

Thank you to the hundreds of Challenge Walkers and volunteers who braved the rain to help us find a cure for MS.



Challenge Walkers participate in a candlelight ceremony honoring those affected by MS.



Luvenia Maul (c), who has MS, walked with friends, Sonia Alcoba (l) and Patricia Cyrus (r).



Greater Delaware Valley Chapter

National Multiple Sclerosis Society Greater Delaware Valley Chapter 1 Reed Street, #200 Philadelphia, PA 19147 NON-PROFIT ORG. U.S. POSTAGE PAID Philadelphia, PA PERMIT NO. 3428



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# msconnection

**Greater Delaware Valley Chapter** 

The National MS Society...Count On Us.

## Assistive Technology: Increasing the independence of people with MS

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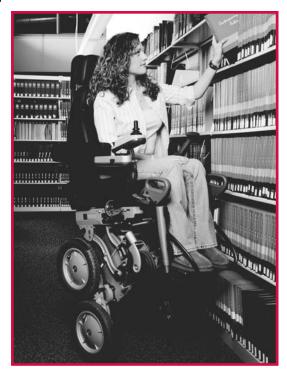


n a world where technology plays an ever-increasing role in daily life, it is important that individuals with MS stay informed of the technological developments that can help maintain long-term independence.

Assistive technology–products that enable people with disabilities to perform tasks–encompass a broad spectrum of devices as simple as a side-opening oven or as sophisticated as voice activated computer programs.

A feature of the Greater Delaware Valley Chapter's Annual Meeting (Nov. 29 at the Valley Forge Convention Center), the iBOT<sup>TM</sup> is one of the most talked about advancements for people with disabilities. The iBOT<sup>TM</sup> is a state-of the-art wheelchair that climbs steps, travels over variable terrain, and has a seat that raises to "eye level." However, the iBOT<sup>TM</sup> is only one of the many devices that can help individuals with disabilities.

Other examples include scooters, modified keyboards, pointers, reachers, text readers, voice input software, and environmental control units that enable



iBOT<sup>™</sup> is the latest development in assistive technology

people with limited mobility to operate appliances and other household devices.

Good Shepherd Rehabilitation Hospital specializes in using many of these devices to help individuals with multiple sclerosis. With eight certified

(Continued on next page)

### ms connection Fall 2005

**National Multiple Sclerosis Society** Greater Delaware Valley Chapter 1-800-548-4611 1 Reed Street; #200 Philadelphia, PA 19147

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Chapter President Judith G. Cohen

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

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

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#### PAGE 1 CONTINUED



Programs Director Karen Mariner (left) and Chapter President Judy Cohen (right) recently presented Jerry Werner (center) of Good Shepherd with a grant for the Nationl MS Society.

assistive technology practitioners and three assistive technology departments including the wheelchair clinic, occupational therapy, and augmentative communication, Good Shepherd has become one of the area's leading resources of assistive technology.

Although some assistive technology devices may be costly and difficult to access outside of rehabilitative institutions, people with MS can take advantage of the many products that are inexpensive and readily available.

The Pennsylvania Assistive Technology Foundation (PATF) specializes in helping individuals with disabilities access assistive devices through several financial aid packages. To learn how to receive financial help to obtain assistive devices, visit the Pennsylvania Assistive Technology Foundation at www.patf.us

Individuals in New Jersey who need more information about assistive technology and funding for these devices can visit the Assistive Technology Advocacy Center at www.njpanda.org/atacprogram.htm

To learn more about Good Shepherd's Assistive Technology Program call 1-877-734-2247.

#### 2005 Annual Meeting Vendors

The Greater Delaware Valley Chapter would like to thank the following companies for exhibiting their products and services at the Annual Meeting:

Accessible Home Products

Accessible Vans and Mobility/Van

Conversions

Adult Care of Chester County, Inc.

AHEDD A Specialized Human Resource

Organization

**American Mobility** 

**Bayada Nurses** 

Berks County Office of Aging

**Berlex Laboratories** 

Biogen Idec

Body Zone Sports and Wellness Complex

Bryn Mawr Rehabilitation Hospital

**Burman's Medical Supplies** 

Center for Disability Law and Policy

Community Legal Services

Council for Relationships

Disability Benefits Law Center

EZ Way Inc.

