MS, and have now published the findings in *Neurology* (2006 Mar 28; 66(6):894-900).

Dr. O'Connor and his team recruited 157 people with relapsing-remitting MS (characterized by clearly defined flare-ups followed by partial or complete recovery periods), and 22 people with secondary-progressive MS (a secondary stage of the disease involving a steadily worsening course, occurring with or

without relapses) with relapses. Participants were randomly assigned to receive inactive placebo, or one of two doses (7 mg or 14 mg) of teriflunomide, once daily for 36 weeks. The primary objective of the study was to determine the effect of treatment on the average number of active areas of disease activity (lesions) observed on MRI scans taken every six weeks. Secondary objectives included the frequency of relapses, and any increase in disability as measured by the EDSS, a standard scale.

Both treatment doses were associated with reduced numbers of active lesions compared with placebo. Significantly fewer people in the group taking the higher dose showed an increase in the EDSS than those in the placebo group. The drug was well tolerated; adverse events included headache and upper respiratory tract infection, and were similar among all three groups.

*Information provided by the Society is based upon professional advice, published experience and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National Multiple Sclerosis Society recommends that all questions and information be discussed with a personal physician.*

*The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any product or service mentioned.*

## “STORY MEMORY TECHNIQUE” MAY IMPROVE MEMORY



Many studies have shown that learning something new is a key problem for many people with MS. A small, Society-funded study last year suggested that using a memory exercise called “story memory technique” significantly improved this ability in people with moderate to severe MS cognitive impairment. Nancy Chiaravalloti, PhD, and colleagues at Kessler Medical Rehabilitation Research and Education Corporation in West Orange, New Jersey,

published their results in the February 2005 issue of *Multiple Sclerosis*.

Story memory technique involves creating mental pictures and a context, or story, to help commit something to memory. The technique was so successful in last year’s study—88% of participants showed significant improvement—that Dr. Chiaravalloti’s team is now testing it in a clinical trial that will involve 200 people with MS-related learning and memory deficits.

The researchers expect to complete the trial in late 2009 and are currently seeking volunteers. For information, see [www.clinicaltrials.gov/ct/show/NCT00166283](http://www.clinicaltrials.gov/ct/show/NCT00166283).

## *Drug Trials: What do the names mean?*

**T**here are many MS therapies currently being studied in clinical trials. You’ve read about some of them, and you’ll be reading about many more in the future, as new drugs and treatment approaches are developed. The current FDA-approved therapies for MS were studied for decades before being released to market, and studies didn’t end with approval. Here’s a look at the process that every drug goes through, from laboratory to local pharmacy.

### “Early studies”; “basic research”

Before a drug can be tested in humans, scientists must have a solid rationale as to why it would be helpful. They must also be reasonably certain that the drug won’t cause more harm than good. Preliminary research under either name usually involves years of experiments in animals and cells mandated by FDA regulations.

MS drugs are often tested in lab animals with an MS-like disease called EAE (experimental allergic encephalo-myelitis). Only humans get MS, so researchers must use a “model” disease at this stage.

If the results are encouraging, they will be submitted to the FDA with a request for permission to begin testing in people.

### “Clinical trials,” aka testing in people

Clinical trials are normally done in three phases. They are defined by the FDA and each successive phase involves a larger number of people.

#### Phase I: Is it safe?

- Usually lasts several months
- Involves a small number of healthy vol-



## ***Drug Trials: What do the names mean? (continued)***

unteers or people with MS

- Determines how a drug is absorbed and metabolized by the human body, including any side effects
- “Open-label,” meaning that everyone knows what the volunteers are taking.

### **Phase II: How well does it work to treat the disease?**

- Lasts from several months to several years
- Involves larger numbers of participants with the disease
- Most are “randomized,” meaning one randomly chosen group receives the active drug, while a second “control” group gets either another treatment or an inactive look alike, or “placebo”
- Can be “double-blind,” meaning neither the researchers nor participants know who is taking what until the trial’s completion

### **Phase III: Does it work over time for many people?**

- Referred to as “pivotal” trials because, if successful, the next step is an application for FDA approval
- Lasts until all endpoints are met (often around two years)
- Involves several hundred to several thousand participants
- Often conducted by multiple teams at different sites around the country—or the world
- Provides more extensive understanding of the drug’s effectiveness and the range of possible side effects
- Typically randomized and double-blind, for the most persuasive data

### **Late Phase III/Phase IV: How does it perform out in the world?**

Just because the FDA has approved a new drug, the research isn’t over. Most of the FDA-approved MS therapies—Copaxone, Betaseron, Rebif, and Avonex—are still in “post-marketing” studies. Tysabri, which was approved for rerelease in June (see NEWS on page 3), will be closely studied for the next five years in some 5,000 people as part of an agreement between Tysabri’s sponsors, Biogen Idec and Elan Pharmaceuticals, Inc., and the FDA.

