



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY

MS Connection

June 2002

Greater Delaware Valley Chapter

When the Road Turns: Finding a New Path When Living With MS

MS brings many changes to the lives of those diagnosed: changes in careers, home life, and recreational activities. These changes can alter one's sense of self, especially if that sense of self was highly anchored to the activity in the first place, which many people find through their jobs, hobbies, home life or important volunteer activities.

How do those with MS regain a sense of self in the face of change? How can we "reinvent" ourselves following diagnosis or a progression of symptoms?

In her book, *When The Road Turns*, Margot Russell says, "We are most defined in our moments of adversity, when we are called upon to be fully human and to embrace the unknown and its outcomes." In a forward to that same book, the National MS Society's Dr. Nicholas LaRocca says, "To a great extent, multiple sclerosis becomes a journey inward and what people ultimately find is a new identity. While



Chapter member Brenda Dudek didn't give up on her dream of skydiving.

people have help from others, each experiences a very personal and individual process."

Through a series of personal stories, Russell's book explores several key concepts that are also illustrated in the stories of local MS clients who have "reinvented" themselves following multiple sclerosis. The new issue, as Russell says, is, "What do I choose? What do I want for myself?"

Learn to Adapt: Re-Direct Your Energies

MS Father of the Year Michael Bannan was a volunteer fireman for over 20 years, receiving awards for acts of

The National MS Society...One Thing People With MS Can Count On.

Finding a New Path After MS *(continued from page 1)*

heroism and service to the community when MS caused him to “retire.” According to his wife, Linda, “This left a gaping hole in his life. But to make up for his loss, and to him it was a huge loss, Mike found other causes to champion in the community. Shortly after his “retirement,” he joined the non-profit organization known as the Exchange Club of West Chester. So although Michael lost the second love

of his life (the fire company) he has moved forward to help others in new ways, ways that are not necessarily seen by or heard about by his peers and friends. Michael spent four years as the group’s treasurer and received national recognition awards each year for his work. He’s on the board of directors and championed the start of a web page, which won the national award for most innovative and best web site. Since Michael does not know what further complications MS might have, he has decided to make sure that he does all that he can for his family, community and friends, now.”

MS Connection 1-800-548-4611

Publication of the National Multiple Sclerosis Society,
Greater Delaware Valley Chapter

Chairman
Kent Griswold

Vice Chairman
Larry Kane

Chapter President
Judith G. Cohen

Chapter Programs Director
Pete Kennedy

Newsletter Editor
Linda A. Smith

Writers
Jeanette Smith
Kevin Wheeler

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

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

© 2002 National Multiple Sclerosis Society,
Greater Delaware Valley Chapter

Hold Fast to Your Dreams

Downingtown resident Brenda Dudek has enjoyed a wide range of careers in her life: sales representative for a California wine venture, credit analyst for a leasing company, sales associate in a jewelry store, and host of her own West Chester radio show about home schooling, which she did with her two daughters, who are now in a local private school.



Finding a New Path After MS

(continued from page 2)

But MS changed all that for Brenda, who has difficulties with her gait, hand motions, and strength and speech. She remains a woman with humor and vision. Sometimes, she admits, she gets depressed, “Then it’s time for a nice glass of wine with Terry Hills” her personal assistant who is with her every day.

Together, the two women visit the chapter’s Wellness Center for courses whenever possible, go to the movies, one of Brenda’s favorite pastimes, and are working on the installation of Dragon Speak software for Brenda’s computer, so she can write the book she now longs to put together.

But most amazingly, Brenda has recently fulfilled another lifelong dream: skydiving! Encouraged by her husband, who knew this was a longtime desire, Brenda was immediately “hooked.” “Now I’m just trying to find ways to raise the money to go more often,” she says.

Let Go of What Might Have Been

About a decade ago, Dr. Richard Radhke was featured in a National MS Society advertising campaign, which showed him sitting in his wheelchair outfitted in divers’ gear at the bottom of the ocean. The photo said it all: here was a man who stopped at nothing to live his

life to the fullest. Radhke, who has progressive MS and is quite disabled, is a professor of biological oceanography at the School of Ocean and Earth Sciences and Technology at the University of Hawaii, the first disabled man to reach Antarctica and the founder of the Sea of Dreams Foundation, which creates programs to assist disabled youth in the U.S. and aboard.

But at one point in his life, Radhke was so depressed he considered suicide. “I felt I wasn’t any use to the human race. How was I going to contribute to society? But then I started doing some things for non-profit organizations and I began to realize, my God, I can contribute to the world. I’ve learned to contribute in ways I didn’t know about before.”

Radhke went to work dreaming how he would put his life back together, not in the same way, but differently. He consciously decided to take strength, determination, courage, stubbornness and focus into this new life. He would discard self-pity and fear. Today he says, he wakes up excited each morning. “I’m excited to be awake. There’s always a new cliff to jump off.”

Living Well

Radhke and others are living proof that, “You don’t have to feel well all the time to live well,” a phrase coined by Sondra Howell, another chapter client in a recent article for *Yoga Living Magazine*. Howell, a registered

Finding a New Path After MS

(continued from page 3)

movement therapist at the Jefferson Hospital Center of Integrative Medicine, writes about accepting illness as part and parcel of life and how she stopped fighting it. "Multiple sclerosis," she says, "has necessitated attending to my mind and body and psyche in a very mindful way. I've learned to pace my energy, to take naps, and to say no to some activities so I can say yes to my Self."

"My life has taken a new direction. I guess I am on a mission to be the best "me" I can be. I now focus now on what I can do and go from there."

Dave Perez

Resources:

The following books are available through the Chapter's Lending Library; please call 800-548-4611, ext. 155 to reserve a book or speak to a volunteer librarian.

- *When the Road Turns*,
by Margot Russell
- *You Are Not Your Illness*,
by Linda Noble Topf
- *Women of Spirit*,
by Katherine Martin

Staff Highlight



John Scott, who has been helping those with MS for 15 years, (right) is shown with Frank McCarry, a long time MS 150 City to Shore Bike Tour fundraiser.

June marks the 15th year of service to those with MS for the chapter's Senior Vice President John Scott. Of those 15 years, John first worked for the North Star Chapter in Minnesota, where he was hired as an events coordinator who later formulated the idea for the initial MS WALK. John later moved East to accept the position of Director of Development for the Greater Delaware Valley Chapter, and his ideas and dedication have enabled the chapter to grow into one of the largest and most successful in the nation.

John's current responsibilities include annual and planned giving, major gifts, special events administration, and the management of the information technology department. In his spare time, he enjoys long distance cycling including the MS 150 Bike Tour, time with his family, and theatrical pursuits with The Savoy Company.

Chapter Names 2002 Mother and Father of the Year

The Greater Delaware Valley Chapter is pleased to name Michael Bannan and Elizabeth Epsaro as its 2002 MS Father and Mother of the Year, following a rigorous selection process that took several months. Mike and Liz were chosen for their involvement with their families and the community, their positive outlook on life despite multiple sclerosis, and their determination in handling the symptoms of the disease, and commitment to educate themselves about MS.

