



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY

MSConnection

December 1998

Greater Delaware Valley Chapter

Nature's Way to Energy

For many people with MS, increasing energy isn't just a way to add more chores to an already crowded day—it's a necessity for getting through the essentials of dressing, bathing and preparing a meal.

Unlike the "plain old tired feeling" others experience, for those with MS there are physiologic and neurologic causes for the fatigue associated with the disease. Getting a few extra hours of sleep or changing eating or exercise patterns probably won't help as much as they would if you were just "burned out."

As a result, the idea of a safe effective herbal energy enhancer or eating organic foods as a way to enhance energy seem quite attractive. For

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herbal remedies, you don't need a doctor's prescription, the products are often less expensive than prescription medication and the word "natural" on the label often gives the consumer the impression that the product is gentle and safe. But before you head on over to the local health food store, there are a few important points to keep in mind.

For Herbal Remedies;

****First, it's always dangerous to medicate yourself and something you buy in a drugstore or at the health food store may interact negatively with medications you're already taking. You should always talk with your doctor and your pharmacist before starting**

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Nature's Way to Energy (Con't. from page 1)

any new treatment. Be sure to advise them of all medications you are currently taking, so he or she can talk with you about drug interactions and adverse effects.

****Herbal remedies aren't classified as drugs, which means they don't have to undergo the extensive testing required for prescription medication and many over the counter products.**

In addition, according to Irene Doniger, founder of the Mind-Body Connection in King of Prussia, since herbal reme-

dies aren't held to the same testing standards as mainstream remedies, there is a question of quality. "I suggest looking at quality control studies to make sure there is no contamination of the herb, and, in fact, to be sure the ingredient is actually there as advertised! It's very important to do your research."

Once the research is done and after talking with physicians and pharmacists, many people do decide to use a combination of herbal food supplements and prescription medications to manage MS symptoms. A few of the most common are:

St John's Wort, the only herbal enhancer that has been studied in any depth, has been widely used in Europe for the treatment of mild to moderate depression, anxiety and unrest. Scientists are uncertain about exactly how it works, but there is some evidence that it may act to regulate the serotonin system. But since this herb is used to treat depression, but not fatigue per se, it may help with a symptom, but not with the cause of fatigue.

There are many kinds of **ginseng**, and all have been used for centuries to increase feelings of well being as well as increase energy and health. In studies conducted by Mary Ann and Joseph

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

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Greater Delaware Valley Chapter

Nature's Way to Energy (Con't. from page 2)

Mayo, it was found that as an adaptogen, Siberian ginseng helps people improve mental performance and is frequently used for those suffering from chronic fatigue. American ginseng is highly prized in Asia, but is so energizing you shouldn't take it before going to bed. Doniger believes that ginseng is excellent for energy enhancement but suggests using the herb with care.

Guarana has a chemical similarity to caffeine and the same physiological action, but has a number of potential negative effects as well. An elevation of temperature is common with ingestion of a high concentration of the herb, also urinary retention, high blood pressure and constipation—all side effects that will make MS symptoms worsen. The concentrate of the drug in most soft drinks will probably be low and not produce any more adverse effect than a cup of strong coffee, however there is no standardization of how much active substance in any product you ingest.

Ephedra or Ma Huang is sold as a stimulant and weight loss product. While the cautions for ephedra and caffeine are similar, ephedra has a greater effect on cardiovascular activity than does caffeine. It is often combined in diet or energy products with caffeine or a natural caffeine source

such as kola nut, guarana or tea. The combination can be especially powerful, with adverse effects such as dizziness, jitters, heart irregularities. It will also cause an increase in blood pressure and has led to stroke, heart attack and seizures.

Doniger also suggests high grade bee pollen as an energy enhancer, liquid aloe to modulate the immune system and high quality antioxidants, such as red wine extract and grape seed extract, which are both excellent in increasing energy.

Dietary Paths to Energy

With the many health food stores and “natural” supermarkets now in the area, organic foods are easier to obtain than in the past and appear in a wide array of appealing products.

Although it's very difficult to eat only organically grown food, everyone can try to eat a little healthier. Doniger says, “I tell everyone to scrub their fruits and vegetables well, get plenty of green drinks with chlorophyll and to increase intake of the essential omega 3's and 6's—very important oils for the myelin sheath. Flaxseed oil and salmon are excellent sources, and you can grind flaxseeds yourself for oil or sprinkle them on salads,” she continues.

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Nature's Way to Energy (Con't. from page 3)

Doniger also feels that lifestyle choices are an important part in energy enhancement. She asks her clients at the Mind-Body Connection to keep a food and beverage log, note their exposure to possible allergens and pets, and note how much exercise they get.

"Almost immediately, I teach a few stress reduction techniques," Doniger says, "And I start them on my herbal cleansing process. Sometimes that alone will increase energy."

"When I counsel clients I also look at support systems, and pacing. Many people with MS run at 60 m.p.h. when they feel well, to make up for the times they're not able to get much done. Of course, that doesn't really serve their systems very well."

Doniger, a registered nurse, a licensed psychologist and herbalist, believes in

integrative medicine and works with the clients physician in everything she does.

"Sometimes my clients will say," My doctor really won't like it that I'm trying....whatever it is. But I say this is about you, at the same time that I consult with the physician."

Whatever you're doing to increase energy, it's important to look at the whole system of your life, Doniger says. "All area of life are important for maximum health."

Doniger also reminds people that, "You can experience amazing spiritual healing yet still have the physical symptoms of MS. For every loss, you may find at least two or three gains in life, or have learned at least two or three things about life. For most of us, that's a big part of healthy living."