Generally, those studies fall into one of three categories:

- Comparisons with other available drugs
- Studies of long-term safety and effectiveness and impact on the quality of people’s lives
- Cost-effectiveness relative to other therapies

### **Clinical Trials in MS**

The National MS Society’s 2006 listing of clinical trials in MS features ongoing MS trials, trials being planned, and recently completed trials. This year’s list includes 141 studies in MS research, with everything from small, early-phase studies to later-stage trials involving hundreds and even thousands of people.

“Clinical Trials in MS” can be read on our Web site at [nationalmssociety.org/clinicaltrials](http://nationalmssociety.org/clinicaltrials), where it is available in two versions: a basic chart of agents under study, and an extended version with detailed scientific information and results. There is also a list, by state, of the clinical trials recruiting volunteers.

No Web access? Call us at 1-800-FIGHT-MS and request a copy.

## DYSTEL PRIZE WINNER

**P**rofessor William A. Sibley, MD, of the University of Arizona, Tucson, has been chosen to receive the National MS Society/American Academy of Neurology's 2006 John Dystel Prize for Multiple Sclerosis Research. Dr. Sibley was honored for clarifying the influence of infections in the occurrence of MS relapses and for the ramifications of these pivotal findings on MS treatments.

The Dystel Prize is funded through the Society's John Dystel Multiple Sclerosis Research Fund established by Oscar Dystel and his late wife Marion in honor of their son John who died in June 2003 from complications of MS.

Dr. Sibley earned his medical degree from Yale University, and completed his internship in medicine at University Hospital of Cleveland and a residency in neurology at Presbyterian Hospital in New York City. He also served as Captain in the U. S. Air Force in charge of the Neurological Section at FEAM-COM Hospital in Japan. He became a faculty member at Columbia University in 1955 and later joined the University of Arizona College of Medicine as Professor of Neurology.

Dr. Sibley's major contribution to MS research surrounds his efforts to clarify the influence of environmental factors



*William A. Sibley*

such as infections on MS relapses. He and colleagues published a study that was the first to suggest that viral infections, such as colds, could trigger relapses of MS.

Most individuals start with a relapsing-remitting course, in which they experience episodes of neurological disability and

then full or partial recovery. Dr. Sibley studied the influence of environmental factors, such as infections, trauma and stress, on MS relapses. In this study, trauma and stress were not found to be major risk factors. However, Dr. Sibley and his colleagues found for the first time, that during periods surrounding viral infections (two weeks before onset of infection until five weeks afterwards) annual relapse rates were almost three-fold greater than other times. This conclusion has been confirmed by a number of independent studies.

Dr. Sibley's seminal finding that infections were often triggers for MS attacks was one rationale for future trials of interferon beta in the treatment of MS. These studies were the basis for approving Betaseron® as the first drug to alter the underlying course of relapsing-remitting MS.

The National MS Society and the Academy are please to honor Dr. Sibley with the 2006 John Dystel Prize for Multiple Sclerosis Research.

## *The Armchair Activist—Keep it to the letter*

**M**ost people don't plan to be activists. But there are times when problems or issues shake our lives. We don't have to join a rally to make our opinions known. We can make a rallying cry from the comfort of home: Write a letter!

### **Some general guidelines for letters**

- Include your name and complete address. Legislators pay attention to constituents.
- First paragraph—state your purpose for writing. Name the legislation or issue.
- Next paragraph—state what you want your legislator to do, such as vote for or against a bill.
- Say why the issue is important to you. Give it a “hook”—tell your personal reasons in a few sentences. If you use some prewritten text from a form letter or petition, alter it a bit by adding personal comments.
- Last paragraph—thank the legislator for considering your letter and, if possible, for past efforts on issues important to you. Try posing a question so their office will follow-up with you. Say that you look forward to a reply.
- Keep it to one issue and make it short—don't go beyond one page.
- Stick to the facts. You are educating your reader. Never use the “BAT”—don't **beg**; don't **assume** knowledge you aren't sure of; and never **threaten**.

