

msconnection

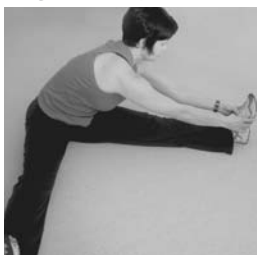
Summer 2005

Greater Delaware Valley Chapter

The National MS Society...Count On Us.

MS 150 City to Shore Bike Tour: 25 Years Of Making a Difference

Yoga & MS p 4



Gardening p 10



Day on the Hill p 15



READaTHON p 19



Each year the Greater Delaware Valley Chapter holds a number of events to raise money for important research, services and programs that serve more than 11,000 area individuals living with multiple sclerosis. Celebrating its 25th Anniversary this year, the MS 150 City to Shore Bike Tour has become one of the chapter's most important activities.

It began in 1981 with only 78 cyclists who pedaled 150 miles from Philadelphia to Ocean City, NJ. A humble affair, it had one rest stop, one route option, and lunch consisted of peanut butter and jelly sandwiches. Now the bike tour has four route options: 25, 45, and 75 and 100 miles, over 1200 volunteers, several thousand

cyclists, and five rest stops. Starting in Cherry Hill, NJ the Tour ends with a festive finish line in Ocean City, NJ.

The MS 150 City to Shore Bike Tour has raised millions of dollars to help in the fight against multiple sclerosis. Equally important is the amount of awareness the Tour raises for MS. Each year more and more cyclists

participate in the event; many have no connection to the disease and yet they insist on riding and raising money for the MS community. Others, like Nancy Pomilio, hop on their bikes in honor of friends and family members.

After years of volunteering at the Tour with her husband Ron who has MS, Nancy decided this was the year for her to ride her husband's



"It's my turn," says Nancy Pomilio. Shown here with her husband, Ron.

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National Multiple Sclerosis Society

Greater Delaware Valley Chapter
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Greater Delaware Valley Chapter

"Whether I have to stop five or fifty times I'm going to ride the 150 miles," Nancy explains. "This is my way of saying thank you."

honor. A teacher at Eastern Regional High School, Nancy has been actively recruiting people from her school to join her in this event.

"Whether I have to stop five or fifty times I'm going to ride the 150 miles," Nancy explains. "This is my way of saying thank you to every person who participated and continues to participate in the Tour. Their dedication and their fundraising has helped my husband and thousands of others living with MS. Now it's my turn."

Ron plans to volunteer at the starting line for the MS 150 City to Shore Bike Tour again this year. After that he will head to the shore to cheer his wife on and see her cross the finish line wearing the Bandana of Hope with his name on it. When talking to Ron you can hear how proud he is of his wife. After all, he and Nancy will not only be celebrating the 25th Anniversary of the MS 150 City to Shore Bike Tour on September 24 & 25, they will also be celebrating Nancy's 60th birthday.

Join Ron, Nancy and the Greater Delaware Valley Chapter of the National Multiple Sclerosis Society, September 24 and 25, to celebrate 25 years of pedaling for a cure. To register or for more information visit www.ms150biketour.org or call 1-800-445-BIKE. To volunteer or to become a Pedal Partner contact Kathie Cronk at 1-800-548-4611 or kathie.cronk@pae.nmss.org.

Most people think of summer as a time to relax and enjoy the benefits of another year of hard work. While trying to fit in as much water ice and as many weekend trips to the mountains and Jersey shore as possible, July and August happen to be one of our busiest periods as the Greater Delaware Valley Chapter gets ready for the MS 150 City to Shore Bike Tour, the MS Challenge Walk and other major events designed to raise funds and awareness.

The working day for those of us involved in providing programs and services to local clients is just as busy. It is during the summer months that both staff and volunteers take the time necessary to review the accomplishments of the past year and begin planning our activities for the fall and winter.

And that's where you come in. As an organization committed to meeting the needs of its community, we want to know which National MS Society programs were useful and which were not. By getting your feedback, we can continue to refine our activities to help meet existing needs and re-deploy resources to meet new ones.

In the past, member feedback has played a role in the creation of many of our most innovative programs, including the creation of specialized MS centers, Coffee and Conversation, networking for young adults, case and



Judith G. Cohen

care management programs and the peer-counseling network. Many of the programs created by chapter volunteers and staff have been so successful, such as the recent African American Experience outreach program and the information and referral program, that they have been adopted for use by chapters across the country.

Efforts such as these have allowed the Greater Delaware Valley Chapter to remain a positive force in local lives affected by MS for over 50 years. Our ability to remain relevant and truly make a difference depends on you. In short, we need your help.

I encourage everyone involved with the chapter to fill out the questionnaire located in this newsletter or contact me with your thoughts and suggestions by sending an email to judith.cohen@pae.nmss.org or by mail to:

Judith Cohen
National MS Society
Greater Delaware Valley Chapter
1 Reed Street, #200
Philadelphia, PA 19147

Enjoy the summer.

Sincerely,

Judith Cohen President

Yoga: Ideal for People with MS

By Debi Lewis, yoga instructor

The practice of yoga can be of great benefit to those with multiple sclerosis. Because yoga is a holistic art, the benefits are physical, mental and emotional. Another added benefit of yoga is that it can be done virtually anywhere. Once the basic principles of yoga are learned a student can continue these exercises outside of the class and in the privacy of their own home.