Family Support Center of NJ

The Fitness Center by Doylestown

Hospital

Good Shepherd Rehabilitation Hospital

Griswold Special Care

Home Delivery Incontinence Supplies

**Inglis Foundation** 

Internal Revenue Service

JEVS Support for Independence

John Hancock

Johnson & Johnson

King Financial

Laurel Rehabilitation Services, Inc.

Magee Rehabilitation

Medtronics Neurological

Moss Rehabilitation

Neumann College DPT Program

PA Office of Vocational Rehabilitation

Parkhouse Providence Pointe

PATF-Pennsylvania Assistive Technology Foundation

Rascal Insurance Services: A Division of **Electric Mobility Corporation** 

**Rodale Aquatics** 

Serono/Pfizer

Sterling Glen of Center City

Teva Neuroscience

Tristate Open MRI- Mainline Diagnostic **Imaging** 

Wheelchair Getaways

**United Spinal Association** 

#### ANNUAL MEETING

November 29

#### VALLEY FORGE **CONVENTION CENTER**







Teri Garr, Actress

#### Get a College Degree Online: Taking the First Step

by Dr. Kenneth E. Hartman, Director of Academic Affairs Drexel eLearning-Drexel University, Philadelphia, PA

or some adults with MS, the dream of earning a college degree has been seemingly unobtainable due to a number of barriers.

Fortunately, times are changing and, thanks to the Internet, many adults are now receiving their degrees entirely online. In fact, the United States Distance Learning Association estimates there will be more than two million students taking distance-learning courses over the next few years.

Distance learning affords busy adults the option of taking college courses anytime and anywhere. It's learning without the hassles and expense of driving to campus, taking time off from work, or being prohibited from coaching your child's soccer team. It is, by all accounts, the future of post-secondary education.

While distance learning is an excellent alternative for those who want the convenience and flexibility that such a program provides, it's clearly not for everyone. You will need to consider and assess the following three factors when deciding whether online learning is right for you:

#### **Your Skills**

Three sets of skills are important for an online learner:

#### Computer Skills

You don't need to be a computer whiz, but you will need to be proficient enough to send e-mails, write papers and surf the Internet. In addition, you should be comfortable downloading and installing software and be able to use instant messaging and online chat rooms.

#### • Study Skills

The three R's are an important success factor for online learners. Most of the communication is written, which means most of what you'll do is read. Are you a good researcher? You'll be working independently and the ability to write clearly and concisely is your ticket to good grades and smooth sailing.

#### • Time Management Skills

Can you set goals and meet deadlines? While online learning gives you the freedom to learn at your own pace, the pace needs to be steady and consistent for you to fulfill course requirements without burning yourself out.

## Your Preferred Learning Style

In what learning environment do you thrive? Do you enjoy exploring new subjects on your own? Do you like to work in a systematic, well-organized manner? Do you communicate well using e-mail and/or message boards? If you answered "yes" to these questions, then online learning may be a good fit for your preferred learning style. However, if you have a high need to be "face-to-face" with other people (classmates, professors), then online learning may not match your learning style.

#### **Your Motivation Level**

Are you independent and self-motivated? When taking an online course, you'll need to be both. You'll also need a good deal of discipline and persistence to overcome the typical and everyday distractions that accompany learning from home.

#### **Final Thought**

Remember to check with your local community colleges since the cost may be less and the personal help better. While earning a college degree, either on-campus or online, will greatly increase your earning potential, it will also enhance your sense of personal growth and development. The secret is taking the first step or, more appropriately, the first-click.

## You're invited to "click on" the Drexel eLearning Web site, as well as the following additional online resources:

Drexel eLearning: www.drexel.com

About: Distance Learning: distancelearn.about.com

US Distance Learning Association: <a href="https://www.usdla.org">www.usdla.org</a>

#### **Choosing a Degree Program**

Before you enroll in a single course, take the time to research and compare each college by:

- Accreditation. By whom and how recent?
- Tuition, fees, and other costs (sometimes hidden)
- Class size. Is there a minimum and maximum class size?
- Qualifications and experience of the faculty
- Degree requirements. Length? Residency requirements? Completion rate?
- Technical and academic support. 24/7? Extra cost?