- Proofread before you send.



- Find contact information for legislators at [capwiz.com/nmss/dbq/officials](http://capwiz.com/nmss/dbq/officials). Or call your chapter.

### **Mail vs. e-mail**

Every letter has impact. But be aware that due to security issues, postal mail to legislators may be delayed. The quickest way to send a letter is by e-mail or fax if you can. Otherwise, mail your letter. Legislators will receive it.

### **Other things to do**

- Ask friends and family to write a letter. And ask them to join the **MS Action Network**. Responding to timely issues is easy. Go to [nationalmssociety.org/ActionNetwork](http://nationalmssociety.org/ActionNetwork). The more people who respond, the greater the impact on legislators.
- Write a letter to the editor. It's a widely read part of the newspaper.
- If you listen to talk radio, call in when an issue important to you is brought up.
- Make a phone call to your legislator, especially if time is a critical factor.
- **Vote on election day!** If you need transportation, call your political party.

**RETIREMENT  
PAYMENTS  
YOU CAN  
DEPEND ON**



With all the ups and downs in the financial markets, many of the Society's friends are turning to our gift annuity program.

A gift annuity is a contract between a donor and the Society wherein the donor transfers money or property to the Society in exchange for our promise to pay the donor fixed annual payments for life. It provides an ideal way for people to support the Society while making certain they have first provided for themselves.

**How it works**

Mr. and Mrs. Smith are both 75 years old. They donate \$50,000 to the Society in

exchange for a charitable gift annuity that pays them 6.3% percent (based on their combined ages) or \$3,150 every year for the rest of their lives. And even when one of them dies, the surviving spouse will continue to receive the same fixed payments for the rest of his or her life. Because the payments are backed by the full assets of the National MS Society, the Smiths can have confidence that their annuity checks will always be there for them. They also have confidence that their charitable donation supports the Society's mission to end MS.

You don't have to be married to obtain a gift annuity—single-life annuities pay a higher rate. Also, the older a donor is, the higher the payment rate. To learn more, call our Special Gift Office at 800-923-7727.



# Workplace Giving

Fight MS without leaving your desk



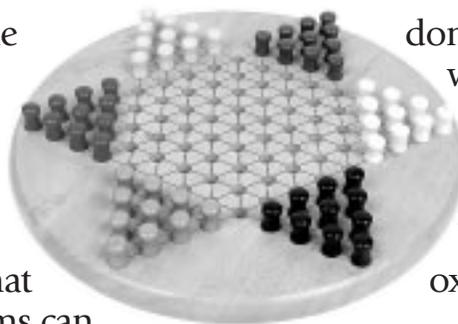
**Designate the National MS Society in the Combined Federal Campaign.**

**Or ask about designating the National MS Society in your company's workplace giving campaign.**

**CFC #0549**

## Mind Games: Make the best of your cognition

**T**he doorbell rings. The baby cries. The dog barks. You freeze. There's too much coming at you at once and you've lost—in this moment—that executive function: what to do next. Cognitive problems can sneak up on people with MS. There are many things that help: keep a notebook and pen on hand for your to-do list; use an electronic organizer or digital recorder; post a family calendar on the refrigerator. But what else?



dominant) hand. Button a shirt with your eyes closed, sitting down," Bednarik added. "And remember physical exercise helps too. The brain benefits from the increased oxygen that exercise brings."

### Keep the brain on its toes

"Anything that keeps your mind engaged and that's fun is beneficial," said Patricia Bednarik, a speech language pathologist at the University of Pittsburgh MS Center, which sees over 2,000 people with MS. "Puzzles and games of all kinds are wonderful for the brain and really help exercise concentration, organizing, planning, and memory skills," Bednarik said.

### While waiting . . .

Challenge yourself whenever you have to wait. Count backwards by 2, 3, or 5. Name states that start with "M." Carry puzzle books or crafts.

### Speaking of interactive

Solitaire is good but playing games with others is better. If there's a club for your hobby or favorite game, join it. "Interacting with other people has cognitive benefits," Bednarik said.