“Choosing a candidate is always an extremely difficult process,” says Judith G. Cohen, chapter president. “Our selection committee, composed of staff and volunteers, carefully reviews all our applications. We see so many excellent and noteworthy candidates, that’s its hard to make a final selection.”

“We want to thank all chapter members and their children who sent, faxed and emailed nominations for this important award. Whether your candidate was chosen for the award or not, we can see there are many beloved and hard working parents in our chapter area,” Cohen continues.

Michael Bannan

There is nothing more important than his family to West Goshen Township resident, Mike Bannan. His wife, Linda says, “Michael has devoted his life to me and my ten-year-old daughter, Jennifer. Since he does not know what further complications MS may bring, he has decided to make sure that he does all he can for his family, community, and friends now.”

Mike has a wide range of community activities to his credit. For example, he proudly served as a local volunteer fireman for more than 20 years, receiving awards for acts of heroism and service, before MS forced his “retirement.” But rather than endlessly mourn the loss of the fire company, “his second love,” Mike quickly turned his energies to other ventures, including his vital involvement with the National Exchange Club.

As a member of the Board of Directors of the Exchange Club, Mike is devoted to the group’s mission: to prevent child abuse and promote patriotism. “The club,” he says, “has become a vital part of the social service fabric of the West Chester area and thanks to recent growth, now has full and part time staff members as well as about 20 volunteers.”

Mike’s activities also include participation in the MS WALK at West

Chapter Names

2002 Mother and Father of the Year

(continued from page 5)

Goshen Township Park, where he has been a top fundraiser, as well as support of his daughter's team of 30-plus walkers, "Jennifer's Crew." In addition, he serves as a mentor for those with MS taking one of the new MS drugs on the market and has held numerous leadership positions on the West Goshen Township planning commission.

As Father of the Year, Mike is, of course, highly involved with Jennifer's school activities, the YMCA Indian Princess program, family camping activities and other community events. The father-daughter duo is "extremely close" and enjoys car trips, outings and other bonding moments together.



Mike Bannan with his daughter, Jennifer.

Liz Epsaro

Diagnosed with MS 17 years ago when she was just 20, Liz never would have guessed that she would be chosen as anyone's "Mother of the Year." "When my doctor told me I had MS, I figured I would never get married or have children," Liz says, "I can't describe what a blow the diagnosis was for me. For the first year, I was an emotional mess."

Seventeen years later, Liz has gained valuable perspectives on living with MS, beginning, she says, when she visited a nearby MS Society support group. "If it weren't for those group members, I couldn't have gotten where I am today," she says. "I saw them and realized that life went on and that people lived full, happy lives with MS." Today, Liz, herself, is the co-leader of the self help group at Good Shepard Hospital in Allentown and serves as an informal peer counselor for the chapter. She also is involved in the chapter's READaTHON program, volunteers or walks at the MS WALK and is active in the Notre Dame Church of Bethlehem. But her consuming interest is her children, Michael, 9, and Lauren 6.

"My children have never seen me out of a wheelchair," Liz says, "and I made a pledge to myself years ago that I would never let my wheelchair hold them back from anything they wanted to do. I go everywhere with them—I may not be able to play baseball, but I will always be there to support them. This

Chapter Names 2002 Mother and Father of the Year

(continued from page 6)

is a wonderful time in their lives and I'm too busy to sit and worry about what might happen next."



Liz, Tom, Lauren and Michael Epsaro.

Because of her positive, can-do attitude, Liz's kids don't see her as "having a problem." Once, she says, her son's friends asked what was wrong with her. Michael responded, "Nothing's wrong with her—she just uses a wheelchair."

Liz is also grateful for the support of her husband, Tom, who, she says, should win the "husband of the year

award." Nothing is ever too much trouble for him, from carrying me to a chair on the beach to offering help when I need it in a way that still empowers me."

Both Mike and Liz will be publicly honored at the chapter's annual meeting in November, where they will receive their recognition as well as a chance to introduce their families. If you have a nomination for 2003 Mother or Father of the Year, please watch your MS Connection newsletter for nomination information for next year or email Linda Smith at linda.smith@pae.nmss.org.

KEEP S'MYELIN

Now Available on the Web

K *keep S'Myelin*, a newsletter for children about MS, is now on the National MS Society's website.

Designed for children 5-12 years of age who have a parent or loved one with MS, *Keep S'Myelin* includes regular articles about different aspects of MS, a question-and-answer column, interactive puzzles and games, photos, book reviews, tips and more. Go to www.nationalmssociety.org. Scroll down the front page and click on the button in the Features section. Other links to the site will be included in the Library section.

If you'd like your child to receive *Keep S'Myelin* by mail, please contact Eleni at 800-548-4611 or email her at eleni.beldecos@pae.nmss.org.

Chapter's Jean Griswold Featured in New Book

The Greater Delaware Valley Chapter is pleased to announce that Jean Griswold, a local member and entrepreneur is featured in the new book, *Women of Spirit*, by Katherine Martin, the second in the author's *People Who Dare* series. *Women of Spirit* tells the stories of 37 inspirational, courageous women who followed their own inner dreams and have made, and continue to make, a positive difference in the world.

Although diagnosed with a progressive form of MS, Jean went on to become the founding director and chief executive officer of *GRISWOLD SPECIAL CARE*, a multimillion-dollar company that provides health care services for the elderly, the disabled and children with special needs. She also serves as the director of the *SPECIAL CARE* foundation, which provides funds to those in need of home care who cannot afford the service.

"I live a ridiculously remarkable life," says Jean. "I am physically capable of doing almost nothing. Yet I have managed to do a great deal." To accomplish so much, Jean has drawn on her remarkable experiences as a pastor's wife, teacher, guidance counselor, and geriatric social worker as well as her degrees in business management and economics, counseling and her studies in geriatrics. She added

this wealth of knowledge and experience to, "the cornerstone of two lifelong dreams: to be a businesswoman and to help others." She has been recognized in



Forbes, *Entrepreneur* and *Success* magazines as well as on the *Today Show*. In addition, Jean has been locally and nationally recognized with honors including Pennsylvania's Best 50 Women in Business and as a Woman of Vision, Rutgers University's Hall of Distinguished Alumni and received a tribute from former Pennsylvania Governor Casey for bringing "joy and hope to countless people."

In *Women of Spirit*, Jean joins other courageous women in telling their stories: where they started, how they fulfilled their dreams, and who inspired them. The book is described by reviewers as "a remarkable journey...stories that go to the

Chapter's Jean Griswold Featured in New Book

(continued from page 8)

heart...and an inspiration to be everything you were meant to be.”

To borrow *Women of Spirit* from the chapter's Lending Library, please call 800-548-4611, ext 155; on Tuesdays and Thursday, you can speak with a librarian from 10 a.m. to 2 p.m. You may also leave a message at any time.

Jean will also be selling books at her next book signing:

Thursday, June 13, 7:30 p.m.
Borders

80 E. Wynnewood Road
Wynnewood, PA

For more information, please call
Susan Rehr at 215-412-2943.