While yoga is not a cure, it can increase circulation, improve muscle tone, help with balance and assist in the ability to deepen your breath and relax.

On a physical level, it is important to find the right yogic approach and remember the specific needs of people with MS. There are many styles of yoga and not all yoga classes would be helpful. It is very important that the person/student with MS focus on simple movements, relaxation techniques and avoid anything that increases heat, stress and fatigue.

Since MS is a breakdown in the nerve fibers and not the muscles, often the student has more ability than they realize, and it is important to utilize as much muscular capacity as possible.

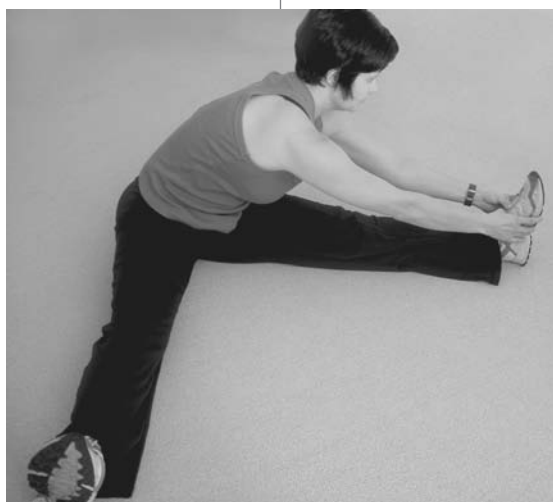
Simple movements, coordinated with the breath, help to locate and strengthen neural pathways and keep

joints and muscles mobile. An example would be to lift the arms on the inhale and lower them on the exhale. In Gary Kraftsow's book, *Yoga for Wellness*, there is a complete practice developed for one of his students who has MS. The Viniyoga style, which Kraftsow has made well known, is an effective approach for many conditions, including MS.

When we are stressed, our breath becomes shallow, and we hold the muscles in a "fight-flight" state of tension. It is important to observe places in the body that are holding tension and address them through simple stretches and

movements, while encouraging long, relaxed, diaphragmatic breathing. Neck rolls and slow twists, for example, help to release tension in the neck, back and shoulders. Also, holding the yoga postures isometrically, pulling muscle to bone, will help to strengthen the muscles and bones as well as improve coordination.

I have found the "quick-release" method very valuable as well. To do "quick-release," go through the entire body, starting with the toes, and squeeze the muscle tight, one body part at a time. Hold for 4-5 seconds and then quickly let go with a "falling-out" exhale, aaahhhh...



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The Iyengar style of yoga, because of its emphasis on the creative use of props to assist in postures, its therapeutic approach and the slow, detailed focus on the physical action, is also an effective modality. A person with MS will have to modify if they are in a regular class, however, and be sure not to hold the postures very long. An inspiring Iyengar teacher, Eric Small, has managed MS with the benefits of yoga. He has had MS for over 45 years and is 70 years old.

To help a person with MS learn to relax, supported stretches are a wonderful way to receive the benefits of yoga in a passive way. Supported postures, also affectionately called “advanced lying around,” involve positioning bolsters and blankets to allow the student to relax in simple forward bend, backbend and inverted positions. People with MS should particularly make a daily practice of simple inversions; such as supported shoulder stand and “legs up the wall” pose, to improve circulation.

What is so wonderful about yoga is that its benefits extend beyond the physical. This can help someone with MS in several ways. Understandably, people with MS often have to deal with feelings of anxiety, depression and/or frustration. The ability to do the most basic things are uncertain and often unpredictable.

By practicing pranayama, yogic breathing techniques, the student will gain skill in relaxation and mental focus, so that he or she can take each moment as it comes with a feeling of empowerment. Yoga helps us to open a channel, to clear a frequency, to become still and listen for the “still, small voice” that speaks to our hearts and gives us hope.

Resources:

- Suza Francina, *The New Yoga for People Over 50*, Health Communications, Inc. 1997. With sections on MS by Eric Small who teaches MS students in L.A.
(Pp. 60-62)
Web site: www.hci-online.com
- Gary Kraftsow, *Yoga for Wellness*, Penguin, 1999.
Email: info@viniyoga.com
Web site: www.viniyoga.com.
- Dr. Robin Munro, *Yoga for Common Ailments*, Gaia Books, 1990

MARIE NAPOLITANO CHILD ENRICHMENT SCHOLARSHIP

The Marie Napolitano Child Enrichment Scholarship provides funding for childhood summer programs. This year the Scholarship was awarded to:

- Allen family of Reading, PA
- Frulla family of Glenmoore, PA
- Lieberman family of Mt. Laurel, NJ
- Sload family of Coatesville, PA

The Chapter would like to thank the many applicants as well as the Napolitano family for making this scholarship possible.

Medford Picnic Brings Families Together

On June 22, more than 26 families attended the chapter's JCC Picnic in Medford, NJ. Families enjoyed a day filled with activities including swimming, outdoor sports, and a picnic. Sponsored in part by Serono/Pfizer, the picnic allowed families to enjoy the day together and network with other individuals living with the daily effects of MS.



TEENS SPEAK OUT

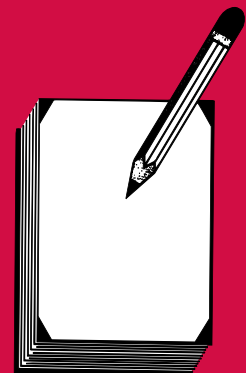
Voice your opinion, share your stories, artwork, and poetry. Are you helping in the fight against MS? Tell us about it. Teen InsideMS Online is the magazine written for you and by you. Spread the word.