### Get physical

"Work the other side of your brain. Brush your teeth or hair with your other (non-

### Brain Games

#### On the Web

[www.gotofreegames.com](http://www.gotofreegames.com)

Offers games for sale—picture matching, card games, jigsaws, and more—and samples to play for free.

[www.cut-the-knot.org](http://www.cut-the-knot.org)

Has math games galore involving probability, illusions, fractals (if you play you'll find out what they are).

[www.puzzledpot.com](http://www.puzzledpot.com)

Has everything from traditional board games to animated cartoons. Some require good hand-eye coordination or may be hard to see, but sound effects and lively graphics make them fun.

[www.terrystickels.com](http://www.terrystickels.com)

Offers excellent brain stimulators from syndicated columnist Terry Stickels.

#### In the Books

Puzzle and game books are quieter and easier to carry. Moreover books can be used with magnifiers if MS is fuzzing one's vision.

To discover what's personally appealing, sample crosswords, Sudoku, word search, acrostics, mazes, and more. Puzzle books can be found everywhere from dollar stores to bookstores. [Amazon.com](http://Amazon.com) has a huge selection.

## Have you been diagnosed with “Progressive MS”?

by Sharon Brown

**M**aybe some words from a veteran like me will help. Let me skip to the “end of the story” first. About 15 percent of us are progressive from the start, as I was. Within two years of my diagnosis, I was using a scooter almost full-time, although I could and I can still walk. The scooter didn’t stop me from playing with my daughter, or helping to care for my mother. I have also dated, worked, and socialized.

The past 11 years have had highs, lows, tears, laughter, and change. For me, MS has not been a smooth, sight-seeing kind of train ride, but it hasn’t been an endlessly dark tunnel, either ...

Back when I was a full-time health writer I was often asked if I liked the idea of managed health care. My answer was, “Sure, as long as I do the managing.” I believe no one knows my body the way I do and no one can be my medical advocate better than me.

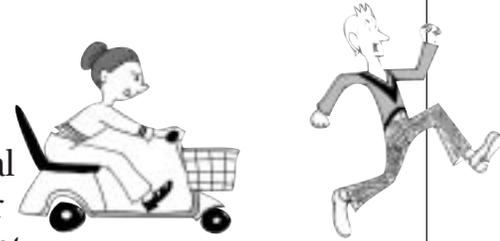
That doesn’t mean I do everything alone! Far from it. Having support is vital. Finding support sometimes takes a bit of work. I found I needed more than a good doctor and good friends. I’ve had a counselor of one type or another ever since I thought my bizarre symptoms meant I was going crazy. Unlike family members, I don’t have to worry that a counselor won’t be able to handle it. It’s a professional relationship ...

I wish I had learned sooner to keep track of my health as it changed. So, here’s a suggestion: Keep a journal in a bedside drawer and whenever something changes start a new page with the date at the top. Draw a stick figure and use circles or

arrows to indicate changes.

Take your journal with you to your next appointment.

Write down your questions, too, as you think of them.



Adapted from “So You Have Progressive MS” by Sharon Brown. Read it at [nationalmssociety.org/Brochures-Progressive.asp](http://nationalmssociety.org/Brochures-Progressive.asp) or call us for a copy.

### Progressive MS Resources on the Web

The National MS Society has devoted a comprehensive Web page to progressive MS at [nationalmssociety.org/ProgressiveMS](http://nationalmssociety.org/ProgressiveMS) with links to more than two dozen articles on prognosis, symptom management, treatments, current research, life planning, and resources.

If you cannot access the Web, call us and ask for our progressive MS materials.

**KNOWLEDGE**  
**Is Power**

**Knowledge Is Power** is a 6-week free, at home educational program for people who are newly diagnosed. Mail or e-mail formats. To register, call **1-800-FIGHT-MS (1-800-344-4867)**, or visit [www.nationalmssociety.org](http://www.nationalmssociety.org)

This is why we're here.