## Laugh About It: A Young Adult Program (20s & 30s)

When: Friday, December 2, 2005

Time: 6:30 pm-7:30pm (hors d'oeuvres)

8:00 pm-10:00pm (show)

Location: Helium Comedy Club,

2031 Sansom Street, Philadelphia, PA

Enjoy a special evening at Philadelphia's newest comedy club, located in the heart of Rittenhouse Square, while socializing with other young adults from the area.

Register: ASAP. Space is limited.

## MS Symptoms Series: Gait & Walking and Speech & Swallowing

When: Saturday, December 3, 2005 Speaker: Jerry Werner, Sue Golden,

and Jeannie Metzger, Good

Shepherd Rehabilitation

**Time:** 10:00am-1:30pm

(Lunch will be served)

Location: Holiday Inn Conference

Center, Breinigsville, PA

Physical, occupational, and speech therapists will discuss tips and tools for managing symptoms.

Register by November 25

## **Understanding Healthcare Benefits Teleconference**\*

When: Thursday, December 8, 2005 Speaker: Kim Calder, Manager, Health

Insurance Initiatives,

National MS Society

**Time:** 7:00pm-8:00pm

National MS Society staff member Kim Calder will educate clients on the best way to maximize their health insurance benefits.

Register by December 1

## Organizing Your Space Teleconference\*

When: Thursday, January 5, 2006

**Speaker:** Darla DeMorrow,

HeartWork Organizing

**Time:** 7:00pm-8:00pm

Learn how to organize your home and office to make daily tasks more manageable.

Register by December 30

#### Is It My MS or My Age?

When: Saturday, January 14, 2006

Speaker: Dana Breslin, Esq.,

and Dr. Mark Tullman

**Time:** 10:00am-1:30pm

(Lunch will be served)

Location: Airport Marriott, Philadelphia, PA

Learn how to ease the challenges of growing older with MS.

Register by January 6

#### Medicare: Part D Teleconference\*

When: Wednesday, January 18,

2006

**Speaker:** Patricia Lowry, Center for

Medicare and Medicaid

Services

**Time:** 7:00pm-8:00pm

This teleconference will help you understand how the new Medicare prescription drug plan works and how to make the most of its benefits.

Register by January 11

#### **NAEC:** Genetics

When: Saturday, January 21, 2006

**Time:** 10:00am-1:00pm

(Lunch will be served)

Location: Blue Heron Country Club,

Cologne, NJ

Join the National MS Society to learn about the latest research on MS and its genetic components.

#### Register by January 13, 2005

This program has been made possible through an unrestricted educational grant from Teva Neuroscience.

## Planning Your Financial Future

When: Tuesday, January 24, 2006

Speaker: Christine Walker,

Millennium Wealth Management & Private

Banking

Darla DeMorrow,

**Heartwork Organizing** 

**Time:** 6:00pm-8:30pm

(Dinner will be served)

Location: Holiday Inn City Line,

Philadélphia, PÁ

The speakers will address the financial issues of living with MS and how to organize the paperwork necessary for easier financial planning.

Register by January 16

To register for these events please call 1-800-548-4611 or visit

www.nationalmssociety.org/pae

\*After registration you will be given a call-in number to access the teleconference.



Keep S'myelin, a newsletter for children about MS, is available through NMSS chapters as well as on the National MS Society's Web site.

Designed for children 5-12 years old, who have a parent or loved one with multiple sclerosis, Keep S'myelin includes regular articles about different aspects of MS, puzzles and games, photos, book reviews, tips, and more.

For a copy of the latest issue call 1-800-FIGHT MS, or to access the newsletter through the Internet, go to www.nationalmssociety.org.

#### Local Students Awarded NMSS Scholarships

he Greater Delaware Valley
Chapter of the National MS
Society extends their
congratulations to the five local
students who were the recipients of the
National Multiple Sclerosis Society
Scholarship: Eric Hahn of Dresher, PA;
Meaghan Henrici of Wayne, PA; Cara
McGuinness of Merion, PA; Hugh
McStravek of Prospect Park, PA; and
Dominic Rucci of Whitehall, PA.