Call for 1999 Nominations For Chapter Mother/Father of the Year

Do you know a mother or father with multiple sclerosis who's a terrific parent? Does that person demonstrate qualities of courageousness, and determination and live as a positive role model? How about getting involved in his or her children's activities, participating in the community and church or other life affirming activities? If so, you should consider nominating he or she for the Chapter's

1999 Mother /Father of the year award!!

Each local chapter winner from across the country is also entered into the National Society's Mother/Father of the year competition, in which the winning candidate visits the President, right in the Oval Office! To nominate a candidate for Mother/Father of the Year, please call Linda Smith at 1-800-548-4611 as soon as possible.

CLASSIFIED

FOR SALE: 1988 GMC CONVERSION VAN. Handicapped adapted/lift in back. Five captain chairs, tie-down for wheelchair; color television; air conditioning; AM/FM/Cassette; roof rack; 49K original miles. Recently painted. Asking \$10,000/will accept offers. Call 215-884-0769.

FOR SALE: 1991 PLYMOUTH GRAND VOYAGER LE VAN. Vantage loaded conversion. Great shape. 12,000 miles. Asking \$10,800. Call 610-449-5067.

FOR SALE: ALL ITEMS LISTED BELOW, PLEASE CALL NUMBER AT BOTTOM OF AD:

WHEELCHAIRS—QUICKIE TS. 18" wide. 16" seat. 18" high. Great features. Like new. Asking \$2,500
MANUAL WHEELCHAIRS. Removable footrest/adjustable arms. Asking \$150 each.

COMMODE WHEELCHAIR. Asking \$1600.

SHOWER BENCH. New. Asking \$100

JAY CUSHION. Never used. \$200.
NYLON MESH "SEAT AND SWING." One piece full body wrap. \$25.

RICHER LIFE EXERCISER BIKE FOR WHEELCHAIR.

Exercises arms and legs. \$1000.

BALL BEARING FEEDER. Automatic feeder with plate. \$25.

FOR ALL THE ABOVE LISTED ITEMS, PLEASE CALL 610-449-5067.

FOR SALE: 1994 VOLVO 850 SEDAN. 4 door. White with gray cloth interior. MC. Hand controls, Braun wheelchair life. 47,000 miles. \$16,500. Call 609-728-4979.

FOR SALE: 1983 FORD CLUB WAGON VAN. Ricon side lift, hand controls, six-way power driver seat for handicapped transfer. Raised roof, air conditioning, approx. 75,000 miles. Good overall condition/excellent running condition. Wheelchair tie-downs. AM/FM/Cassette player. **Estate van looking for needy owner.** Call 609-387-8317.

FOR SALE: DYNAMO PRIDE ELECTRIC SCOOTER. Inc. batteries/charger. Black and gray in color. Good condition/runs well. Asking \$800. Call 609-910-9563.

FOR SALE: 1991 4-DOOR OLDSMOBILE SEDAN. Hand controls, all automatic. 46,000 miles. Inc. Braun car topper for wheelchair. Asking \$7,000. Call 610-868-0220.

FOR SALE: BRAUN WHEELCHAIR LIFT FOR CAR. Good condition. Call 609-728-4979.

FOR SALE: PATRIOT SCOOTER. Good condition. With battery & charger; basket. Tilt arms. Asking \$1,200. Call 215-969-1254.

Bryn Mawr Rehab Launches New MS Day Treatment Program

Bryn Mawr Rehab recently launched a comprehensive, multidisciplinary MS Day Treatment Program to respond to patient's needs and to provide a treatment bridge between its inpatient and outpatient programs.

Geared to accommodate newly diagnosed as well as relapsing patients, the programs' goals are to return participants to the highest level of function and independence possible through aggressive therapy programs and to educate patients and their families about management of MS symptoms. Core therapies include physical, occupational and recreational therapies, plus other areas of concentration such as speech, assistive technology and psychological counseling added, depending upon the individual.

To be considered a candidate for the MS Day Treatment program, a resident must be able to live safely at home, have more than one area of functional deficit, have the ability to tolerate an intensive half-day or full-day program plus transportation. Patients may refer themselves or be referred by a physician, insurer, case manager or family member. For more information, please call 610-251-5664.

PVA Publishes MS Wellness Guide

The Paralyzed Veterans of America Research and Education program has recently published an informational guide for those with MS, emphasizing how those with the disease can lead full lives.

Entitled, "**Multiple Sclerosis: A Self Care Guide to Wellness**," "the 150 page book emphasizes that wellness can be achieved through education and commitment," says Kenneth Huber, PVA national president. "The guide outlines a broad spectrum of topics related to MS and their implications. Practical tips on self care are designed to promote maximum independence, well being and productivity." The guide also outlines treatments and symptom management

Copies of the Guide are available for \$9 each by calling the PVA Distribution Center at 888-860-7244 or by sending your request to P. O. Box 753, Waldorf, MD 20604-0753. The Guide is also available on loan through the chapter's Lending Library; please call 1-800-548-4611 to obtain your copy on loan.

Lending Library

Several new additions to the chapter's Lending Library are now available to members for loan. Just call 1-800-548-4611 on Tuesday or Thursday, 10 a.m. to 2 p.m., to reserve your selection, or call anytime and leave a voice mail message at extension 155.

Lending Library (Con't. from page 6)

Changing Lanes, By Michael Creuer
A Guide to Help When Aging, Illness or
Disability Forces Us Into The Slow
Lane

The chapter's librarian reviewed this book, saying, "This is a good thought provoking book for someone who is chronically ill or disabled. The author is a polio survivor and counselor who writes about his own experience and how one can still lead a full, rewarding life despite limitations." 84 pages.

The Resourceful Caregiver, By
NFCA

The guide was created by family caregivers for family caregivers, by people who know what it's like to care for and about a loved one with a chronic illness or disability. It contains over 500 resources to help caregivers help themselves and their loved ones with everything from caregiver support organizations to national respite organizations, toll-free numbers for medical transport and many other useful services, including home shopping opportunities to make life easier.