## Talkin' Teens — A Chat Room for Teens with MS

- Is open to teens ages 13-18
- Teens must register with MSWorld in order to participate in the chat room (see below for registration instructions)
- MSWorld is the official bulletin board and chat room site of the National Multiple Sclerosis Society
- The chat room will be open every Thursday at 7 pm ET
- The chat room will be moderated by an adult and a teen with MS
- The chat room is closed – participants will need to be pre-approved by the chat room moderator

### Registration information:

- Go to [www.msworld.org](http://www.msworld.org)
- Click on Chat and then Click on Register
- Complete the registration information and hit Submit
- Next go the MSWorld home page, scroll down to about midway on the page and click on Staff (left side)
- Then click on JoyceCOC – email Joyce your user ID (that was sent to you upon registration)

## CHAPTER NEWS

### *The Dystel Memorial Golf Classic For MS* Another Successful Year

**J**uly 31<sup>st</sup> marked the date of the re-scheduled 2006 Dystel Memorial Golf Classic for MS – now in its eighth year – at the scenic Metropolis Country Club in White Plains. The field was once again full with 140 golfers swinging their clubs for a cure, joined by an additional 30 guests for the sumptuous buffet dinner in the evening. This year's event was further enhanced by the attendance of several major donors and the participation of local professional musicians Shavonne Conroy, chanteuse; Robert Lindner, singer/pianist; Nicole Pasternak, jazz singer; and Robert Jacoby, orchestra leader/saxophonist, giving a little bit of a different spin to the usual club outing program.

Committee co-chair Joe Kasell said, "This is a fail-proof event, with our dedicated supporters coming out year after year to help fight MS. The Golf Committee feels that we have a well-oiled wheel that keeps spinning for the cause." Members of the Golf Committee, who truly made this event the great success it is are: Tobi Rogowsky, Ira Kotler and Joseph Kasell, co-chairs; and Stan Brettschneider, Michael Brooks, Dorothy Cooper, Jane Dystel, Oscar Dystel, Herbert Levine, Eliot Minsker, Steven Schwinder, Ben Wetchler and Harriet Whelan. These dedicated individuals recruit participants, secure in-kind and monetary donations and con-

*continued on page 14*

## ■ The Dystel memorial Golf Classic

— continued from page 13

tribute their expertise as it pertains to golf year-round. The 2006 Dystel Memorial Golf Classic raised \$114,000 for services and research.

Among the supporting companies and individuals participating at different sponsorship and signage levels were: the Amy and Larry Robbins Foundation; A.W. Graziano; Vicki and Rick Birdoff; Allstate Insurance Company, the DiNuzzo Agency; Susan Bridges; Arthur and Linda Brainson; CJS Securities; Commerce Bank; Dorothy Cooper; Sarita Gantz; Glenview Capital Management, LLC; Hess Energy Trading Company; Larry Hughes; Iridian Asset Management, LLC; the Joseph F. Stein Family Foundation; Junket Productions; Merrill Lynch; Gotham Books; New Castle Partners; Newsweek; Oscar Dystel; the Honorable Martin L. Rogowsky; the Jack and Anita Saltz Foundation; Barbara S. Samuelson; Schur Management Company, LDT; Sempra Energy Trading Corporation; Simon and Schuster, Inc.; The Neuwirth Foundation, Inc.; Varsity Bus Co., Inc.; Ken and JoAnn Wellner; Whispering Bells Foundation; and Williams, Jones & Associates, Inc.

A silent and live auction highlighted the day's events, with a Day of Golf for Four at Manhattan Woods Golf Club in West Nyack and tickets to the **US Open** on the live auction block, and many top New York City restau-

rants, foursomes at the area's finest clubs and more on the silent auction roster. WFAS Radio personality Dave Ashton served as live auctioneer/program emcee, and kept the evening's raffle drawings and contest winner announcements moving at an exciting and humorous pace. A grand raffle featuring tickets to Yankees' Games with Seats Behind the Dugout and a Golf Foursome at Trump National Golf Club, along with other exciting items saw a clamoring of purchases before and during the event.

Our in-kind sponsors included: 103.9 WFAS, who provided us with a generous amount of air time advertising the event; Heineken USA, who supplied a multitude of prize items and gift bag items; Tommy Hilfiger, whose shirts were a special feature in the golfer gift bags; Astoria Graphics, who printed our Golf invitation; 107.1 The Peak, who ran public service announcements preceding the event; The Westchester Business Journal, who offered the talents of their design staff in putting an ad together and the space in the publication for same; and BMW of Greenwich, who brought the beautiful car for the hole-in-one prize and contributed to the golfer gift items and silent auction items so generously.