The scholarship, which was created to assist those with MS or those who have a parent or guardian with MS was awarded to 88 students nationwide. Students were chosen based on their academic record, extracurricular and community activities, financial need, and an essay about how multiple sclerosis has affected their lives.

"We understand that when an individual is diagnosed with MS the entire family is

affected. Too often MS causes financial hardships making it difficult and sometimes impossible for some children to attend college," stated Chapter president Judith G. Cohen. "We are here to ensure that MS doesn't prevent children from bettering themselves, personally, socially, and academically."

To apply for the 2006 National MS Society Scholarship visit www.nationalmssociety.org and click on the "Living with MS" section and then the "Family and Friends" link.

If you have questions about the application process please contact Scholarship America at 1-800-537-4180, ext. 141. All applications should be sent directly to Scholarship America between January 1 and February 16, 2006.



Eric Hahn



Meaghan Henrici



Cara McGuinness



**Hugh McStravek** 



**Dominic Rucci** 

- msconnection

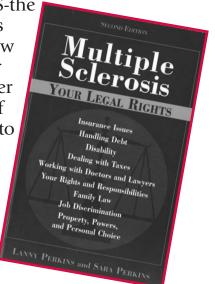
#### **Lending Library**

he 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 <a href="https://www.nationalmssociety.org/pae">www.nationalmssociety.org/pae</a>. Click on "Library and Literature" at the top of the page. New materials include:

Multiple Sclerosis: Your Legal Rights
The book provides information about

The book provides information about the legal rights of people with multiple sclerosis. Written by two lawyers-one of

whom has MS-the book educates readers on how to prepare for the future after a diagnosis of MS and how to ensure that your individual rights are upheld.



# Computer and Web Resources for People with Disabilities

This updated book provides a wealth of knowledge about assistive technology, including stories about how assistive technology has improved the lives of individuals, assistive technology Web



#### WORLD CONGRESS & EXPOSITION ON DISABILITIES

December 1-3, 2005 | PA Convention Center | Philadelphia, PA

Visit the World Congress and Exposition on Disabilities and speak with dozens of leading associations, see hundreds of the newest products and services, and meet thousands of people like you - people with disabilities, their families and caregivers. For more information or to register visit <a href="https://www.wcdexpo.com">www.wcdexpo.com</a>.

#### PRESCRIPTION:

#### ENROLL IN MEDICARE PART D TODAY



## THE NEW PRESCRIPTION DRUG BENEFIT WILL SOON BE AVAILABLE TO ALL MEDICARE BENEFICIARIES.

Medicare is the federally-funded health insurance program for everyone over 65 and for people with disabilities. This new coverage may be a good option for people with limited insurance.

Act now if you:

- Will be on Medicare in 2006 and you have no prescription drug coverage or have drug coverage that is not as good as the Medicare plan
- Are a Medicare beneficiary who receives free or low-cost drugs from a pharmaceutical company patient assistance program
- Receive MS drug coverage from the Medicare Rx Demonstration Project
- Receive Avonex in a clinic or doctor's office

People who are on Supplemental Security Income, qualify for Medicare and Medicaid or are in a Medicare Savings Program are automatically enrolled and do not need to apply.

Benefits take effect January 1, 2006. Enroll today.

For more information, call Medicare at 800-633-4227 or visit <u>www.medicare.gov</u>

- msconnection

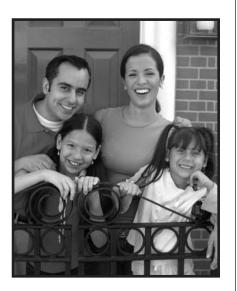
#### **Network for Families Who Have a Child with MS**

"Young Persons with MS: A Network for Families with a Child or Teen With MS" is a support network with many program options for families living with a child or teen who has been diagnosed with multiple sclerosis.

The program is a collaborative effort between the National MS Society and the MS Society of Canada. In recognition of the unique needs of these children and the variety of support services and programs their parents and siblings may require.

#### The network targets two distinct populations:

- Children with MS (18 and under).
- Parents of a child or teen with MS.