Legal Rights: A Family Guide,
Second Edition By Joseph Romano

Our chapter librarian says, "This volume answers every question that could possible arise." In addition, the

Lending Library has **Legal Rights of the Catastrophically Ill and Injured: A Family Guide**, for those who need legal information.

Sign Up To Receive Annual
Meeting Videotapes On Loan

Unable to attend the 1998 annual meeting but want information about the sessions? Then call the chapter's Lending Library today and sign up for a copy of our helpful meeting videotapes. Sessions available on tape include the Yoga workshop with Master Eric Small; the Research Update with eight local physicians who specialize in treating multiple sclerosis; Choices, a question-and-answer session with area nurses, and information on medical insurance, featuring a local insurance representative. Call today at 1-800-548-4611 to reserve your copy of these informative tapes.



1998 Annual Meeting

Legislative Leaders

The Greater Delaware Valley Chapter has many “legislative leaders,” in its midst. Foremost among them are the dedicated volunteers who serve on our Government Relations Committee, a group that meets throughout the year to address issues of legislation and education as they relate to those with disabilities.

The chair of this vital committee is the **Honorable Nicholas Maiale**, a former Pennsylvania State Representative and Ward Leader who is an active member of the chapter’s local Board of Trustees. His tireless efforts have attracted the notice of organizations throughout the city and for his many efforts, Maiale was named the chapter’s 1998 Chapter Achievement Award winner. The key issues Maiale is concerned about include accessibility for all new public buildings, and funding from the National Institutes of Health.

In addition to leader Maiale, the committee is comprised of dedicated chapter supporters such as **Fred Lublin, MD**, the chairman of our local clinical advisory committee, internationally known researcher, neurologist and director of the MS Center at Allegheny University East Falls. Key concerns for Lublin include NIH funding and regulation of the Federal Drug Administration.



Mechelle Loper Connors, Esq., the chapter’s new advocacy coordinator, (left) recently met with the Princeton Public Affairs Group coordinator Claudine Leone in Trenton, NJ. See story on this page.

Claudine Leone Esq., a member of the Princeton Public Affairs Group, has a great deal of legislative experience as the advocate for the Trenton Capitol area and chapter consultant for the New Jersey National MS Society Coalition. With her broad range of experience, Leone has many issues she would like to see addressed, including catastrophic funds for adult onset disabilities, tax breaks for people with disabilities, and the establishment of an Office of Disabilities within the Department of Health and Welfare.

Consultant for Pennsylvania Protection and Advocacy, **Terry Roth, Esq.**, is another member of the committee who has a broad range of experience and

Legislative Leaders (Con't. from page 8)

interests. Roth is currently focusing on the governor's budget issues especially attendant care, adaptive technology funding, managed care, educating state representatives, and building grass roots advocacy. Roth serves as the Harrisburg Capitol advocate, the chair of the Disability Budget Coalition and Managed Care accountability Coalition, and has previously consulted in the areas of mental health, school reform, and women's issues.

Mechelle Loper Connors, Esq., was a legislative assistant for Jamie Blackwell of City Council in Philadelphia, the assistant attorney for the Philadelphia Public Defender, a judicial law clerk and is currently the chapter's new advocacy coordinator. Loper Connors is concerned about

accessibility to all government buildings, handicapped parking rights, Action Alert notification and other vital issues.

"In addition to these chapter advocacy leaders," says Pete Kennedy, community programs director, "We have hundreds of individuals working within their communities to bring awareness of our needs to local merchants and legislators, who lead support groups, rally for the rights of the handicapped, and who regularly contact their local legislative representatives to support the rights of those with disabilities in the community."

Interested in getting involved? Please call Mechelle Loper Connors at 1-800-548-4611.

Wendy's: A Victory for the Disabled

As the result of an out-of-court settlement, Wendy's restaurants have agreed to widen or remove the zigzag arrangement of railings they use to line up people at the counter. The problem inherent in such an arrangement is that there's no provision for the handicapped, except to shunt them off to the side.

"People with disabilities do not want special treatment," said Attorney

General Janet Reno when she announced the settlement with Wendy's. "They just want to be treated like everyone else."

It's one of those little everything things the nondisabled take for granted. But when you're disabled, the ability to roll up to the counter and order a "single with cheese," is precisely the kind of thing that makes all the difference.



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY

Confused About Who We Are And What We Do?

The next time you receive a telephone call or a mail request to donate to those with MS, be sure you're contributing to the National Multiple Sclerosis Society. Here's how:

* There is only one National Multiple Sclerosis Society, comprising more than 85 chapters across the United States.

- Founded in 1946, it is the nation's oldest and largest voluntary agency working on behalf of those with MS.
- It is the **ONLY** national voluntary MS organization that meets the standards of **ALL** major agencies that rate non-profit groups.
- The local Greater Delaware Valley Chapter of the National MS Society is governed by a volunteer Board of Trustees. The chapter receives funding through special events, individual donations, the United Way donor option program and special grants. Of those funds, 40 percent of all money raised is forwarded to our National

office to support research and education on MS throughout the country, including our own region. At present, the Society is funding more than \$3 million for scientific grants right here in the Greater Delaware Valley.

- The remaining 60 percent of funds raised by the chapter enable us to provide a diverse service portfolio in the seven county Southern New Jersey and 11-county Pennsylvania area. Programs and services include:

- Information and Referral, Community Education, Public Policy Advocacy, Programs for Newly Diagnosed Persons, National Teleconference, Medical Equipment Loans, Peer Self Help Groups, Professional Led Counseling Sessions, Lending Library, Specialized Care at MS Centers, Home Health Care, Transportation for Neurologist's Visits, Educational Programs such as the Annual Meeting, Employment sessions, exercise programs, Complementary Therapies and more.