Send letters, stories, and poems by email. Please send SCANS of artwork (photographs, cartoons, drawings, or pictures) via email or on a CD (jpeg format). We cannot return material, so do not send original artwork. We will notify you if your work has been posted. Please include your age, name, and address or e-mail address. All information will be kept confidential.

Visit the Web site at: www.nationalmssociety.org

E-mail: editor@nmss.org

Teen InsideMS
National MS Society
733 Third Avenue
New York, NY 10017-3288



Summer Safety: Ways to be Safe in the Sun

Once again summer has come to the Greater Delaware Valley and with it intense heat and humidity. To ensure everyone's safety in the sun, use the following safety tips.

Sunburn Prevention

- Use sunscreen with a high SPF to prevent burning and UV exposure
- Wear hats and sunglasses to protect face and eyes
- Stay in the shade if possible and reapply sunscreen often
- Children should try to stay out of the sun during peak sun hours (10 a.m. and 4 p.m.)
- If children are outside during peak hours, keep them covered in loose-fitting, lightly colored-clothing

Sunburn Treatment

- Use aloe vera and other moisturizers generously to cool and relieve sunburn
- Take a hot shower when sunburn is first noticed, this will promote the burn to peel sooner
- Use external anesthetics for the skin and internal anesthetics such as aspirin or ibuprofen for pain

Heat Exhaustion & Heat Stroke

- Heat exhaustion is when the body's natural cooling system shuts down and the surface blood vessels collapse, usually as a result of dehydration and lack of fluids
- The symptoms experienced are headache, rapid pulse, dizziness, loss of coordination, moist skin that's cool to the touch, and anxiety
- Heat stroke is life-threatening and occurs when the body has no water or sodium and body temp has risen to a very high level
- Heat stroke symptoms include difficulty breathing, hot red skin, rapid pulse, vomiting, confusion and possible seizures
- Prevention of these two heat illnesses are precautionary and avoidable
- Drink lots of fluids, water and electrolyte ("sport") drinks
- Avoid caffeinated and alcoholic beverages
- Wear light, loose-fitting clothes
- Sleep enough at night and use air conditioners and fans as often as possible
- Condition yourself to the heat slowly to allow your body to build heat endurance

Taking Responsibility for Your Personal Safety

Do you and your family have an emergency plan in case of a fire, flood, or other disaster situations?

According to the National Organization on Disability, 54 million people in the United States have a disability and 61% of them have not made plans to quickly and safely evacuate their homes. In fact, all of us have a tendency to avoid thinking about and planning for emergencies. However, this tendency has greater consequences for people with disabilities than for people without.

Emergency planning should be integrated into our lives, but if you haven't done it before, how do you get started?

The Office for Homeland Security has a website: www.ready.gov. It will walk you through the steps necessary to make a general plan for you and your family.

The Red Cross has a web page dedicated to emergency

preparedness for families:

www.redcross.org/services/disaster/0,1082,0_601_,00.html and a web page specifically for people with disabilities: www.redcross.org/services/disaster/beprepared/disability.html.

You will find information on these web pages about creating a personal safety plan, gathering emergency supplies, and creating a personal support network.

The Center for Disability Issues and the Health Professions has a publication called: *Emergency Evacuation Preparedness: Taking Responsibility for Your Safety — A guide for people with disabilities and other activity limitations*. This booklet offers specific suggestions on how to give quick information to someone who is helping you, equipment that can be used for evacuation, and some tips on deciding if you are a person who needs special assistance in case of evacuation.

June Isaacson Kailes, the author of this booklet says, "No matter what laws and public policies say, it's up to us as people with disabilities to do what we need to do to prepare for disasters. If we just rely on employers, building managers, or fire inspectors to make sure things are in place, it may or may not happen.

You can find the *Emergency Evacuation Preparedness* booklet at no cost through the following link: www.cdihp.org/products.html#eeguide.



*Thank you to our
2005 MS PA Dutch Cyclists
and Volunteers!*

*Your efforts help us provide
programs, services and research
for those living with MS.*

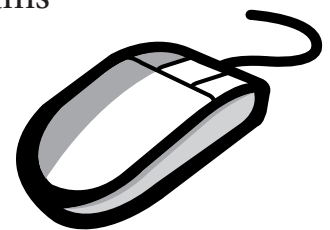


MS NATIONAL
MULTIPLE SCLEROSIS
SOCIETY

MS LEARN ONLINE – PARTICIPATE ONLINE TODAY!

The National MS Society has an exciting menu of MS Learn Online Webcasts currently available on it's Web site. Each Webcast features experts speaking on pertinent topics for those affected by multiple sclerosis. Programs and their written transcripts can be accessed at www.nationalmssociety.org/mslearnonline.

Would you like to be notified via e-mail of upcoming MS Learn Online programs? Please send your e-mail address to: MSLearnOnline@nmss.org.



Developing a Green Thumb and Independence

Many people gain a great sense of satisfaction, independence and high self-esteem in caring for living plants.

A garden can be a wonderful tool to help people recognize they can continue an activity that is meaningful to them, regardless of their limitations. Exercising your green thumb helps to burn calories, improve motor skills and can be a wonderful outlet for stress and creativity.

People of different ability levels are able to garden because they can do as little or as much as they want, and at their own pace. An increase in adaptive gardening is making it easier for people with disabilities to stay active.