2002 Employer of the Year Nominations Requested

Each year, the Greater Delaware Valley Chapter recognizes companies who demonstrate a special effort to encourage employment of people with multiple sclerosis and other disabilities. Nominations are accepted from our membership and the winning employer is recognized at the chapter's Annual Meeting and Volunteer Recognition Luncheon in November.

The Employer of the Year usually receives local media coverage for their contributions to the daily life of all those with disabilities.

Do you have an employer or know of an employer who fits the following criteria?

- The company currently has an employee with multiple sclerosis.
- The company has taken several actions that have increased or enhanced employment opportunities for the person with MS, for example, arranging special rest periods, providing special parking or heat relief, or arranging work from home.
- The company has taken a leadership role and serves as a role model in advancing disability rights.
- The company supports and complies with the Americans with Disabilities Act.

The chapter also needs to know how many employees are retained by the company; this can be a broad estimate of either over 100 employees or less than 100 employees.

If this sounds like a company you know of, or work for, please write to us illustrating the above points and send your nomination to:

Linda Smith
National MS Society
1 Reed Street, Suite 200
Philadelphia, PA 19147

Or email Linda.smith@pae.nmss.org

**Nominations must be received by
September 30, 2002.**

Unless otherwise noted, please contact Jeanette Smith at 1-800-548-4611, x169 for more information.

June

Nutrition and MS Teleconference

DATE: Monday, June 10

TIME: 7:00-8:00 pm

PLACE: Call toll-free,
from your home

Join us by phone as we examine the importance of nutrition to those with MS. Learn what foods are good, what's not so good, and what you need to do to make your eating habits the best they can be.

Women's Day

DATE: Wednesday, June 12

TIME: 9:00 am - 2:00 pm

PLACE: Holiday Inn Select,
Trevose, PA

Explore issues of health and wellness with other women who have MS. Gain inspiration and knowledge from presenters who have extensive experience with women's issues and chronic illness.



MS Learn Online Internet Program

DATE: Thursday, June 20

TIME: 8:30 pm

PLACE: Log onto:

www.nationalmssociety.org

Visit the World Wide Web for the program, Understanding and Controlling Bladder Dysfunction. The program begins with a live audio presentation, followed by a question-and answer segment where participants can e-mail questions to the presenters. To access learn on line programs, log onto www.nationalmssociety.org.

Fitness Network: Aquatics, Cardio-Balance, & Strength Training

Joint Effort

DAY: Tuesday & Thursday

TIME: 11:00 am - Noon

Walk & Stretch

DAY: Monday, Wednesday, Friday

TIME: 11:00 am - Noon

Strength Training

DAY: Tuesday & Thursday

TIME: 9:30 am - 10:30 am

DATE: June 23 – August 24

PLACE: Family YMCA of
Burlington County
Mt. Laurel, NJ

Learn to increase flexibility, enhance self-image, build strength, improve metabolism, decrease stiffness, alleviate stress, and lessen fatigue through a variety of exercise methods. Qualified instructors will modify activities for all abilities. For more information, contact Kathy Custis at the YMCA, 1-856-234-6200.

July

Treating the Symptoms of MS

DATE: Tuesday, July 16

TIME: 9:00 am – 2:00 pm

PLACE: Adam's Mark Hotel,
Philadelphia

and

DATE: Thursday, July 18

TIME: 9:00 am – 2:00 pm

PLACE: Holiday Inn,
Fogelsville, PA

Learn and develop good coping skills as MS becomes more involved and increase the tools you can use to help handle the changes of progressive multiple sclerosis. Join area professionals who will lead discussions on rehab, research/treatment areas and symptom management. **For more information, contact Eleni at 1-800-548-4611, x170.**



NJ Wins Teleconference

DATE: Monday, July 15

TIME: 7:00-8:30 p.m.

PLACE: Call toll free,
from your home.

Join us for this special edition of our Teleconference Series—*especially for New Jersey residents!* NJ WINS (Work Incentive Network Support) is an organization committed to helping those with disabilities make informed decisions about their futures. If you have questions about how work or a change in income might affect your disability benefits, call in for the information you need.

Depression and MS Teleconference

DATE: Thursday, July 18

TIME: 7:00-8:30 pm

PLACE: Call toll-free,
from your home

Depression is a common symptom of those with chronic illness, particularly those diagnosed with MS. Join us as we examine this sensitive subject and learn how to better manage depression and its effects.

Balancing Your Body**DATE:** Tuesday & Thursday
July 16 - August 29**TIME:** 11:00 am - Noon**PLACE:** *GRISWOLD SPECIAL CARE*
Wellness and Education Center

Participate in classes hosted by Elyse Axelrod, a physical therapist from Magee Rehabilitation, who will emphasize balance, coordination, and strengthening exercises. She'll also include an endurance component to focus you on the importance of maintaining a healthy balanced body.

Gentle Yoga Series**DATE:** Wednesdays
July 17 - August 28**TIME:** 10:00 am - 11:30 am**PLACE:** *GRISWOLD SPECIAL CARE*
Wellness and Education Center

Join Pat Albright, certified yoga instructor, and learn the value of stretching to increase your flexibility and allow you to move more freely. This workshop will teach a variety of relaxation and flexibility techniques and movements modified for you!

**Breathing and Meditation
Techniques for Stress Management****DATE:** Wednesday, July 17**TIME:** 1:00 pm-2:30 pm**PLACE:** *GRISWOLD SPECIAL CARE*
Wellness and Education Center

Join Michelle Carlino, holistic educator and yoga instructor, to learn breathing and meditation techniques for stress management. Learn to focus the mind, breathe, and incorporate visualization techniques.

**August
Legal Day****DATE:** Saturday, August 10**TIME:** 20 min. appointments
between 9:30 am and 2:00 pm**PLACE:** Clients receive calls
in their homes

Receive free legal direction offered by local attorneys during a one-on-one personal telephone consultation.

**Understanding Home Care
Teleconference****DATE:** Tuesday, August 13**TIME:** 7:00-8:30 pm**PLACE:** Call toll-free,
from your home

Our teleconference series continues with an examination of the ins and outs of home care, the different types, how to choose a home care agency and how to pay for services.

Men's Retreat**DATE:** Wednesday, August 21**TIME:** 10:00 am - 1:30 pm**PLACE:** *GRISWOLD SPECIAL CARE*
Wellness and Education Center

Men can spend a day with peers and explore the sensitive issues males with MS face daily. Topics include bladder and sexuality symptoms, importance of coping with role changes and cognitive issues. There will also be a presentation on the ability of men with disabilities to advocate for themselves when dealing with the health system, health care providers and their insurance companies. Learn how to take charge of your health care and to assure access to needed health care

services. Don't miss this chance for networking with peers!