**WE SERVE MORE PEOPLE WITH MS THAN
ANY VOLUNTARY AGENCY IN THE WORLD.
For more information, please call 1-800-548-4611.**

Help for Restless Legs Syndrome Available

Do you experience burning, itching, pulling or tugging sensations in your legs? Do feel the need to relentlessly walk, especially at night? If so, you may suffer from Restless Legs Syndrome, a potentially serious and debilitating condition that affects three to eight percent of the population.

In 1990, a group of those who suffered from Restless Legs Syndrome or RLS, met and founded a group to provide support, encouragement and coping strategies in dealing with the symptoms of the syndrome. The group cur-

rently provides education, research information on diagnosis and treatment, and materials on pharmacologic therapies. In addition, the RLS Foundation publishes, Night Walkers, a newsletter one physician has called "the most comprehensive treatment of the subject ever seen."

For more information about Restless Legs Syndrome, please call the Resource Connection at 1-800-548-4611 or contact the RLS Foundation at 4410 19th Street NW, Ste. 201, Rochester, MN 55901. Or e-mail the group at rlsf@millcomm.com

Thanks to Action Alert Members Increase in National Institute of Health Funding For MS Research

Thanks in large part to the efforts of hundreds of local Action Alert members who contacted their legislators, the Senate and House recently passed a 15 percent increase in the National Institutes of Health Budget for fiscal year 1999.

As many members know, cures for chronic diseases such as MS are not possible without long-term predictable investments in biomedical research. Thus, funding for the National Institutes of Health remains a top federal issue. In fiscal 1998, the NIH

funded \$80 to \$100 million in MS related research, and the increased support will allow additional funding for scientific studies into the causes and treatments of MSA and many other devastating diseases.

According to Pete Kennedy, chapter programs director, "Calls to legislators really help accomplish our goals and my sincere appreciation to all who helped push this vital measure through Congress. We can all make a difference."

Anne Schmid

When Collingswood, NJ resident and chapter volunteer Anne Schmid was diagnosed with MS in 1978, "It was a tremendous shock," she says now. "I felt later like I had been in the dark for about 10 years (after the diagnosis). And in some ways, Anne was, "in the dark." Her presenting symptoms of MS were optic neuritis in both eyes, although not at the same time, she is quick to add. "But for a woman who needed her eyes to do her job, I was pretty upset." says this former copywriter for W.B. Saunders, a medical publishing company.

Work was a vital part of Anne's life, so her inability to meet her job responsibilities was upsetting and unsettling. At the same time, her company was purchased by another publishing house, and her once excellent medical benefits were diminished. "I decided to go out on disability before I lost additional medical benefits," Anne says. "I'm still glad I left when I did, but I needed to find a way to restructure my life.

As a member of the Burlington County Support Group, Anne found that the chapter's local MS self help groups programs were extremely helpful in making the transition, coping with MS symptoms, and meeting new people. "I found the interactions with other people with MS very important," she says.

"I didn't feel so sorry for myself because you can see what other people are dealing with. The coping tips were also great. I'd recommend support groups to anyone."

Anne also attends many chapter educational programs and volunteers for the Society in numerous ways. She is best known to the chapter staff at the Penn Jersey office for her work as an administrative volunteer, where she organizes the work flow and plans duties for the Penn Jersey office administrative volunteers. In addition, she is well



Collingswood, NJ resident Anne Schmid has volunteered for the chapter in a variety of ways for many years. See her story on this page.

known in her local community for her work at the Moorestown MS WALK,

Anne Schmid (Con't. from page 12)

where she works in the registration area and sets up the finish line picnic lunch.

This active volunteer is also involved in the Collingswood Community Chorus, where she has been a talented member for 12 years. "There are about 60 members of the chorus and we sing at the local high school, senior citizen homes and other local organizations," Anne says, "It's a real source of pleasure for me."

Anne is also a member of St. John's

Catholic Church and, at 6' tall, a bona fide member of the local Tall Club, which plans social activities and sponsors a yearly convention for "those of height."

As the oldest of nine children, Anne also enjoys visiting her brothers and sisters and playing aunt to her many nieces and nephews. "I've learned to deal with MS," she says, "Make the most of what I have and enjoy each day to the fullest."

Sunflower Basket Company Donates Proceeds to Chapter

Looking for a great way to commemorate a special occasion and donate to the Greater Delaware Valley Chapter? Call the Sunflower Basket Company of Blackwood, NJ and ask them to put together a beautiful fruit, gourmet food, or bath-and-body gift basket for your next birthday, shower, graduation or anniversary. "Ten percent of all proceeds from items sold in the month of January will be donated to the chapter," says business owner Lorraine Pantarelli. "And we ship or deliver anywhere and accept Visa and Mastercard."

Pantarelli has a long time interest in multiple sclerosis due to her sister

Rosanne Kassab-Perno, a chapter member with MS who has headed the South Jersey Friends of MS for many years and conducted numerous fund raisers on behalf of those with the disease. "I want to do everything I can to help," Pantarelli says. "All I ask is that customers mention the MS Society when they call, so I can properly credit the donation to the chapter."

For more information and to place your order, please call the Sunflower Basket Company at 1-609-435-8900.

DECEMBER



Yoga is very beneficial for those with MS

JANUARY

Yoga

Yoga has been shown to increase flexibility, coordination, strength and self esteem. Explore this relaxing form of exercise in a class for all ability levels. Instructed by Samantha Seddon. To register, call Gavi at 1-800-548-4611. **Registration deadline is Monday, December 28, 1998.** Space in all fitness series sessions is limited; first-come, first-serve!