Simple tricks, like modifying garden styles and using innovative tools, are allowing more people to roll up their sleeves and get into the dirt.

Helpful hints to make gardening easier:

- Use equipment that is easy on the body. Buy lightweight tools with large handles. Mechanical seeders and seed tape eliminate the need to pick up tiny seeds. Garden shops, nurseries, gardening catalogs and Web sites sell specially adapted tools for easy grip.
- Wear an apron with large pockets to carry seeds and tools. Adapt tool pouches to hang from walkers,

wheelchairs/scooters or flowerbeds.

- Design raised beds or window boxes that you can easily reach without stretching or bending.
- Choose the size of the garden and types of plants to meet your needs. Consider the plant's height, the amount of attention it requires and its life span. For example, vine plants (peas, beans, etc.) can grow on a trellis and are then easier to harvest.

Plants that need less water may be easier to maintain.

- Make your work area accessible for you. Build handrails or handgrips if needed.

- Pace yourself. Have a cool resting place nearby and be careful you don't get overheated.

For more tips on gardening, visit your local bookstore or library, or call a nearby garden store. And, try these Web sites:

- www.ahta.org (American Horticultural Therapy Association)
- www.icangarden.com
- www.garden.org, or 800-LETSGRO (National Gardening Association).

Many cities have community gardens. Check with the chamber of commerce in your area.

"To nurture a garden is to feed not just the body, but the soul."

-Alfred Austin

Just Wondering: Private Disability Insurance

In this column, we address some of the most common questions and concerns about MS. Please let us know what questions you'd like answered, and we'll consult with the experts. To submit a question, leave a message at 1-800-548-4611 extension 411 or e-mail msconnections@pae.nmss.org.

Q: WHAT ARE PRIVATE DISABILITY INSURANCE POLICIES?

A: They are insurance contracts that provide monthly cash payments to insured individuals once the requirements of the insurance policy have been met. In basic terms, they provide benefits for individuals who are unable to work.

Q: WHAT TYPES OF POLICIES ARE THERE?

A: There are two basic types of insurance (short term and long term) and two types of policies, individual and group. Most people who are insured by one of these policies are members of a group policy that is provided as a benefit by their employer. Other individuals, such as those who are self-employed, may purchase their own individual policy from an insurance agent. Some persons may have coverage through both group and individual policies.

Q: WHAT QUESTIONS SHOULD I ASK ABOUT MY POLICY?

A: Some of the most important questions you should ask are:

- Does my employer provide short or long term disability benefits?
- Am I covered now?
- If I'm not covered now, what is necessary to be covered?
- If there is a policy, do I have the policy booklet and have I read it?

Q: WILL THERE BE A WAITING PERIOD?

A: Most policies will have a waiting period before benefits are payable. If so, you do not want to quit work and apply for benefits before you would be eligible. Further, almost all policies have "pre-existing condition" provisions that would allow the insurance company to deny the claim if it is filed too soon.

Q: HOW CAN I BE SURE THAT I AM CHOOSING THE RIGHT POLICY FOR ME?

A: Request a copy of the policy or the policy handbook now and read it carefully. If you have any questions about whether you would be covered (e.g. due to waiting period or pre-existing condition provision) you should contact the employer's benefits office or the insurance carrier for clarification. If there is still a question about coverage, it would be a good idea to contact an attorney to review the policy and the facts of your case.

For questions about private disability insurance benefits or Social Security disability benefits at any time, call attorney Ted Walkenhorst of the Disability Benefits Law Center for a free consultation at 215-886-0660 or, toll-free, 1-866-886-0660.

Lending Library

The Lending Library gives you access to hundreds of books and audio visual materials. To borrow an item or to receive a copy of the catalog, please call 1-800-548-4611, ext. 137. You may also request your selection at www.nationalmssociety.org/pae. Click on "Library and Literature" at the top of the page. New materials include:

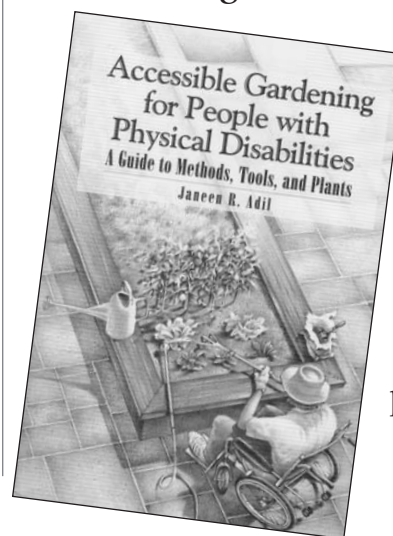
Yogability and You

This video/DVD provides an introductory approach to "chair" yoga. The hour-long program helps reduce stress while teaching basic breathing and stretching techniques.



Instructor Shelley Sidelman designed this program for individuals with MS who want to practice yoga in the privacy of their own homes.

Accessible Gardening for People with Physical Disabilities: A Guide to Methods, Tools and Plants.



Designed for all ages, this book provides the knowledge necessary for creating and maintaining an accessible garden including: specialized tools, instructions, and plant descriptions.

Knowledge
Is
Power!



Do you have the knowledge to overpower MS?

Knowledge Is Power! is a free, at-home educational series designed to help people who are newly diagnosed learn to live with the devastating effects of MS.