- * Lunch will be provided
- * Registration begins at 9:30 am

September

Fitness Series: Healing Meditations of Tai Chi

DATE: Wednesdays,
September 4-25

TIME: 10:00 am – 11:00 am

PLACE: *GRISWOLD SPECIAL CARE*
Wellness and Education Center

Back by popular demand! Join instructor George Graham, who has been teaching adaptive Tai Chi, for nearly 10 years to people with MS. This class will demonstrate different styles of Tai Chi from around the world. Discover what form is best suited for your needs

Rekindling Your Spirit

DATES: Tuesdays, September 3-24

TIME: 10:00 am – 11:30 am

PLACE: *GRISWOLD SPECIAL CARE*
Wellness and Education Center

Back by popular demand! Popular speaker and chapter member, Dr. Trena Pelham will facilitate four interactive and inspirational sessions on coping with the depression and stress that often accompany a diagnosis of multiple sclerosis. Journals will be provided for personal reflection to be used in the workshop series.

Revitalizing the Caregiver

DATE: Thursday, September 19

TIME: 11:00 pm- 2:00 pm

PLACE: *GRISWOLD SPECIAL CARE*
Wellness and Education Center

Caring for or about someone with MS can be exhausting, but the National MS Society can help! Join Lara Rogers Krawchuk, M.S.W., L.S.W., M.P.H., staff therapist with Penn Council for Relationships, to learn more about the emotional/physical impact of caregiving, the importance of stress management and simple ways to care for yourself while supporting your loved one. This invigorating program is specifically designed for adults who provide emotional and/or physical care for someone with MS.

*Lunch will be provided.



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY



Everything You Ever Wanted to Know About Social Security Disability

Guest writer, *Ted Walkenhorst, is an attorney at the Disability Benefits Law Center and maintains offices in center city Philadelphia and Jenkintown; he has been in practice for 28 years. Walkenhorst has specialized in Society Security and private disability cases for the last seven years.*

What are the basic eligibility requirements for Social Security and SSI disability benefits?

To qualify for either of these disability benefit programs, a person must not only meet the disability definition, but also must qualify on a financial basis. To qualify for disability insurance benefits, a person must have worked and paid wage taxes long enough to be insured for receipt of those benefits. Generally, that means a person must have worked five out of the last ten years before s/he became disabled. These benefits are also available to certain disabled adult children and widows(ers) and surviving divorced spouses. SSI is a Federal Welfare Program. To qualify for those benefits, a person must be both low income and have low assets. If married, their spouse's income and assets are included in the eligibility determination.

How does Social Security define disability?

In general, the definition created by Congress is one of the more difficult disability standards to meet.

- 1-First, this is a long-term disability program. A person must establish that he or she has been disabled for at least 12 continuous months, or that the disability is expected to last at least that long.
- 2-Second, applicants must show that the symptoms of their medical conditions prevent them from performing any of the work that they have done in the last 15 years.
- 3-Third, depending upon a person's age and past work experience, he or she must also show an inability to perform any easier types of jobs. In other words, if a person used to do factory work and can no longer perform that job, due to standing lifting and carrying required, he/she could still be found ineligible for benefits if the person retained the ability to perform an easier job in an office setting, such as receptionist or telephone operator.

When should a person apply for these benefits?

I recommend that a person file an application for these benefits as soon as he/she feels able to demonstrate an inability to work for at least 12 consecutive months.

Social Security Disability (continued from page 14)

How does one begin the application process?

At this time, applications can be made in person at your local Social Security office or by telephone, by contacting Social Security's toll-free number at 1-800-772-1213 (7:00 a.m. to 7:00 p.m.). Social Security has announced plans to accept applications over the Internet, but has not indicated when that method will be available.

If I have questions about Social Security or private disability benefits, can I call to discuss my issues with you?

I will be happy to answer questions over the telephone and all consultations are always free of charge. For Social Security disability cases, attorney's fees are regulated by the Social Security Administration. In almost all cases, there is no fee unless benefits are awarded and all attorney's fees must be approved by the Social Security Administration.

I can be reached at the Disability Benefits Law Center, 610 Old York Road, Suite 210, Jenkintown, PA 19046; by phone at 215-886-0660; by fax at 215-886-7848 and by email at tedwalkenhorst@yahoo.com.

Next Newsletter: Watch for Ted's tips on completing the Social

Security Disability application and involving your doctors in support of your disability application.

Other resources include ADA attorney Steven Gold who can be reached at 215-627-7100 and paralegal Debbie Kooperman, a longtime chapter volunteer, at 215-981-3728.

MSWorld.org Offers New Message Boards For Kids With MS

MSWorld.org is putting the world wide web to work for young people with multiple sclerosis. Children, teens and young adults with MS and their parents are invited to communicate and reach out to others with the newly added message boards. Through their postings, people from around the world share thoughts, ideas, encouragement, and advice on MS. There are also sections for caregivers and people with MS in their 20s.

Users need to register, a quick application process, before posting questions to the boards, but anyone can read the questions and answers of other members. To access the MS World message boards, go to www.msworld.org, and click on the "See what's new! [here](#)" hyperlink.

FOR SALE: LANCER 2000 ELECTRIC WHEELCHAIR.

Electrically tilts, two sets of controls. Brand new batteries. Good condition; hardly used. Asking only \$4000. Call 610-837-0770.

FOR SALE: POWER TRAINER.

Exerciser for arms and legs/never used. Original price, \$1000; best offer. Call 610-837-0770.

FOR SALE: ELECTRIC

WHEELCHAIR. Includes gel pad and charger. Seldom used. \$850. Call 610-998-0463.

FOR SALE: WALKER. Modified with wheels and pressure brakes. Like new. \$50. Call 610-998-0463.

FOR SALE: WHEELCHAIR; COMPAX SELF DRIVE. No. 17CSP. 19 lbs, 25" width, 250-pound capacity. Perfect condition. Original price: \$972. Will sell for \$300. Call 610-666-6055 or email piperGerry@aol.com.

FOR SALE: FITNESS FLIER EXERCISE MACHINE. Asking \$200 or best offer. Call 215-245-4993.

FOR SALE: FREE STANDING TRAPEZE BAR. Helps user re-position him/herself in bed. Excellent condition. Asking \$150. Call 856-983-4678 or email nancyws27@aol.com.

FOR SALE: QUICKIE WHEELCHAIR. Excellent condition; lightweight; removable arms and legs. Inc. removable backpack and J-cushion. Excellent condition. Asking \$700. Call 856-983-4678 or email nancyws27@aol.com.

FOR SALE: ORTHOKINETIC EXPLORER SCOOTER. Four wheels with foam tires, two Panasonic batteries, basket, walker holder, lights, battery charger. Originally priced at \$4000; asking \$1800. Call 610-828-6934.

FOR SALE OR TRADE: 1987 CADILLAC. Sedan DeVille. Runs excellent. Has 157,000 miles. Asking \$2,000 or best offer, or willing to swap for van or pickup. Call 610-385-9667.

FOR SALE: CRAFTMATIC TWIN BED. Has control w/various massage and height settings. New mattress. Asking \$700. Call 609-463-8468.

FOR SALE: LAZY BOY LIFT CHAIR. Multi-position controls. Blue/like new. Asking \$700. Call 609-463-8468.

FOR SALE: PRIDE DYNAMO SCOOTER. Almost new. Inc. two never used batteries. Original cost: \$2500; asking \$1000. Call 215-338-5503.

FOR SALE: ELECTRIC TILT TABLE. Model 801E. Very good condition. \$500. Call 610-323-2407.