Day: Mondays

Date: January 11 to March 1, 1999

Time: Noon to 1:00 p.m.

Location: Burlington County YMCA, Mt. Laurel, NJ

Fee: \$15 class fee for current YMCA and Society members. \$40 for NMSS members who are joining the YMCA as a new member.

Yoga

Experienced instructor Pat Albright will be teaching sessions for all ability levels. Her class features a variety of movements and breathing techniques combined with beneficial exercise and fun! For registration information, call Gavi at 1-800-548-4611. Space is limited so sign up today. Registrations are accepted in the order received!

Registration deadline is December 30, 1998

Day: Wednesdays

Date: January 13 to March 3, 1999

Time: 6:00 p.m. to 7:00 p.m.

Place: Carousel House, Philadelphia

Fee: \$25

January (Con't. from page 14)

Pennsylvanians With Disabilities Day
Celebrate the 10th annual Pennsylvanians with Disabilities Day, recognizing and celebrating the accomplishments of persons with disabilities in the state's communities. Held on Franklin D. Roosevelt's birthday, this popular event will be held this year:

Date: Friday, January 29, 1999

Time: 11:00 a.m.— Social Hour
Noon—Luncheon

Place: Green Pond Country Club,
Bethlehem

Cost: \$13 per person

To receive an invitation or reserve your place at lunch, please call 1-610-866-8092, Ext. 350.

FEBRUARY

Women's Day

Join the Greater Delaware Valley Chapter for a day devoted to women with multiple sclerosis! Explore issues of health and wellness, make new friends, gain inspiration and knowledge from experienced speakers. A popular program—sign up today! To register, call Gavi at 1-800-548-4611.

Day: Saturday

Date: February 6, 1999

Place: West Jersey Hospital, Voorhees,
NJ

Time: 9:30 a.m. to 2:00 p.m.

Staying Fit:

An Exercise Clinic For You

Ready to discover your fitness potential? Work out with Julie Mount, Ph.D., PT or Carol Leiper, Ph.D., PT and their team of physical therapy students, who will serve as personal trainers, in this personally- designed, eight week program, which offers individual and group activities, including resistance training, aerobic exercise, stretching and coordination exercises.

You'll first receive an individual physical therapy evaluation, then follow up with an exercise regimen designed just for you. The trainer to participant ratio is one to two!!

The program is offered in two convenient locations but SPACE is LIMITED! Call Gavi to register today, 1-800-548-4611. **Registration deadline for both locations is January 8, 1999.**

Philadelphia Location

Thomas Jefferson University

Instructor: Julie Mount, Ph.D., PT

February (Con't. from page 15)

Days: Mondays and Fridays

Dates: February 1 through March 29, 1999

Time: 8:30 a.m. to 9:30 a.m.

Place: Thomas Jefferson University

Fee: \$75 plus a doctor's referral

Glenside Location

Beaver College Campus

Instructor: Carol Leiper, Ph.D., PT

Days: Mondays and Fridays

Date: February 15 to April 12, 1999

Time: 11:00 a.m. to Noon

Fee: \$75 plus a doctor's referral

Volunteers Needed!

MS Campaigns HELP DESK
January-September

Volunteer your time for this innovative project! Members needed to staff a general assistance phone line, where you'll be answering questions about fundraising events such as the MS WALK, MS 150 Bike Tour and other campaigns. We'll train you and provide all necessary information. You'll help us by giving directions, sending pledge sheets, taking phone registrations for events and more. Good telephone skills needed! Call Angela at 1-800-548-4611.



Chapter member Mike Monaghan and his family volunteer for the chapter through the MS WALK. See all the ways, including the WALK, that you can get involved as a volunteer on the next three pages.

Volunteer-Community Relations
January-September

We need your help in spreading the word about the activities and events of the National MS Society. Please contact us if you are willing to distribute event brochures to local stores in your neighborhood. No solicitation is necessary.

If you're interested in volunteering or have questions on how to volunteer for any of the fundraising or marketing activities of the local chapter, please call Angela DiGuiseppe at 1-800-548-4611, ext. 119.

VOLUNTEERS NEEDED

Lending Library Volunteer Needed

Do you like to assist in the chapter's Lending Library? A volunteer is now needed on Tuesdays from 10 a.m. to 2 p.m. to help answer member telephone calls for information, file and categorize materials, assist callers in making selections and sending/reviewing requested materials. We'll train you! Call Barbara Messing today at 1-800-548-4611 for more details.

Clinic Liaison Health South Rehab in Reading

We're looking for a Clinic Liaison at the Health South Rehab Hospital of Reading. This services liaison provides education and support to clients and family members seen at the MS Clinic at that location. The position includes assisting the Rehab Nurse with scheduling appointments for the monthly clinic as well as attending the clinic to establish rapport with MS clients, provide peer support and information about community resources and the MS Society. Successful candidates will need excellent communication skills, knowledge of MS and experience working in a health delivery field. For more information, please call Rebecca Polss at 1-800-548-4611.

Chapter Public Relations Volunteer Opportunities

MS WALK Publicity Volunteer

Would you like to help the chapter publicize the MS WALK and educate people in the community about multiple sclerosis? Then you may be interested in serving as one of our MS WALK publicity volunteers! For 1999, we're looking for volunteers to help contact local newspapers and radio stations. We provide the news releases, mailing lists, postage and contact names: all you do is make a personalized telephone follow-up to local reporters. No public relations experience needed, but you must have an excellent telephone manner, good communication skills and enjoy informing others about the MS Society. Volunteers needed for the Montgomery County, Valley Forge and Downingtown sites in Pennsylvania, as well as in the Vineland area, New Jersey Shore and Voorhees, NJ. For more information, please call Linda Smith at 1-800-548-4611.