For more information or to register, please call 1-800-FIGHT-MS, e-mail us at info@nmss.org or visit us at www.nationalmssociety.org.

Karen Mariner *Director of Programs*

A graduate of Bryn Mawr College with a master's degree in Clinical Social Work, Karen Mariner, the new Director of Programs, has spent the last four years managing the chapter's Information and Resources Center.



Karen Mariner

Karen says the experience will help her greatly as she tackles her new position. "Working with so many clients and their families has been the highlight of my career and I feel that these relationships and connections will continue to grow in the future," she said.

In her new role, Karen will continue to be in charge of the I & R Department as well as all of the programs and services. In the past year, the chapter has sponsored 99 programs including, teleconferences, professional education, family events, young adult socials, and symptom-based seminars. The chapter also provides a variety of services such as transportation, speech and physical therapy, home health care assistance and numerous others that help to improve the quality of life for those living with MS.

As the Director of Programs, Karen wants to develop even more programs and services for the MS community. She stated, "It's important that we continue to reach out to young adults and caregivers and provide educational opportunities for healthcare professionals."

It is with deep regret that we announce that Barbara Loneragan, longtime assistant at Thomas Jefferson's MS Center has died.

Ms. Loneragan was deeply committed to providing people with MS the information, care and resources they needed.

She will be missed.

If you are a mom or dad who has multiple sclerosis, we have a resource for you!



Keep S'myelin is a free newsletter designed to help kids ages 5 to 12 learn how to live and be comfortable with MS by providing accurate information in a format that is easy and fun to read. Puzzles, games and a parents' section are included, too!

Keep S'myelin will surely keep both kids and parents smiling and informed about MS.

For more information, call the National MS Society at 1-800-FIGHT-MS or visit www.nationalmssociety.org.



CALLING ALL ARTISTS

The Greater Delaware Valley Chapter invites artists with multiple sclerosis and their families to submit their works to help raise funds for the fight against MS. If selected, your art will be featured on the front cover of memorial and tribute cards, with a short biography on the back cover.

The winning artists will be profiled in the winter edition of MS Connection. Artwork may also be exhibited at the chapter's Annual Meeting in November.

ENTRY RULES:

1. All artists must enter on their own behalf.
2. Candidates may submit up to three works of art in each category of Memorial and Tribute
3. Deadline for entries is October 30, 2005
4. Please send artwork as well as your name, address, phone number and e-mail address to:

Contribution Cards
c/o Christine Ginty
National MS Society
1 Reed Street, #200
Philadelphia, PA 19147

or e-mail photos/electronic files of artwork to christine.ginty@pae.nmss.org.

5. By submitting their work, artists grant the NMSS the right to use, reuse, publish and republish their name and artwork.

Calendar of Events**The Special Issues of Coping with MS and Being Gay**

Date: Wednesday, August 10, 2005
Time: 7:00 p.m. - 8:00 p.m.
Location: By phone from your home or office

Program information: People often report that their MS causes a lot of challenges in their personal relationships. Add being gay, lesbian, bisexual or transgender to the mix, and the challenges reach a whole new level. Let's start talking about easing this challenge with presenter Eliana Kuhn.

To register: 1-800-548-4611 ext. 256

BACK BY POPULAR DEMAND!**Managing MS as a Team: A Special Night Out for Couples**

Date: Thursday, October 20, 2005
Time: 6:00 p.m. - 9:00 p.m.
Location: Drexelbrook, Drexel Hill, PA

Program information: Join Cheryl and Len Chatman for this program that focuses on a host of interpersonal skills including understanding different communication styles while identifying specific needs of individuals and families. Throughout the evening you will explore the SPARK principle and develop a few ways to get the whole family involved in the care and management of MS.

To register: Call 1-800-548-4611.
Space is limited.

This program is made possible by an unrestricted educational grant from Teva Neuroscience.

MS Reps Ask for Increase in Research Funding, More Support for Respite Care and Housing

The National Multiple Sclerosis Society once again converged on Capital Hill to take part in the Annual Public Policy Conference on May 3. The Greater Delaware Valley chapter staff and volunteers met with representatives from both Pennsylvania and New Jersey to advocate for legislation that affects people with MS and their families.

Although it was a tight budget year, advocates asked representatives for an increase of at least 6 percent for the National Institutes of Health (NIH). In addition to increased funding for research for MS, attendees requested that the NIH be encouraged to communicate with other research departments and organizations to share scientific data.

Staff and volunteers also asked senators from Pennsylvania and New Jersey to consider sponsoring the Lifespan Respite Care Act, which provides federal dollars to the states for respite care services. Advocates also requested that legislators assist the Society in clarifying

the in-home restrictions for wheelchairs from the Centers for Medicare and Medicaid Services. According to the provision, Medicare does not pay for wheelchairs for those who do not need to use it in the home. For people with MS, this provision may have a significant impact.

Finally, legislators were asked to restore full funding to Section 811, the federal program that creates affordable accessible housing. Last year the budget for Section 811 was cut in half, making it more difficult to find affordable/accessible housing across the country. Decreasing Section 811 funding will have disastrous consequences for low-income people with disabilities.

According to chapter advocate Sue Barber, "After my diagnosis of MS I realized that the government needed assistance in recognizing the needs of people with chronic illness. I was gratified and encouraged by the legislators' response to our concerns, however we need more people rallying for these important causes."

For more information contact Karen Mariner at 1-800-548-4611 or karen.mariner@pae.nmss.org.