FOR SALE: AMIGO THREE WHEEL SCOOTER. \$500. Call 610-323-2407.

FOR SALE: INVACARE-INVALEX LIFT. \$500. Call 610-323-2407.

FOR SALE: AMIGO J-DELUXE SCOOTER. Swivel seat/ white with black leather. Inc. basket, good batteries, never-go-flat tires. Good condition overall. Asking \$1200. Call 610-525-0244.

Prepare Today To Offset Financial Headaches Of Tomorrow

The unpredictable nature of multiple sclerosis means leaving as little as possible to chance, including your financial future. In fact, a quick meeting for anyone over the age of 25 with a financial consultant can reap dividends for a comfortable retirement, or should the unforeseen occur. Joseph Dinoto, Esq. is a financial consultant who specializes in estate and long-term financial planning for people with disabilities and he says, "It's easy to ignore the future, but start saving now so you don't have to worry later."

If you are still working, or have a spouse who is working, Dinoto recommends the following plan of action for your future comfort:

1. How much you can put away for a rainy day depends on your financial stability. You need to have a budget. A visit with a financial consultant can help you decide how much money you can afford to save.
2. Look into your options. Annuity Plans, IRAs and 401Ks are sensible options where the participant contributes a small percentage per paycheck. Your contributions to your future would also be untaxed. The self-employed have a variety of plans including Keogh/Roth IRAs.

For the unemployed struggling with a disability, Dinoto recommends applying for social security and medicare benefits. With some foresight, it may also be possible to acquire income replacement insurance to make up the difference between your salary and social security.

One of the most important things Dinoto stresses is getting your estate in order. This includes appointing someone you trust with the power of attorney, and establishing a separate living will. By offering the power of attorney to a trusted advisor, you are enabling him/her to manage your future health care, and make business decisions. Dinoto also suggests investigating long-term care insurance policies to help pay part or all of possible home care needs. This is especially important for a person with MS who may be living alone.

With the help of an attorney, your next step should be to create a will to ensure your legacy lives on to benefit your loved ones. A letter of instruction should be given to your Executor stating the exact location of your most current will. Should you use a safety deposit box to secure your will, the Executor's name should also be on it, to prevent delays in realizing your final wishes. Planning your will or estate will vary in cost depending on the amount of work involved, and the size of your estate.

Preparing Today for Financial Future

(continued from page 17)

For those struggling with debt and a fixed income, Dinoto recommends discussing debt problems with any number of non-profit financial consultants (see sidebar). "Once again, it depends on what you can pay, and a consultant would help you establish a budget, and help you begin the process of climbing out of debt," says Dinoto.

An advisor can also help you decide whether bankruptcy would be a viable option. While the debt consolidation commercials may sound tempting, Dinoto cautions strongly against signing anything before an attorney reviews it. "Whether you are planning your estate or swamped in debt, you should always move carefully before you act. Attorneys and estate planners may cost a little more, but will save you time, aggravation and money in the long term," he says.

The following is a list of available resources to help you decide your financial future.

www.financenter.com — financial tools; calculators

www.mfea.com — mutual funds under \$50

www.gomez.com — online consumer reports comparing brokers, banks, insurance companies

www.smartmoney.com
to find a financial advisor:

www.fpanet.org

www.nafpa.org

Patient Recruitment for Studies Now Underway

Inosine

Up to 30 patients are needed for a six-to-eight month study of Inosine, to determine if the agent, given as an oral capsule, is safe and has an effect on disease activity in patients diagnosed with multiple sclerosis. During the double-blind, placebo-controlled study, Inosine will be administered in a pill form; the study is under the direction of Dr. Clyde Markowitz at the Hospital of the University of Pennsylvania.

Inosine is a dietary supplement that can be purchased in health food stores and is a natural substance in our bodies. Inosine is absorbed in the gastrointestinal tract and turned into uric acid. Low levels of uric acid may be a factor that contributes to the progression of MS, thus elevated levels of uric acid may be beneficial in stopping the progression of the disease.

Who Qualifies for the Study:

Patients must be between the ages of 18 and 60 years of age and have a diagnosis of relapsing remitting MS. In addition, for consideration, patients must have had NO treatment within three months of the start of the study with Avonex, Betaseron, Copaxone, Novantrone or Rebif. Other exclusions may also apply at the beginning of the study.

Patient Recruitment Underway

(continued from page 18)

Study Procedures:

Patients enrolled in the trial will make monthly visits to the University of Pennsylvania for MRI's, blood draws, and examinations by a neurologist. Patients will be expected to take the medication twice-daily on a daily basis. The Inosine study will last approximately six-to-eight months.

For more information, please contact Tara Ordille at the Hospital of the University of Pennsylvania at 215-662-4893.

Investigational Drug

A Phase II research study at the Hospital of the University of Pennsylvania, Department of Neurology, is looking for six patients for a new study, which will evaluate the safety and efficacy of an investigational drug in those with relapsing remitting MS. Funded by Bristol Myers Squibb, the study is a ten-month double blind, placebo controlled effort, with nine intravenous infusions. The drug is being used for the first time in MS, but studies suggest that the agent is involved in the blockage of the T cells in the immune system, which is involved in MS.

Inclusion/Exclusion Criteria

Female and male volunteers 18-55 years of age with relapsing remitting MS who have been unable to tolerate or have never used immunomodulating therapy to treat MS. (For example, interferons (Avonex, Betsaseron), glatiramer acetate, (Copaxone) or mitoxantrone). Patients cannot participate if they are pregnant or planning a pregnancy and must practice two forms of birth control. Volunteers cannot have had an exacerbation within two months of enrollment in the study, but must have had one relapse in the past two years. Tests and evaluations will be paid for by the study. Additional eligibility criteria will be discussed at time of enrollment.

For more information, please call Tara Ordille at 215-662-4893.

WE WANT TO HEAR ABOUT YOUR HOBBIES!

Traditional or unusual, we want to know what our members like to do for fun and relaxation! Responses will be published in a future edition of MS Connection. Please send responses to: National MS Society, One Reed Street, Philadelphia, PA 19147, Attn: Jeanette, Fax: 215-271-6122 or email Jeanette: jeanette.smith@pae.nmss.org

Mutual Help Network

TO PLACE AN AD: Write to the
MUTUAL HELP NETWORK
 National MS Society
 1 Reed Street, Suite 200
 Philadelphia, PA 19147.
 Since space is restricted, we ask that
 you limit your ad to 40 words or less.

WANT TO RESPOND TO AN AD?

All names and addresses of those
 placing ads are strictly confidential.
 To respond to an ad, please send a
 short response letter, including your
 name, address and phone number,
 and mail to: **National MS Society**,
 AD #_____, 1 Reed Street, Suite 200,
 Philadelphia, PA 19147.

Ad #109. I am looking for a part-time
 office or home position. Bright, outgoing
 woman w/excellent communications
 skills. Accomplishments include teaching
 computer literacy, creation of manuals,
 bookkeeping, and varied clerical duties.
 Quick learner who is open to any work.
 Live in Chester County, western suburbs
 of Philadelphia.