Resource Connection Volunteers

The Chapter needs you! We are currently seeking additional volunteer support to work in our popular Resource Connection area.

You can provide support for individuals with MS, family members/friends and professionals by offering information and referrals from our database. Excellent communication and basic computer skills needed! We'll train you!

The position requires a one day weekly commitment from 10 a.m. to 2 p.m. in the Penn Jersey office on Philadelphia's waterfront area. For more information, please call 1-800-548-4611 and ask for our volunteer coordinator. Please leave your name, address and telephone number so we can send a volunteer enrollment form right away!

Volunteer Writers Needed To Write and Research Community Feature Stories And Newsletter Articles

Would you like to add your byline to our MS Connection newsletter? We're looking for experienced writers with an English, journalism or public relations degree to help interview members and professionals for newsletter stories, edit articles, and assemble the

research materials we receive from the National office. Volunteers must be able to meet newsletter deadlines. Although initial interest interview is required, volunteers can receive assignments by phone or mail following that first meeting, and work from home. Please call Linda Smith at 1-800-548-04611 for more information!

Volunteer READaTHON

Ambassadors

Various times from January - April

Schools throughout the Greater Delaware Valley area frequently request that individuals with MS attend our READaTHON assemblies with a chapter staff person so students can learn more about the disease. Participants must feel comfortable speaking in public and sharing their experiences with MS, as well as answering questions about living with MS. Programs last about one hour and speakers need their own transportation to area schools. Interested in assisting with the READaTHON, our most effective way of reaching children with a disability awareness program? Call Angela at 1-800-548-4611 today.

VOLUNTEERS NEEDED

Volunteer Office Assistants **Tuesday, Wednesday, Thursday and/or Friday available** **10am to 2pm**

Volunteer for one day or all four! Assist with various clerical duties and informational mail preparation in our Penn Jersey office. If you enjoy working with other volunteers and getting to know our staff while helping with important clerical duties, you'll enjoy this volunteer position. Call Angela at 1-800-548-4611.

Volunteer-MS WALK **April 18 & May 2, 1999**

Volunteer for one of the Society's largest fundraising events at one of 20 convenient locations near you! Help is needed with registration, rest stops, set-up, handing out food at the finish site, and offering encouragement to the thousands of participants. Call Angela at 1-800-548-4611.



Volunteer READaTHON Assistant **Part-time from January-May**

Assist with the READaTHON program by answering general phone questions, tallying and writing results from students participating in our popular reading motivational program! You'll follow up with schools on the phone to ensure they have received materials, too. Prefer at least 10 hours each week. Call Angela at 1-800-548-4611.

American Express Selects Society for Promotion

American Express has selected the National MS Society as one of three charities to which cardholders enrolled in the Membership Miles reward program can donate points.

Cardholders can contribute in blocks of 1000, 5000 and 10,000 points and American Express will donate \$3 per 1000 points to the charity of your choice. To participate or for more information, please call 1-800-297-3276.

Irv Stein, (right) the president of the Delaware Valley Volvo Retailers Association recently accepted the chapter's 1998 Corporate Citizen of the Year award from Vice Chairman Larry Kane.

The Role of Human Herpes Virus HHV-6 in MS: Moving Beyond the Media Hype

National media attention has been drawn to National Multiple Sclerosis Society sponsored research on the possible role that human herpes virus-6 (HHV-6) may play in MS. Over the past three years, investigators from several laboratories have gathered evidence that HHV-6, a common virus that causes roseola in children and to which virtually everyone has been exposed may be present in MS brain lesions and active during disease relapses.

New work, supported by the MS Society and reported at the 1998 meeting of the American Neurological Association in Montreal, examined HHV-6 in the central nervous systems and immune tissue from autopsy samples of people who had had definite MS.

In this small study, Drs. Konstance Know, Daniel Harrington and Donald Carrigan, from the University of Wisconsin in Milwaukee, reported that 7 out of ten subjects had nervous system cells that were actively infected by HHV-6. They also reported that there was a significantly greater chance that active virus would be found in nervous system tissue with active myelin destruction, compared to tissue with no active demyelination. Immune tissues in six of the nine individuals who had

had MS showed active HHV-6 infection. Three of eight individuals with MS showed evidence of HHV-6 in the blood. Compared with tissues from individuals with other diseases, active HHV-6 infection was more commonly found in MS. Finally, in a single patient followed over time, active HHV-6 infection of blood cells tended to be correlated with disease attacks or relapses.

This work adds to the evidence that HHV-6 is associated with MS, but does not demonstrate that HHV-6 is a cause of MS. However, because of the association between HHV-6 and MS, clinical trials of antiviral agents that are effective against this virus, such as ganciclovir, are ongoing or in planning stages in the United States and abroad. The media reports included an anecdotal story of one individual undergoing such therapy, with unsubstantiated claims of benefit. At this point, there is not evidence that treatment with agents effective against HHV-6 will have a role in treatment of multiple sclerosis.

The National MS Society is actively funding and following research related to HHV-6 and other viruses in MS, and looks forward to further studies that will indicate whether this or another virus triggers MS.

(Con't. from page 20)

For First Time In Organization's History The National MS Society Recommends Use of Three MS Drugs

For the first time in its 52-year history, the National MS Society has made recommendations about the use of specific drugs that control multiple sclerosis.

The organization's position on the drugs, Avonex, Betaseron and Copaxone, was enthusiastically received by more than 500 volunteer leaders and key staff members from across the country attending the organization's National Leadership Conference in Chicago, October 14-16, 1998.