#### **Network Programs**

#### **Parent Teleconferences**

Teleconferences featuring specialists in the field of pediatric MS are offered for parents. Topics typically relate to research, treatment, cognitive issues, and children's rights within their school system.

#### **E-mail Group for Parents**

Connects parents through an e-mail list group where they can share concerns and information, and develop a support network.

#### E-mail Group for Teens with MS

Connects teens with MS through an e-mail list group where they can share concerns and information, and develop a support network.

#### **Short-Term Counseling**

A licensed social worker is available to provide short-term telephone counseling at no cost to families living with a child with MS.

#### Parent Handbook

Kids Get MS Too: A Guide for Parents Whose Child or Teen has MS, is now available. This handbook contains articles on a variety of topics written by specialists in childhood MS.

#### **Activity Book for Children**

Mighty Special Kids is a 20-page activity book for children ages 5-12 with MS. The book contains educational games, activities and age appropriate articles to help children better understand their diagnosis.

Parents can receive information about MS and local resources from the Chapter by calling 1-800-548-4611.

#### Just Wondering: Filing A Disability Claim

n 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 do I need to know before I file a claim?

A: You should be familiar with the terms of your short or long-term disability policy before you file your application. This is especially true if you are applying soon after you became insured or if the insurance carrier may allege that you have a pre-existing condition. If you stop working too soon and file your claim too early, your application may be denied on a technicality. When in doubt, ask an attorney to review the policy.

## Q: Do I need to contact my physician before I apply?

A: Before you file any application for disability benefits be sure to talk with your doctor(s). The insurance company will ask your doctor(s) to complete a form to provide your diagnosis(es) and assess your ability to work before the claim is approved. You want to know before you apply that your doctor will support your claim. The sooner you talk with your doctor about your need to stop work the better.

## Q: What do I need to include in my application?

A: Provide a detailed description of your medical conditions and the symptoms that are preventing you from working. Just saying "I have MS" will rarely be sufficient.

Many claims are denied because of lack of medical evidence. Therefore, do what you can to get all of your medical evidence in the hands of the carrier. If the insurance company asks for your help in obtaining medical evidence from your doctors, be sure to provide that help. The more medical evidence you and your doctors provide, the stronger your case will be.

Also, be sure that every time you speak with your doctor or other treating source you give an accurate and detailed account of your symptoms and functional limitations. BE SPECIFIC. When the insurance company evaluates your claim, they will only believe that you have the symptoms and functional limitations that have been recorded in your treatment records.

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

ADVOCACY msconnection

#### 15 years later: The effects of the ADA

he Americans with Disabilities
Act recently celebrated its 15th
Anniversary. This law, passed in
July 1990, prohibits the
discrimination of individuals based on
disability and ensures full participation in
American society. According to the ADA a
disability is any impairment that limits an
individuals life activities, this includes
seeing, hearing, walking and working.

According to the ADA, people with disabilities are protected from discrimination in the following areas:

- Employment employers are prohibited from discriminating against any individual with a disability who is qualified for a position. New employees and employees who become impaired are protected under this law.
- Public Accommodations People with disabilities are guaranteed the right to use all public services and facilities. Modifications must be made to public accommodations to ensure accessibility to all people with disabilities.
- Transportation Urban transit, paratransit, publicly funded rail systems and transit facilities must meet the needs of people with disabilities. All new transportation systems must be fully accessible.
- Telecommunications People with speech or hearing impairments must be given services by the telecommunications company without additional costs.

Over the past fifteen years the ADA has brought about considerable changes to ensure that people with disabilities have equal rights. Despite these improvements much more needs to be done in order for individuals with disabilities to be fully integrated into Society.

While many buildings are now accessible as a result of the ADA, they still lack the necessary space that people in wheelchairs, scooters, and walkers need to move with ease. There is also a lack of public funding to make housing accessible; curbs and sidewalks are still difficult to navigate, and discrimination in the workplace is still rampant.

In order to guarantee the efficacy of the ADA, individuals need to learn about their rights under this law and file any complaints.

For more information about the ADA and enforcement of the ADA visit: www.ada.gov

U. S. Equal Employment Opportunity Commission www.eeoc.gov

Architectural and Transportation Barriers Compliance Board www.access-board.gov

#### THIS IS WHY...

Disability discrimination is real. This is why we fight for equal rights. Join our advocacy efforts at http://capwiz.com/nmss/mlm/.