Ad #111. 50-year old woman with MS
 has just been diagnosed with breast
 cancer. Would like to talk to others
 who have been hit with a "double
 whammy." Let's compare notes.

Ad #112. 44-year-old-woman with MS
 and 16 years of experience as a
 paralegal in Southern NJ (Cumberland
 County), is looking for full time flexible
 work schedule with a compassionate
 employer. Willing to work from home
 or in the office.

Ad #113. Woman looking for same to
 share two bedroom, two bath condo in
 Mount Laurel Township. Share
 utilities. Condo has accessible ramp;
 pool facilities extra.

Ad #114. Anyone interested in
 receiving a flyer or buying candles
 please write. A portion of the proceeds
 from all sales goes to the National
 MS Society.

Ad #115. My life has just begun!
 Care to share? Average build, WWWF,
 47-years-young ISO 40-to-50 year-
 young WSM who also enjoys relaxing
 day trips, dining and dancing. If need
 be, I will drive within 1 1/2 to 2 hour
 radius of Lehigh Valley area.

Ad #116. Female looking for disabled
 female to share accessible house in
 nice neighborhood in South Jersey.
 Aids services and transportation
 readily available.

Ad #117. 61 Year-old man with MS
 would like to help others as handyman,
 driver, with cleaning and more.

Abington area woman needs driver
 two days a week to transport her
 using her handicapped accessible van
 from home to center city Philadelphia
 in morning, then back again in the
 afternoon. Willing to pay \$8-\$10 per
 hour. Approximately five hours
 between morning and afternoon trips.
 Urgent! Call Elinor at 215-657-3762.

Information for Health Care Professionals

The Greater Delaware Valley Chapter is pleased to provide information to health care professionals in the area about a multitude of opportunities to learn more about multiple sclerosis. In addition, this vital information will help them care for their patients with MS in a more comprehensive manner.

Professional Resource Center

Health care professionals can obtain the information they need and resources that can help their patients through the National Society's Professional Resource Center (PRC). A full service resource for internists, physical therapists, gynecologists, urologists, mental health counselors, neurologists and other health professionals, the PRC offers professional information and library services providing consultation about MS and its management and a range of library and literature search services, continuing education programs, and more. For more information, please call 866-MS-TREAT or email, MD_info@nmss.org for physician or HealthProf_info@nmss.org for all others.

Educational Opportunities

The first federally funded MS training program for neurologists, developed by

the University of Texas in collaboration with the National MS Society, is now available. The *Multiple Sclerosis Comprehensive Treatment Training Program*, under the direction of Dr. Elliott Frohman at the Southwestern Medical Center in Dallas, combines a comprehensive self study curriculum with an intensive on-site clinical preceptorship. The program is approved for 35 hours of continued medical education credits.

Applicants accepted into the program will first complete an extensive 15-module self study program; after completion, participants will travel to Dallas for a two-day comprehensive preceptorship, working directly with MS specialists to observe new patient consultations and follow up evaluations.

This opportunity for neurologists who want to learn more about MS is offered at **NO CHARGE** and includes travel, lodging, on site meals and instructional materials. The program will be offered 25 times in 2002. For more information about this program, please call the MS Comprehensive Treatment Training Program at 214-648-9559.

Literature Available

Area health care providers are also welcome to contact the chapter's Resource Center at 800-548-4611 for the following clinical bulletins and professional information. All information is provided free of charge.

Information for Health Care Professionals

(continued from page 21)

Clinical Bulletins:

- Basic MS Facts
- Bladder Dysfunction in MS
- Bowel Management in MS
- Cognitive Loss in MS
- Community Resources for People Dealing with MS
- Complementary and Alternative Medicine in MS
- Diagnosis and Management of Vision Problems in MS
- Disease Management Consensus Statement
- Emotional Issues of the Person with MS
- Management of Fatigue in MS
- Pain in MS
- Primary Care of the MS Patient
- Talking with Your MS Patients About Difficult Topics: An aid to physicians and other healthcare professionals to help them talk more comfortably with their patients about sensitive MS-related issues such as diagnosis, disease progression, elimination difficulties, sexual dysfunction, emotional changes and cognitive dysfunction.
- Pam Cavallo Professional Education Series: Focuses on maintaining a high level of quality care for people with MS. The series includes: Multiple Sclerosis: A Model of Psychosocial Support; Multiple Sclerosis: The Nursing Perspective; and Multiple Sclerosis: A Focus on Rehabilitation.

For more information about the materials listed in this article, please call Stephanie at 800-548-4611, ext. 163.

Website Section Answers Questions on Annual Giving

To keep supporters up-to-date on issues involving ways to give to the National MS Society, the Society has launched a new portion of the website at www.nationalmssociety.org.

For information, click the DONATE button, then GUIDE TO GIVING. Discover the tax and income benefits of

various kinds of special gifts and read about trusts and annuities that provide payments for life; how to make gifts from life insurance policies, retirement plan assets or appreciated property.

In addition, you can find out how a particular gift will work for you or calculate your income tax deduction for a specific plan with our gift calculator. For information please email us at giftplanning@nmss.org or call 800-923-7727.

Chapter Needs Your Help For New Event: Women Against MS

Would you like to help the chapter make the most of its “women power?” Then consider getting involved in the planning of the first local Women Against Multiple Sclerosis (WAMS), event scheduled for the late fall of 2002.

This new initiative joins women throughout the area from all walks of life: chapter members, women in business, the sciences, the arts and education—all in the fight against MS. “WAMS has several purposes,” says Event Manager Christine Funchion. “Through the event, we’ll educate more women about MS, while we raise funds for the mission. We’re very excited about this new venture, which will also build camaraderie among chapter women and their supporters. It’s also a great chance for the public to learn more about MS: how it affects more women than men and how targeted research is now underway to determine the cause of these differences.”

The chapter is looking for members to “captain” table sales, help with the planning of the luncheon or dinner, identify sponsors and other women and men who would like to be involved. Tickets for the event will be approximately \$100 per person; the event will feature an exciting speaker as well as luncheon or dinner in a beautiful setting.

“When Sylvia Lawry founded the MS Society over 50 years ago, she was setting an example for all women involved with our organization,” Funchion continues. “Today, led by her example, women are still a driving force in raising awareness and funds for research and programs.”

For more information about WAMS, please call Christine Funchion at 800-548-4611 ext. 112 or email her at Christine.funchion@pae.nmss.org.

Fight MS With The Camden Riversharks Sunday, July 28

Special thanks to Gerald Feigin, a Gloucester County resident and MS 150 Bike Tour cyclist, who is organizing a special outing to fight MS with the Camden Riversharks Baseball team.

You and your family can join Gerald on Sunday, July 28 at 1:35 p.m. in the Camden Riversharks Stadium, right on the Delaware River waterfront for an exciting game and a chance to meet with other MS Society supporters. Tickets are \$7 each, with 50 percent of Gerald’s ticket sales going directly to benefit the National MS Society.

Interested? Just send a self addressed stamped envelope as well as your check or money order to Gerald Feigin, 63 Berkshire Drive, Sewell, NJ 08080 or email Gerald at gfeigin@co.gloucester.nj.us to let him know how many tickets to reserve for you. Tickets will be mailed to you or can be picked up at the game.