Based on the work of a task force of nationally recognized MS experts who reviewed data from controlled trials and clinical experience, the Society recommends:

- * Avonex, Betaseron and Copaxone reduce future disability and improve the quality of life for many people with MS;
- * The use of these drugs should begin as soon as possible following a definite diagnosis of MS and the determination of a relapsing course of the disease;
- * Access to the drugs should not be limited by level of disability, age or the frequency of relapses;
- * Most concurrent medical conditions do not contraindicate the use of any of these three therapies;

* Therapy should be continued indefinitely, unless there is a clear lack of benefit, intolerable side effects, new data that reveal other reasons for stopping, or a better therapy becomes available. Therapy should not be discontinued during reevaluation for continuing treatment.

* All three agents should be covered by third-party payers and included in their lists of approved drugs. The choice of drug should be made jointly by the individual and her or his physicians, based on professional evaluation and individual preferences. Movement from one drug to another should be permitted.

These recommendations were made because trial data and clinical experience show that all three drugs offer benefits in daily life for people with relapsing remitting MS. Preliminary data from European studies of Betaseron support its use for people with the type of MS that begins as relapsing remitting disease, followed by a steady worsening disease course or secondary progressive MS.

Many studies further confirm that permanent damage to nerve fibers is coincident with the destruction of the myelin sheath that normally protects nerve fibers in the brain and spinal cord. Myelin is attacked in MS. This suggests that even early MS relapses that appear benign may have permanent consequences.

(Con't. from page 21)

Role of Viruses in Multiple Sclerosis Updated

The Americas Committee for Treatment and Research in Multiple Sclerosis held its second annual meeting on September 27, and excerpts from the article, "Role of Viruses in Multiple Sclerosis Updated," Symposium Highlights, October 1998, are included below:

"The nonrandom worldwide pattern of MS suggests that a combination of genetic and environmental factors are involved in its etiology," noted Stuart Cook, MD, UMDNJ-New Jersey Medical School of Newark, as he reviewed the evidence by suggesting a causal role for viral infections. "The evidence that MS may be caused by infectious agents is largely indirect," he noted. "Assuming MS is triggered by an infectious agent, opinion is divided on the issue of whether a few or many viruses are involved."

To implicate a virus in MS, Dr. Cook explained, "It must produce demyelination, should fit geographic disease and population migration patterns and clusters, should be confirmed by serologically positive data and must be identifiable in brain tissue." Currently no agent fulfills all criteria. HHV-6 comes close because it produces neurologic disease with demyelination,

shows serologic positivity and is identifiable in brain tissue.

The idea that different infectious agents may all be associated with MS was explained by Leslie Weiner, MD, using the concept of molecular mimicry. "Molecular mimicry is the ability of molecules to imitate the intercellular interactions of other molecules. This phenomenon is perhaps the most intriguing link between infection and autoimmunity."

"The flexibility and mobility of T-cell receptors allows for sampling of epitopes from various angles and positions to facilitate a fit where no fit is otherwise obvious," said Dr. Weiner. This means that a few viral infections occurring early in life may be responsible for MS later in life by triggering T-cells to confuse self-protein for viral protein by the mechanism of molecular mimicry. If so, future MS therapy may focus on the synthesis of peptide ligands capable of binding viral protein motifs.

FOR MORE INFORMATION ABOUT THE ABOVE MENTIONED STUDIES, PLEASE CALL THE CHAPTER'S RESOURCE CONNECTION AT 1-800-548-4611.

Con't. from page 22)

Hepatitis B Vaccine and Multiple Sclerosis

Media attention has been drawn to anecdotal reports suggesting that vaccination against hepatitis B virus may increase risk for MS.

According to the National MS Society:

- * Such reports have NOT been confirmed by any statistically significant scientific studies to date;
- * Because of the potential for public concern about this issue, further studies of the possibility of association of hepatitis B vaccine and demyelinating disease, including MS are underway in the United States and Europe;
- * Hepatitis B infection can result in a serious, sometimes fatal disease and vaccination is effective in its prevention;
- * In the view of the Society's Medical Advisory Board, there is no evidence of a link between hepatitis B vaccination and MS;
- * People with MS are encouraged to discuss the small general risks of any viral immunization with their physicians.

Mitoxantrone May Help Secondary Progressive MS

Preliminary results of the Phase 3 study of Novantrone (mitoxantrone HCl for injection) were presented

recently at the 14th Congress of European Committee of Treatment and Research in Multiple Sclerosis in Stockholm. Results suggest:

- * This potent immune-suppressing drug may reduce relapses and slow disease progression in those with relapsing-remitting and secondary progressive MS;
- * Full data analysis has not yet been completed, and results have not yet been published to receive full scrutiny by the medical community;
- * Concerns about significant long-term heart toxicity have been raised and await further evaluation.

Effect of Infant Feeding Method and Postpartum Support on Health Status of Mothers with MS

Women with MS who are expecting a baby or who have a newborn baby are invited to participate in a study to explore the potential protective effects of breast feeding and postpartum support on their health (MS symptoms, management of everyday activities, MS attacks) during the first six months following birth. Women will be asked to complete self report, prepaid, mailed questionnaires three times, which will take about 25 minutes each time. Women are also asked to keep a brief weekly diary for the six-month period

Continued on Page 25

From the President

Just a few weeks ago, the Greater Delaware Valley Chapter marked another year of service to local residents and their families at our Annual Meeting and Volunteer Recognition luncheon. As always, this meeting was a wonderful chance to visit with so many of our members and talk with you.

It also gave me a chance to share with you our own chapter highlights of the past year:

** The opening and dedication of the new W. Thacher Longstreth Library and Resource Room. Named for our wonderful founder, this area combines one of the chapter's most innovative service centers: our lending library filled with hundreds of books, audio and video tapes for loan to our members, and our Resource Connection area, where volunteers staff our telephone lines, providing information on everything from finding a neurologist to installing a household ramp and providing resources for everyone from local MS families to students and professionals.