For Donation: Braun hydraulic wheelchair van lift, contact Ed - 914 241-0978

## 2006 TOP 12 WALK TEAMS

We honor the Top 2006 MS Walk Teams that brought in \$298,749 out of a total raised of \$748,800. We thank all who walked, either individually or as a member of a team, that made this such a successful event. Maybe we can top this next year.

Rank	Team Name	Captain's Name	Team \$
1	Hot Flashes	Dr. Alan D. Legatt	75, 916
2	Amici	Ms. Ann Borsellino	41, 878
3	Team J.A. Alternatives	Mrs. Jane A. Genesi	30, 575
4	Reach for the Stars	Ms. Adele Kivel	26, 849
5	Double Digit Superstars	Ms. Samantha Marshall	19, 330
6	Manheim Steamwalkers	Mrs. Keri Grogan	17, 295
7	Movers and The Schleppers	Mrs. Eliz. Goldman-Sider	16, 956
8	HELP RID MS	Ms. Nina Fiorentino	15, 167
9	Einhorn 5	Mrs. Cheryl Einhorn	15, 000
10	Lois' Legs	Ms. Shari Laskowitz	14, 987
11	Ilany & Friends	Ms. Leslie Ilany	12, 316
12	Team Gene	Mrs. Susan M. Seal	12, 062

### 16<sup>th</sup> Annual MS DISCOVERY DAY 2006

SATURDAY, OCTOBER 14, 2006  
9 a.m. to 3 p.m.  
HOLIDAY INN - SUFFERN, NY

Vendor Displays – Continental  
Breakfast & Luncheon

KEYNOTE SPEAKER –  
Randall Schapiro, M.D.

The Schapiro Center for MS  
at the Minneapolis Clinic of Neurology

*Research Through the Eyes of  
an MS Clinician*

OTHER PRESENTATIONS WILL INCLUDE:

*Intimacy and MS*  
Greg McGreer, PhD  
Karen Brash McGreer, RN

*Nutrition and MS*  
Roberta Gershner, M.S., R.D., CDN

### Annual Meeting:

The Annual Meeting of the Southern New York Chapter will be held on Thursday, October 19, 2006 at the Marriott Hotel in Tarrytown. At that time, nominations for the Board of Trustees will take place, as well as reports on chapter highlights and finances. This is also an opportunity for the chapter to recognize its many invaluable volunteers, team leaders and sponsors. The Governance Committee will be considering candidates for the Board of Trustees. Submit nominations to William O'Reilly, Chapter President by September 28.

In addition, we look forward to a research presentation by Mark Tullman, MD. Dr. Tullman is a neurologist and Director of the MS Clinical Care Center, Neurological Institute of NY at Columbia University Medical Center.

## COUPLES WEEKEND GETAWAY

*"Where did you and your partner meet?"*

*"What did you think the first time you kissed your partner?"*

*"What was the dream you had for your marriage?"*



These are a few of the questions addressed during a weekend getaway for couples. The SNY, NYC and LI chapters sponsored a retreat that took place from June 9-11 in the Pocono's. Three workshops were held by Cheryl and Len Chatman. Cheryl and Len have been married for 20 years. While they both are "living" with MS, Cheryl was actually diagnosed 16 years ago. Len, a marriage enrichment specialist, and

Cheryl have developed a passion for reaching out to couples in an effort to teach people how to approach a diagnosis with positive spirit and enrich their relationships.

Thirty five couples participated in the weekend which included 2 nights at the resort including meals, entertainment and activities. Each couple was given a workbook and a signed copy of "The Art of Living with MS: Six Secrets for Managing MS as a Team", written by the Chatmans. This was a great opportunity for people to re-connect as a couple and to meet other couples.

## People Doing Something About MS Through "Third-party Events"

You might have a wish to do something about MS, but your calendar may not fit with ours. So you decide to do something that fits with your schedule, your style and your talents. We call that a "third-party event".

We have had some great ideas that come from our volunteers so we are going to start to pass them on. We love to hear of them. Here are some of the more recent ones.