From (l to r): Sue Kozel, NJ lobbyist for NJCAN; Karen Mariner, Program Director; Sue Barber, Advocacy Volunteer; Megan Bartley, Legislative Assistant for Congressman Menendez, Pat Leavy, Program Director, Mid Jersey Chapter



Community Choice is on the Move

By Terry Roth

The Pennsylvania Governor's Office of Health Care Reform has worked with the Department of Public Welfare and the Department of Aging to create a pilot program to make it quicker and easier to get into home and community services. This pilot program, called Community Choice, is now operating in ten counties: Washington, Fayette, Greene, Philadelphia, Montgomery, Chester, Delaware, Dauphin, Cumberland, and Perry. Community choice is a demonstration program that allows people to have easier access to attendant care services that provide in home health care for people with physical disabilities who need personal care assistance. Application forms have been shortened and waiting times have been reduced. The program has been very popular with consumers, providers, and the general public.

The phone numbers for each of the pilot projects are:

- Chester County
800-566-1901
- Cumberland / Dauphin / Perry
Counties — 866-244-4755
- Delaware County
888-490-8499
- Montgomery County
800-591-8231
- Philadelphia County
888-482-9060
- Fayette/Greene/Washington Counties
800-734-9603

Allegheny County is the next area scheduled for Community Choice. The program is intended for the entire state, but a timetable is not decided. If your county is not among those with a Community Choice pilot, contact the governor and your state senator and representative and ask them to establish Community Choice in your area.

Send your letter to the governor:

Governor Edward G. Rendell's Office
225 Main Capitol Building
Harrisburg, Pennsylvania 17120

To telephone the governor, call:
717-787-2500.

If you need help finding your state senator or representative, on the internet go to www.legis.state.pa.us/ and enter your zip code or county in the box in the top right hand corner. By clicking on the names, you'll get contact information.

MAKE YOUR VOICE HEARD!

Join the MS Action Network

Join the National MS Society's advocacy efforts to maximize your impact on public policy issues affecting individuals with multiple sclerosis. MS Action Network members receive via e-mail all legislative alerts and federal and state updates. You can make a difference! Sign up today at www.nationalmssociety.org.

Self-Help Support Group founded in Lambertville/New Hope

Shortly after they were both diagnosed with MS, friends Angela and Robyn wanted to network with younger individuals who were also newly diagnosed. They formed a self-help group designed to address the needs of younger individuals with MS by discussing a variety of issues including stress, fatigue, exercise, disclosure, and most importantly, the emotional stages that come with diagnosis. Based at St. Martin of Tours Church in New Hope, the group serves Society members in both Pennsylvania and New Jersey. Although the group started just six months ago, they have had several successful meetings and their attendance numbers are increasing every month.

Besides providing information and support for the newly diagnosed, the self-help group also aims to help the family members of individuals with MS. According to Angela, "We want to give a place of solace for those of us

that have the disease and for our friends and family who try to be a constant source of strength for us." In addition to having open discussions, Robyn and Angela also bring in speakers to provide information about diet, exercise and medication. The group will also be hosting a game night to give members an opportunity to socialize and keep their cognitive skills sharp.

When asked what she enjoyed most about being a self-help group leader, Robyn replied, "It's been a wonderfully rewarding experience for me. Through the group I've learned that I can really make a difference in someone's life."

If you would like more information about self-help support groups, please contact Elise Mendelsohn at 1-800-548-4611 or elise.mendelsohn@pae.nmss.org.

GLBT SUPPORT GROUP

The National MS Society has received several requests for a peer group providing support to assist both families and friends of gay, lesbian, bi-sexual, and transgender (GLBT) people with MS.

If a significant number of individuals are interested in this group, the chapter will do its utmost to champion the effort.

For more information contact Elise Mendelsohn at 800-548-4611 extension 170 or elise.mendelsohn@pae.nmss.org

30 New MS Research Projects Launched

The National Multiple Sclerosis Society has just committed \$14.3 million to support 30 new MS research projects around the globe. The commitment of these funds is only the latest investment in the Society's relentless research effort to cure, treat and better understand MS.

This year, the Society will spend some \$35 million to fund more than 300 new and ongoing MS research projects. This investment is paying off: new treatments and better methods of diagnosis, rehabilitation and symptom management are now available to all those with MS.

To determine the scientific merit of research proposals, the National MS Society relies on the judgment of expert advisory committees. These panels include more than 70 scientists who volunteer their time to carefully evaluate hundreds of proposals each year.

The new research projects involve scientists at Harvard University, Cleveland Clinic, Stanford University and scores of other outstanding institutions here and abroad. The new projects focus on many different aspects of MS, including myelin and nerve tissue repair, rehabilitation and immune studies. Three of the new projects are large-scale Collaborative MS Research Centers that take a multidisciplinary approach to better understand MS and find new treatments.

There are presently five FDA-approved drugs that can impact the underlying

disease course in people with the more common forms of MS: Avonex, Betaseron, Copaxone, Novantrone and Rebif. However, none of these drugs can stop or cure the disease.

The National MS Society funded basic research that led to the development of several of these drugs, and continues to advance research that will help end the devastating effects of MS.

Summaries of the new projects and a list of all research projects funded by the National MS Society are available online at www.nationalmssociety.org.

THIS IS WHY...

MS strikes adults as they start college, start families, start careers.

This is why we care.

Learn about local MS services at www.nationalmssociety.org/pae

MS never takes a holiday.