Thanks for Your Support

Chapter's 5th Dinner of Champions Honored Joe Paterno

More than 600 local residents joined the Greater Delaware Valley Chapter on March 1 to pay tribute to a living legend, the Head Football Coach at Penn State University, Joe Paterno.



The festive event, the chapter's fifth Dinner of Champions, featured a black tie tailgate reception complete with cars and SUV's at the Adam's Mark Hotel, followed by dinner, dancing and the awards program, when "the winningest coach in college 1-a football," received the Hope Award for his outstanding philanthropic and community service.

The event, which received exceptional media coverage, raised \$500,000

toward MS Society programs, services and research thanks in large part to the efforts of Dinner Chair, Ira Lubert of The Lubert Organization (in photo, right); Vice Chair, Nicholas Maiale, (left); shown with Joe Paterno.

New MS Ambassadors Join the Cause

The National MS Society welcomes three celebrities as new National Ambassadors for the MS cause and work of the Society.

Chef Kathleen Daelemans, a renowned chef who can be seen on the popular weekly program, *Cooking Thin* on the Food Network, also has a new book published by Houghton Mifflin in which she promotes healthy, tasty and easy to prepare meals. Her book and show are life enhancing for all, but especially for people with MS who are frequently seeking ways to conserve time and energy.

David Baldacci, a former trial lawyer turned writer, became involved with the Society after his sister was diagnosed with MS. Each of Baldacci's seven novels has hit the national and international bestseller lists and *Absolute Power* was made into a feature film starring Clint Eastwood and Gene Hackman. You might have caught his 'plug' for our cause in the travel magazine, *Arrive*.

Country music star Clay Walker, who holds four platinum and two gold albums was diagnosed with MS in

MS Ambassadors

(continued from page 24)

1996. Clay says that having MS has taught him that he cannot control everything, which has changed the way he interacts with his family. In support of our cause, Clay has recently done a

PSA and a number of radio interviews promoting our WALKS.

Thanks to these and all celebrities who take their time and effort to help those with MS and spread the word about our mission: to end the devastating effects of multiple sclerosis.



Thanks to Our Walkers

More than 11,000 local residents and chapter members stepped a little closer to a cure at the chapter's 14th annual MS WALK at 21 sites throughout the Delaware Valley in April and May. "Thanks to our teams, individuals and all who volunteered, the chapter raised an amazing \$1 million plus through the WALK," according to Megan DiPanni, local WALK manager, "making us, once again, one of the largest WALKS in the nation."

As always, the day offered camaraderie with others, the fun of walking and enjoyment of the outdoors, the joy of greeting old friends and making new acquaintances and, of course, raising funds for our vital mission; to end the devastating effects of MS. Our sincere thanks to ALL who made this exciting event a reality.

In addition to the traditional MS WALKS in 2003, the chapter is also planning for the future with the Society's new Challenge WALK, a three day, 50-mile WALK that is being held in seven sites across the United States in 2002. "We hope to unveil this event in our area in 2003," says John Scott, the chapter's senior vice president. "Although this exciting event is not for everyone, it will offer a real challenge to those who want to challenge themselves and their abilities, as well as raise public awareness. We're eager to get started on this new event as well as looking forward to another year of our traditional WALKS." For more information about the Challenge WALK, please call Jennifer at 800-548-4611, ext. 103 or visit the website at www.walk4ms.org; for more information about the MS WALKS, please call Megan at 800-548-4611, ext. 115.

PATF Announces New Interest Rate

The Pennsylvania Assistive Technology Foundation (PATF) now has a 4.25 % interest rate on loans for individuals with disabilities to purchase assistive technology.

The PATF recently created two new partnerships with lending institutions to make assistive technology loans more affordable and flexible for those with disabilities and/or their family members. Assistive technology devices include items such as visual aids, hearing aids, wheelchairs, scooters, entry ramps, computers with adaptive peripherals, adapted vehicles and home modifications. Services that directly assist an individual with disabilities in selecting, acquiring, using and customizing assistive technology are also included in the program. For instance, training on how to use equipment or devices is considered a valid service.

With unique benefits that no other traditional lending program offers, the PATF has become the premiere financing program for assistive technology in Pennsylvania. Special benefits to those with disabilities include: an exceptional low interest rate; an ability to guarantee a loan; flexible repayment terms based on the equipment purchased; no application or

service fees and an easy application process conducted by mail.

PATF is a nonprofit organization with a statewide financing program supported by the PA Department of Community and Economic Development and the National Institute on Disability Rehabilitation Research through the U.S. Department of Education. Applications may be obtained by calling 888-744-1938.

Pharmaceutical Companies Offer Price Discounts For Eligible Medicare Recipients

Four pharmaceutical companies are offering a prescription discount program for Medicare beneficiaries with no prescription drug coverage. GlaxoSmithKline, Novartis, Pfizer, and Eli Lilly are offering varying terms of specific drug coverage, and size of discount for eligible recipients. There is no cost to join these programs, and more information can be found at the companies' websites, or by calling the numbers listed below.

There is a possibility that all four of these plans may be combined into one discount prescription program that will include any latecomers to the program. Discussion of the plan is currently in progress. *(continued on page 28)*

Prescription Discounts for Low-Income Medicare Recipients *(continued from page 27)*

	GlaxoSmithKline	Novartis	Pfizer	Lilly
Card	Orange Card	Care Card	Share Card	Lilly Answers
Medicare Recipient	Yes	Yes	Yes	Yes
Income/ Individual Couple	\$26,000 \$35,000	\$26,000 \$35,000	\$18,000 \$24,000	\$18,000 \$24,000
Discount	25% off wholesale list price	25% off wholesale list price	\$15 per 30 day supply	\$12 per 30 day supply
Drugs Covered	All out-patient products	Selected out-patient products	All products	All products
Sample of Drugs Covered	Paxil	Lescol	Lipitor Neurontin Zoloft	Prozac
Enrollment	1-888-ORANGE6	Pharmacists	1-800-717-6005	1-877-RX-LILLI
Website	www.gsk.com	www.novartis.com	www.pfizerforliving.com	www.lillyanswers.com

- GlaxoSmithKline and Novartis use 300% of poverty level for their guidelines
- Alaska and Hawaii may have higher eligibility than these figures

Local Researcher Receives Pilot Research Project Grant

Franca Cambi, MD recently received a pilot research award grant of \$33,000 to study “PLP splicing: in vivo analysis in a mouse model.” In her studies, Dr. Cambi hopes to determine how a gene that controls a protein in myelin-making cells may contribute to the loss of myelin and damage to the nerve fibers in MS.

Identifying the factors that contribute to the progression of MS is one of the greatest challenges for researchers. It is increasingly recognized that this progression is associated with damage to nerve fibers. Dr. Cambi is investigating one factor that might contribute to this

damage. In previous studies, her research team found that deleting a mouse gene that controls a specific protein in myelin resulted in the loss of nerve fibers. This suggests that the protein—known as proteolipid protein (PLP), might be crucial to the health of nerve fibers.