- "Indoor Relay Walk": Boys and Girls Club of New Rochelle (Remington Flyers)
- "Cut-a-Thon": Illusions Hair Design, Slate Hill, NY (Catherine Cole, Owner)
- "Hot Dog Sale": Suzanne Dariano, Rye, NY.
- "Jeans Day": Mayors Health Awareness Program, Middletown, NY
- "Walk-a Thon and Carnival Day": Tri-Valley Intermediate School, Neversink, NY

Your donors or your customers will want to know you are raising money for a legitimate charity. We will provide you with the materials to help you prepare for your event. Contact Lauren Goldberg at (914) 694-1655 (ext 39) or by e-mail at [lauren.goldberg@nyv.nmss.org](mailto:lauren.goldberg@nyv.nmss.org). She will send you what you need. Thanks for being one of the millions who want to do something about MS.

**PROFESSIONALLY LED AND SELF-HELP GROUPS**

Please contact the facilitator prior to attending meetings.

**WESTCHESTER COUNTY**

White Plains – Newly diagnosed and for those with little or no symptoms. Family and friends welcome.

Westchester Independent Living Center  
– 200 Hamilton Ave  
2<sup>nd</sup> Wednesday, 6:30 – 8:00 pm – Call Ed (203) 445-0118

**Scarsdale**

Scarsdale Library – 50 Olmstead Rd  
3<sup>rd</sup> Wednesday, 7:00 pm – Call Chris (914) 694-1655 ext. 33

**Scarsdale**

Scarsdale Library – 50 Olmstead Rd  
2<sup>nd</sup> Wednesday, 5:30 pm – Call Gordon (914) 948-4630

Pleasantville – Newly diagnosed  
Pleasantville Library – 350 Bedford Rd  
2<sup>nd</sup> Monday, 6:30 pm – Call Donna (914) 245-3029

Mount Kisco – Cognition Support  
Presbyterian Church-605 Millwood Rd  
2<sup>nd</sup> Wednesday, 6:30 pm – Call Renee (914) 241-4240

**Mount Vernon**

Dole Center – 250 South 6<sup>th</sup> Ave  
Last Thursday, 5:00 -7:00 pm – Call Tracey (914) 664-3472

**Valhalla**

Hebrew Home – 61 Grasslands Rd  
2<sup>nd</sup> Thursday, 3:30 – 5:00 pm –  
Call Ed (203) 445-0118 or  
Joanne (914) 694-0056

**Social Group**

Location and time determined monthly – Call Laura (914) 793-8733 or Greg (914) 690-9199

**Health/Mental Health Professionals w/MS**

Call for location details  
3<sup>rd</sup> Wednesday, 6:30 – 8:00 pm - Call Rob (914) 747-2008

Phone Connections – Professionally led conference call for people who seldom leave home.

Westchester Jewish Community Services – Call Debbie, MSW (914) 381-5560

**ROCKLAND COUNTY****New City**

New City Library – Squadron Blvd  
Call for dates, 10:30 am – 3:00 pm –  
Suzanne (845) 634-9064

**Pearl River**

Pearl River Library – 80 Franklin Ave  
2<sup>nd</sup> & 4<sup>th</sup> Tuesday, 7:00 – 8:30 pm -  
Call Laurie (845) 352-7189 or  
Ian (845) 365-2652

West Haverstraw – For in-patients & those exhibiting symptoms  
 Helen Hayes Hospital – Rte. 9W, 4<sup>th</sup> floor conference room  
 4<sup>th</sup> Thursday, 6:15 pm – Call Dianne (845) 425-3520

### ORANGE COUNTY

Castle Point  
 Castle Point VAMC, Bldg. 13-12511  
 Route 9D  
 3<sup>rd</sup> Tuesday, 4:00 – 5:30 pm – Call Don (845) 565-2240

Cornwall  
 Cornwall Hospital, Conference Room B-19  
 Laurel Avenue  
 1<sup>st</sup> Wednesday, 6:30 – 8:00 pm – Call Kathy (845) 534-3306

Goshen  
 Orange Regional Medical Center, Arden Hill Campus- 4 Harriman Dr.  
 3<sup>rd</sup> Saturday, 9:00 – 11:00 am – Call Debi (845) 986-6497 or Lucille (845) 783-1071

Newburgh – Residents of facility and community friends  
 Elant Nursing Home, 56 Meadow Hill Road  
 1<sup>st</sup> Tuesday, at 2:30 pm – Call Don (845) 565-2240

New Windsor  
 Marasco Center-244 Union Ave.  
 2<sup>nd</sup> Monday, at 7:00 pm – Call Don (845) 565-2240