** Our continued commitment to advocacy through the employment of Mechelle Loper Connors, Esq., the chapter's new advocacy coordinator, who has already visited many support groups and talked with numerous

photo of Judith cohen
pick up from previous
issues

members about grassroots issues to focus upon in the legislature;

** The chapter was honored with the National Society's new "Technology Trailblazer" award at a recent country-wide conference, marking us THE leader in MS Society technology. On a local level, you can now visit our award winning home page, thanks in part to a donation by GDA Digital Media; the site receives about 1000 "hits" a month and marks a turning point in the way we communicate with you, our clients.

** A substantial increase in the range and depth of our programming, with special emphasis on our innovative fitness series, family and children's programs, such as Kid's Camp and Family Getaway Weekend, and our new chapter Legal Day.

(Con't. from page 24)

For the national organization, this year also marked a turning point. For the first time in our 52-year history the National MS Society made recommendations about the use of specific drugs that control the disease: Avonex, Betaseron and Copaxone. This position was enthusiastically received by more than 500 volunteer leaders and key staff members attending October's National Leadership Conference. At this same meeting, the chapter was also honored for reaching the highest level of giving for MS research in 1998. We are very proud of our chapter's leadership role in supporting scientific studies into the cause, prevention and cure of MS, and our commitment to new research funding, which will be matched through the year 2001 by the Conrad Hilton Foundation. For more details about this incredible matching gifts program, please call our office at 800-548-4611.

As always, I am grateful to all of you who have so generously contributed to our efforts, for without funding, it would be impossible for us to build and increase our services, as well as provide continued support of innovative research. It is through your generous and enthusiastic participation in our many special events such as the MS WALK, our Bike Tours, UGLY program, your direct contributions through campaigns such as the Golden

Opportunity Fund our annual appeal and other special programs that such work is possible. If you have not yet made your yearly tax deductible gift to the chapter, please use the envelope enclosed in this issue for that purpose.

Again, my thanks for all you do and my personal warm wishes for a happy, healthy new year. Together, we will end the devastating effects of multiple sclerosis.

Sincerely,

Judith G. Cohen
President

Research Update

(Con't. from page 23)

about the type of infant feeding (percent breast, percent formula), and any health problems they or their infant may experience. Interested women may call Dr. Gulick at 973-353-5375 or e-mail at eegulick@aol.com for more information. Dr. Gulick is a nurse and research professor at Rutgers, The State University of New Jersey, and has worked with and conducted research with MS persons for many years.

'Tis the Season...To Save on Your Taxes!

The end of the year is a time for putting our financial houses in order and considering the charitable contributions that will benefit causes we care about deeply.

The National Multiple Sclerosis Society is totally dependent on the generosity of friends to help end the devastating effects of MS. The programs we offer to people with MS and their families, and the research we support to find answers to the disease, all happen because people are willing to make heartfelt financial commitments to our mission.

A year end gift from you will benefit more than 8,300 people in the Greater Delaware Valley Chapter and their families — that is an estimated 20,000 neighbors! And there are a variety of ways you can help PLUS receive a tax benefit at the same time. YOU CAN:

- ☞ GIVE THROUGH THE UNITED WAY'S DONOR OPTION PROGRAM
- ☞ MAKE AN ANNUAL CONTRIBUTION (BEFORE 12/31/98) AND RECEIVE THE TAX BENEFIT
- ☞ GIVE GIFTS TO THE SOCIETY IN THE NAME OF FRIENDS OR LOVED ONES FOR THE HOLIDAYS OR OTHER SPECIAL OCCASIONS
- ☞ INCLUDE THE MS SOCIETY IN YOUR WILL
- ☞ GIVE A GIFT OF STOCK TO THE SOCIETY
- ☞ DONATE YOUR USED CAR (IN ANY CONDITION) AND CLAIM ITS FULL VALUE ON YOUR TAXES
- ☞ STRUCTURE A SPECIAL GIFT THAT OFFERS YOU LIFETIME INCOME AND GENEROUS TAX ADVANTAGES AS WELL (LIKE A POOLED INCOME FUND OR CHARITABLE REMAINDER TRUST)
- ☞ ENCOURAGE A FRIEND OR RELATIVE TO GIVE TO THE MS SOCIETY
- ☞ FIND OUT IF YOUR COMPANY WILL MATCH YOUR GIFT

REMEMBER! To receive the tax benefit, your gift must be postmarked by December 31, 1998!

If you would like more information on any of these giving opportunities, please return the form below or call Heather Gee at (215) 271-1500. Please check all that apply:

- I have remembered the Society in my estate plans.
- Please send me a free copy of "Legacies for the Future."
- Please send me information about giving gifts of stock.
- I have questions about gifts of stock, real estate, life insurance policy or retirement plans.
- I am interested in research about multiple sclerosis.

Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: () _____

Please return to:
National MS Society
1 Reed Street, Philadelphia, PA 19147
215/271-1500 Fax 215/271-6122



Stephanie Schultze (left) the chapter's community programs coordinator, works with numerous volunteers, community liaisons and staff members in her efforts to coordinate chapter programs ranging from Kid's camp to the fitness series and complementary therapies. She's shown here with Florence McLeary of the chapter's finance and administrative department.

Pds Disability Facts and Social Security trends

*Now, a quarterly newsletter edited by experienced disability lawyer Doug Smith (author of the respected **Disability Workbook for Social Security Applicants**). For people who apply for Social Security disability benefits and people who have benefits already. **Pds Disability Facts** explains practical ways of responding to challenges of the Social Security disability process including:*

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Three chapter employees recently celebrated a total of 60 years of service to those with multiple sclerosis. Theresa Farina, Florence McLeary and Angela DiGiuseppe (pictured left to right) received recognition from Chapter President Eric Kraeutler, Esq. (second from right) for 20 years of service each. Congratulations!