This is why we give.

Ask us about year-end giving to the fight against MS.

Call 1-800-548-4611.

This year more than 37,000 people in the Delaware Valley area will participate in a National MS Society event.

This is why we need volunteers!

Call us to find out how you can help,

1-800-548-4611.

Phillies Host MS READaTHON MVPs

The National MS Society hosted a READaTHON MVP Awards Program on June 22 at Citizens Bank Park for 42 elementary and middle school students who raised more than \$500 each. Students received a trophy as well as free admission to Six Flags Great Adventure. Fifteen children who raised more than \$1000 each had the opportunity to meet Philadelphia Phillies players Chase Utley and Jason Michaels. To make the night even better, the Phillies beat the Mets 8-4.

The READaTHON encourages children to read as many books as they can during a four-week period (chosen by their school) and raise funds for the

National MS Society. This year more than 15,000 students at 200 area schools participated in the READaTHON raising over \$400,000. These funds are then used to provide programs, services and research for more than 11,000 families in the area living with MS.

To learn more about the program or if you know a school that should participate in the READaTHON, please contact Angela at 800-548-4611 extension 131 or angela.digiuseppe@pae.nmss.org.

Please visit www.nationalmssociety.org/pae for a list of participating schools.

A special thank you to the 15 students that raised \$1,000 or more and congratulations to Taylor Claps, the top READaTHON fundraiser, for raising more than \$3,000!



Front row (l to r): Carter Kelly, Stephanie Pidge, Taylor Claps, Alec Bottari, Destiny Rodriguez

Middle row: Alex Lessner, Rachel Romean, Sarah Haig, Giavanna Pratta

Back row: Phila Phillies' Jason Michaels, Kaitlin Horan, Katie Rein, Sofia Papastamelos, Izzy Boguski, Phila Phillies' Chase Utley

Trumping MS: The Second Annual Bridge Tournament

From May 23 to May 29, Marilyn and Paul Weintraub sponsored the 2nd Annual MS Bridge Tournament to raise awareness about MS and raise funds for research. This year 34 Bridge clubs throughout Pennsylvania and New Jersey participated in this event, tripling last year's numbers.

Each bridge club chose at least one day where all proceeds of games would be allocated to the National MS Society. Players had the opportunity to win extra master points and raffles were held to win an opportunity to play with bridge masters.

According to participant Linda Diluco, "As a person with MS, I enjoy the event not only because it raises awareness and funds for the disease, but also because it

is a great cognitive exercise." Linda had the good fortune of playing with JoAnn Sprung in the event, and also won a raffle entitling her to another game with JoAnn. Ms. Sprung is the winner of the US Women's Bridge Championship and will be a US Representative in the World Bridge Championship in Portugal.

To achieve that goal, Marilyn and Paul Weintraub are seeking volunteers to help them contact more bridge clubs throughout the United States. To help or learn more about MS Bridge Week, please contact them at:

Paul and Marilyn Weintraub
301 Ironwood Circle
Elkins Park, PA 19027

215-885-5244 voice
215-885-8536
215-885-5059 fax
paul.weintraub@axa-advisors.com



2005 MS CHALLENGE WALK: TAKE A PERSONAL JOURNEY

Imagine a journey that begins with one person's courage and determination and ends with a life-changing accomplishment. Join us for the 2005 MS Challenge Walk, October 7-9. For more information call Jennifer Keane 1-800-883-WALK or visit www.walk4ms.org.



Up-to-date Will Means Peace of Mind

Putting your “house in order” by making sure you have a valid, up-to-date will is an important step. Your will is a legal instrument to provide for the future security of your family and your favorite organizations, like the National MS Society.

With your legal documents in place, your loved ones won’t have to second-guess your wishes, or deal with unnecessary legal issues.

The National MS Society has some complimentary materials to make the process easier. Our Ebrochure “Creating a Legacy Through Your Will” contains information about basic estate planning and how to prepare for a visit with your attorney. It also includes sample bequest language should you choose to include the National MS Society in your plans.

Perhaps you have a will that dates back several years and no longer represents your wishes. Your children may be grown, or, you may have experienced major changes in your life. Recent tax law changes could affect the provisions in your will. Most professional advisors urge their clients to review all estate-planning documents every few years, just to make sure they are up-to-date.

Our free Ebrochure “Questions and Answers about Wills,” is designed to help you think through the process of obtaining or updating your will.

You can request a copy on the National Multiple Sclerosis Society Web site at www.nationalmssociety.org. Click on “Get Involved,” then “Guide to Giving” and select the Ebrochure(s) you would like to receive.

You can also request our “Creating a Legacy Through Your Will” brochure by contacting us at 1-800-923-7727 or e-mail us at giftplanning@nmss.org.

Pedal Partners Program Needs You

The Pedal Partners Program offers people with MS and cyclists an opportunity to partner during the MS 150 City to Shore Bike Tour to motivate and inspire each other. We’re looking for people with MS who would like to send a note of inspiration to a cyclist by signing a Red Partners of Hope Bandana. By sharing what it’s like to live with MS, how the chapter has helped you and your family cope with MS, or what it would mean to you to find a cure, you will help to inspire our cyclists to go that extra mile toward raising money for research, programs and services.

Call 1-800-548-4611 to register for the Pedal Partners Program.