Port Jervis – Professionally Led  
 Bonsecours Community Hospital – 160 East Main St, 3<sup>rd</sup> fl. Conf. Rm  
 2<sup>nd</sup> Wednesday, 12:00 – 1:00 pm – Call Barbara, (845) 856-5351 ext. 7122

Warwick – Residents and community friends  
 Schervier Pavilion – 20 Grand St.  
 Wednesdays, 11:00 am – 12:00 pm – Call Michael (845) 986-0802

### PUTNAM COUNTY

Carmel  
 Putnam Hospital Center, Room 270-  
 Stoneleigh Ave.  
 2<sup>nd</sup> Thursday, at 6:30 pm – Call Alice (845) 628-9792

Carmel  
 Putnam Independent Living Center – 1961 Route 6  
 1<sup>st</sup> Thursday, at 10:00 am – Call Lisa (845) 228-7457

Kent Lakes  
 Kent Public Library – 17 Sybil's Crossing  
 3<sup>rd</sup> Wednesday, at 6:00 pm – Call Kristen (845) 228-5607 or (845) 264-0085

### SULLIVAN COUNTY

Liberty  
 Boces Cornell Cooperative – 64 Ferndale Loomis Rd  
 3<sup>rd</sup> Thursday, at 7:30 pm – Call Judy (845) 292-5539

## ■ Women Against MS Luncheon

— continued from page 1

Tolchin and Harriet Whelan.

Serono, Inc. and Pfizer Inc., the manufacturer of Rebif, provided generous underwriting for the event and also supported the appearance of Ms. Garr. Other prominent sponsors and supporters were 103.9 WFAS and AM 1230 WFAS, The Westchester Business Journal/Westfair Communications, The Peak 107.1, Penguin Books, Mamaroneck Flowers, MasterCard International, Pepsico, Inc. and CFS Bank. Generous contributions from sponsors and individuals allowed for a number of complimentary tickets to be made available to people with MS, many residing in nursing homes. Transportation was provided by RV Ambulette and Premier Ambulette. Metro Health Care and VNA Home Health Services donated certified home health aides to accompany those who needed special assistance in order to attend.

The luncheon was also well-supported by local officials and government leaders. Those attending included Hon.

Joan Cooney, Supervising Judge of the Family Court; Hon. Janet DiFiore, Westchester County District Attorney; Camille Failla Murphy, Director, Westchester County Office for Women; Marlene Furtick, Director, Westchester County Youth Bureau; Susan Tolchin, Chief Advisor to the County Executive; Bill Ryan, Chairman, Westchester County Board of Legislators; and fellow legislators, Martin Rogowsky and Michael Kaplowitz.

Speaking with poignancy and humor, Ms. Garr brought tears to many in the audience as she shared her message to researchers and everyone committed to the cause of eradicating MS: "Shoot for the moon baby," she said. "Even if you don't get to the moon, you get a lot of good stuff along the way. I truly believe that by working together, all the people in science, technology and business, as well as (the) patients, can eradicate this disease from the face of the earth...See you on the way to the moon."

### ***If You or Someone You Know Has MS***

*Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with multiple sclerosis.*

*Talk to your health care professional or contact the National MS Society at [www.nationalmssociety.org](http://www.nationalmssociety.org) or 1-800-FIGHT-MS to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.*

**SAVE THE DATE**

<b>Getting a Job and Maintaining Benefits</b>	<b>Sept 27</b>	<b>ILC</b>	<b>Spring Valley</b>
<b>Great TZ Bike Tour</b>	<b>Oct 1st</b>	<b>Kraft Foods</b>	<b>Tarrytown</b>
<b>Getting a Job and Maintaining Benefits</b>	<b>Oct 4</b>	<b>MS Chapter</b>	<b>White Plains</b>
<b>MS Discovery Day</b>	<b>Oct 14th</b>	<b>Holiday Inn</b>	<b>Suffern</b>
<b>Annual Meeting</b>	<b>Oct 19th</b>	<b>Marriott Hotel</b>	<b>Tarrytown</b>
<b>Fall Rec Programs</b>	<b>Oct - Dec</b>	<b>Various Locations</b>	



**Southern New York Chapter**  
National Multiple Sclerosis Society  
2 Gannett Drive, Suite LC  
White Plains, NY 10604

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