In this pilot study, Dr. Cambi and her colleagues are generating a unique rodent model in which certain genes that regulate PLP have been deleted. They are studying the model as the brain develops and myelin forms, to observe how the absence of this protein alters the integrity of myelin and nerve fibers.

These studies can help identify targets for treatments that may prevent or slow down damage to nerve fibers and the progression of MS.

FDA Approves Rebif For Relapsing Forms of Multiple Sclerosis

The U.S. Food and Drug Administration (FDA) has approved for marketing Rebif, (serono Inc., Geneva, Switzerland), a form of interferon beta 1a for the treatment of relapsing forms of MS. Relapsing forms of MS involve clearly defined disease relapses with full recovery or with residual deficit upon recovery.

The FDA approval was based on results from two clinical trials. One, the PRISMS study (Prevention of Relapses and Disability by Interferon beta 1a Subcutaneously in MS), was an international, multi-center clinical trial conducted at 22 centers in Europe, Canada and Australia, which tested two doses of Rebif or placebo, self administered three times a week for two years. This study showed that Rebif caused a statistically significant reduction in relapse number and frequency, slowed progression of disability and reduced lesion activity in the brain, determined by MRI.

Results from the PRISMS trial were first announced in 1997, and based on those results, Rebif is available for use in MS in over 60 countries worldwide. An application for marketing approval in the United States was not approved then by the FDA, due to provisions of the Orphan Drug Act that provide incentives for pharmaceutical companies to develop

medications for relatively rare disorders. One provision, a market exclusivity for a first new drug for a condition for seven years, was in place for Avonex, (Biogen, Inc.), the interferon beta-1a product available for relapsing-remitting MS that was approved by the FDA in 1996. Because of this provision, Rebif was prevented from being on the market in the US until 2003, unless “clinical superiority” of Rebif over Avonex could be demonstrated.

With this in mind, Serono Inc. undertook a direct “head-to-head” comparison study of Rebif and Avonex in the EVIDENCE trial (Evidence for Interferon Dose Effect: European-North American Comparative Efficacy). The trial was designed based on Serono’s belief that Rebif, delivered at 44mcg three times a week, injected subcutaneously, would perform better than Avonex, delivered at its standard dose (30 mcg once a week, injected intramuscularly). The EVIDENCE study was a short-term, six-month trial involving 677 individuals with relapsing-remitting MS, half receiving Rebif and half receiving Avonex. The six-month treatment results were in favor of Rebif on all primary and secondary outcomes of the trial, including fewer relapses and reduced accumulations of lesions in the brain detected by MRI in those treated with Rebif compared to those treated with Avonex.

Relapsing Forms of MS *(continued from page 29)*

At a recent annual meeting of the American Academy of Neurology (AAN), Hillel Panitch, MD, from the University of Vermont College of Medicine and researcher for the EVIDENCE Study Group, presented findings from the Rebif vs. Avonex head-to-head study for the period of 48 weeks. These findings show that the occurrence of relapses and accumulation of active lesions as detected by MRI continue to show a statistically significant difference in favor of Rebif.

Side effects for both agents including flu-like symptoms were well tolerated and in line with what have been reported previously for interferon betas. There were, however, some differences. According to the Medical Officer's Review issued by the FDA, "Abnormalities of liver function tests and decreases in white blood cell counts and injection site reactions, including pain, were more common in the Rebif group, although most were mild to moderate in severity." Decreases in white blood cell counts were not associated with increased incidence of infections. Details of the FDA's analysis of data from the Rebif/Avonex clinical trial are available at the FDA's website at <http://www.fda.gov/cber/products/ifnbser030702.htm>.

In approving the marketing of Rebif for relapsing forms of MS prior to mid-2003, the FDA signaled its view that this form and dose of interferon beta 1a provided benefit for individuals with relapsing forms of MS (from the original PRISMS study), and that, at least within the confines of the EVIDENCE study, Rebif showed superiority over Avonex. How these drugs compare in terms of effectiveness and tolerability in longer-term, regular use remains to be seen.

With the addition of Rebif, there are now five drugs—Avonex, Betaseron, Copaxone, Novantrone and Rebif—approved in the U.S. for treating the major forms of MS. The FDA approval on March 7, 2002 provides additional treatment options for individuals with relapsing-remitting MS in the United States. Each of the approved treatments has pros and cons. The decision of which therapy is best for any individual should be determined in consultation with his or her personal physician.

Rebif is currently available in the United States in pre-filled syringes that can be used with an auto injector. Dosing of Rebif is three times per week, subcutaneously. More information about Rebif is available from the company online at www.rebif.com or by calling 1-877-44REBIF or by visiting your neurologist and requesting a resource kit with product information and a videotape.

Modest Success In Blood Stem Cell Transplants for Severe MS

Chemotherapy, a cancer treatment, has shown positive short-term results in treating those with severe MS. Twenty-six participants received transplants of their own blood stem cells after their immune cells were destroyed by chemotherapy, in hopes of reconstituting new immune systems free from the effects of MS (in effect, completely replacing the subject's immune system). After one year, 20 out of 26 patients have appeared to stabilize, with one fatality due to complications with the procedure. All patients in the study experienced significant progression of their disease in the year prior to the start of the tests, and had not benefited from any other types of treatment.

Larger and more controlled studies are needed to assess the safety and benefit of this potentially life-threatening treatment for those with MS.

Early Studies Suggest Lipitor May Treat Rodent Models of MS

At two recent scientific meetings, study results were presented suggesting that Lipitor (atorvastatin) and other "statins,"

which are drugs used to lower cholesterol, can treat experimental animal models of MS. This research adds to previous basic studies that suggest that statins can alter immune responses in a way that may hold promise in treating human MS, which involves immune attacks against brain and spinal cord tissue. Human clinical trials will be needed to determine whether statins can benefit persons with MS. At least one preliminary clinical trial is now under way.

In the studies, a group of investigators from Stanford University and the University of California at San Francisco reported that treating mice with EAE with oral Lipitor at the onset of their disease could reverse its paralysis, and that treating mice after an acute attack could resolve the attack. Looking at their brains and spinal cords, the treated mice appeared to have less damage than would be expected.

Another group of investigators from the Karl-Franzens University and Heinrich Heine University, in Austria and Germany respectively, examined the influence of different forms of statins on white blood cells in test tubes taken from individuals with MS and healthy control subjects. This study showed that several forms of statins including mevastatin, simvastatin (Zocor), and lovastatin (Mevacor), could inhibit the immune cells' responses, the immune messenger proteins they released and specific markers of inflammation, all of which are hallmarks of the immune attack involved in MS.



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
Permit No. 3428
Phila., PA 19107

Greater Delaware Valley Chapter
1 Reed Street
Philadelphia, PA 19147

Return Service Requested

Contents

What's In This Issue

People with MS	Page 5
Calendar of Events	Page 10
Wellness Center Calendar	Page 12
Social Security Disability	Page 14
Classified	Page 16
Mutual Help Network	Page 20
Fund Raising Update	Page 23
Research Update	Page 29

This issue of MS Connection is co-sponsored by Serono, manufacturer of Rebif.