THANK YOU

- Thanks to the Berks East Gymnastic Team for sponsoring their annual Cartwheel-a-thon to raise money for the National MS Society.
- Thank you to the Golden Rule Chapter No. 390 of the Eastern Star in West Reading, PA for their donation to the National MS Society on behalf of their Community Outreach Program.
- Many thanks to ICT Research Services for their contribution to the fight against MS. Your generosity is greatly appreciated.
- We want to thank the members of the West Deptford Junior Woman's Club who sponsored a fundraiser to benefit the National MS Society.
- Congratulations and thanks to students at The Philadelphia College of Osteopathic Medicine who produced and starred in the theatrical production FOLLIES. In addition to putting on a wonderful show, they also raised over \$1,300 for the fight against MS.

PUT THE "FUN" IN FUNDRAISING

Have fun while raising funds and awareness for the National MS Society by hosting your own event. Whether you have a golf outing or a party you can help us provide services, research and programs individuals living with MS. For more information contact Deb Nonnemacher at 1-800-548-4611 or debra.nonnemacher@pae.nmss.org.



Classifieds

To place a classified ad in "MS Connections," please send an e-mail to: classifieds@pae.nmss.org Be sure to include all details for the ad as well as your name and phone number. If you wish to sell an item, please include the asking price. If you don't have access to e-mail, please call us at 1-800-548-4611, extension 275 and record the pertinent information.

FOR SALE:

1. 1994 Ford Econoline Conversion Van, Hydraulic Lift, handicap accessible, 35,000 miles, Best Offer.

2. Invacare Electric Wheelchair, Brand new, Best Offer.

Please contact Autumn Stewart
610-265-5680.

FOR SALE: 1989 Ford F 150 Van.

Electric doors, electric lift, electric driver seat. Fully handicap accessible, including driving mechanism. 100K miles. Well maintained. \$2,500. Call Nick at 215-427-2934.

FOR SALE: Jazzy Power

Wheelchair. Hardly used. Can be taken apart easily. Best Reasonable Offer 570-992-6765

FOR SALE:

1. Wheelchair Ramp 5 x 2 1/2 feet. Never been used. Made of fiberglass with skid resistant panels. \$50.

2. Pace Saver 3 Scooter. In good condition, new battery and transmitter. \$375.

Contact Karen 610-874-0392.

FOR SALE:

1. Oversized Big Boy Bed. 4 x 8 feet, electric, super heavyweight. Asking \$4,000.

2. Recovercare Air Mattress.

Oversized, alternating pressure, air vents. Asking \$3,000.

3. LexaLift with rechargeable battery pack. Asking \$4,000.

4. Arrow Action Series

Wheelchair. Battery powered, includes battery pack, electric, tilt seat. Asking \$3,500 (or best offer on all items).

Contact Barb at 610-797-6598.

FOR SALE: Jet 3 Power Chair.

Adjustable leg rest, headrest, flip up footrest, reclining seat. Never been used. \$4000 or best offer. Contact Anita 610-558-4804.

FOR SALE: 1992 Chevy Sports Conversion Van.

Has chair lift, electric windows, power steering, back seat converts to a bed. \$4000. Contact Marlene 609-922-0636.

FOR SALE:**1. Jazzy Jet 7 Motorized Chair.**

Two years old. Great condition \$1000 or best offer.

2. Chair lift. Lifts chair into trunk. Best offer.

Contact Marilyn Gilpin at 215-773-8499

FOR SALE: 1992 Ford Conversion Van.

59,000 miles. Wheelchair lift, power driver seat, lumbar window locks, dual air and heat, new tires, radiator and exhaust system. \$6500 or best offer. Call David at 610-380-8696.

FOR SALE: 1994 Ford Custom

Van. 114,000 miles. Wheelchair lift with door cutouts, custom paint, leather interior, reclining/removable captains chair, monarch hand controls for throttle, brakes, horn and high beams, electric activated parking brake, remote start up. Call Ed at 610-269-9406.

FOR SALE: Pronto Sure Step Electric Wheelchair.

Five years old. In great condition. Will also include a heavy-duty walker with seat for \$750. Contact Nancy Rodgers 570-223-0444

FOR SALE: Sinties Scientific, Inc. Power Trainer.

This is an exercise devise that wheelchair bound people use. You roll up to it in your wheelchair, you strap your legs into the boot-type devices and then you utilize arm handles to exercise the legs. Its great for upper and lower body exercise. The machine is in excellent condition. Asking \$350. Contact Susan Hurwitz 215-501-0126

FOR SALE: Two Concord Stair Elevators.

Electric powered. Four years new. Good condition. \$500 each. Contact Robert Hamilton 215-726-5369.

FOR SALE: Sonic Zoom 3 Scooter.

Only used inside about four times. Great for getting around the house. \$1500 or best offer. Contact Ron at 856-983-4381 or e-mail npomilio@verizon.net.

FOR SALE: Eyeglide Manual Assist Wheelchair.

Never used. 16 1/2 w x 18 1/2 d. Asking \$2000. Call 610-258-8880.

**Mark Your Calendar for the
Greater Delaware Valley
Chapter's 2005 Annual
Meeting**

TUESDAY, NOVEMBER 29, 2005

9 a.m - 2:30 p.m.

**VALLEY FORGE CONVENTION CENTER
KING OF PRUSSIA, PA**

For more information, contact Zoe Maltby at
800-548-4611 ext. 183 or zoe.maltby@pae.nmss.org



**Featuring...
Academy Award Nominee Teri Garr**



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