#### Linda Noble Topf: Exceptional, remarkable

n award-winning art director, counselor, ordained minister and writer, Linda Noble Topf did not let her diagnosis of multiple sclerosis at the age of 32 prevent her from doing the things she loved. Instead, Linda decided she would do everything in her power to rise above her illness and help

In 1995, Simon and Schuster published her book entitled You Are Not Your Illness: Seven Principles for Meeting the

others with disabilities.

Challenge, which had a tremendous impact on the disabled community. Determined to do even more for people with disabilities, Linda noticed a lack of representation at the National Liberty Museum in Philadelphia. Created to decrease violence and bigotry and honor those who have made a major difference in their community, Linda felt that there should be a place for people with disabilities at the museum.

Through Noble Design, her award winning design and marketing company, Linda developed a proposal for an exhibit at the National Liberty Museum in 2002. Linda became the inspiration as well as the designer for an exhibit entitled Exceptional Americans Who Have Achieved Remarkable Success, which was completed by the end of 2002. The first of its kind in the country, the exhibit honors 33 Americans who have achieved great success in spite of their physical challenges. According to Linda,

"The 33 individuals have awakened in us the realization that, despite extreme

challenges, life can be extraordinary. The exhibit focuses on the relationship between the inner spirit of mind and body and the outer life of service, action, and contribution." As a result of her persistence and the success of the exhibit, the National Liberty Museum made Exceptional Americans a permanent exhibit in 2004.

Over 65,000 people visit the National Liberty Museum every

year and the vast majority of them are children. Linda believes that it is important to teach children that they can be their own heroes and hopes that her exhibit will inspire all those who see it.

The museum chose to include Linda in the Exceptional Americans exhibit and it is not difficult to understand why. Linda has always been passionate about the "dignity of the human spirit" and her life has been a true testament to this belief. Although multiple sclerosis has greatly decreased Linda's physical capabilities, she continues to dedicate herself to helping the disabled community.

Although she can no longer type she is now in the process of writing her second book via audiotape. She also hopes that she will have the opportunity to replicate the National Liberty Museum exhibit in major cities across the United States including New York, Chicago, Washington D.C., and Los Angeles.

#### Taking Stock at Year-End, and Giving It

any people own appreciated stock-stock that has risen in value over time. For example, if a donor has a stock that has grown from \$15 a share to \$75 a share over the past few years she's facing significant capital gains tax. If she asks her broker to sell the stock she will owe tax on the \$60 of appreciation for each share that is sold.

However, if she gives the stock to the National Multiple Sclerosis Society, she will avoid this tax on the appreciation and instead receive an income tax deduction on the full value of the stock. What's more, because the National MS Society is a qualified charitable organization, the Society can sell the stock and avoid any tax on the appreciation. A win for the donor and a win for the National MS Society.

The end of the year is the perfect time to give stock to the National MS Society.

In fact, most stock gifts occur during the fourth quarter of the year. Many thoughtful donors review their stock portfolio and select stocks which have appreciated the most and which have been held for more than a year. These donors give stock instead of cash because they have discovered the value and enjoyment of stretching their giving power by giving stock. The more they can prudently give to help end the devastating effects of multiple sclerosis, the better they feel.

Have you considered making a gift of appreciated stock to the National MS Society? It may be better for you than making a gift of cash.

To learn more about giving stock, you may want to talk with your CPA and investment advisor. If you'd like additional information, you can also call us at 1-800-923-7727 or e-mail us at giftplanning@nmss.org.

#### Katrina Tax Relief Act of 2005

This past September, legislation (Section B. Suspension of Limitations on Charitable Contributions for Relief Efforts Relating to Hurricane Katrina, H.R. 3786, sec. 301 of the bill) was passed that provides additional tax benefits to people and businesses affected by Hurricane Katrina. This legislation allows temporary tax benefits to anyone making a contribution to a Qualified Charity, like the National MS Society, between August 28 and December 31, 2005. Contributions do not have to relate to hurricane relief. For more information contact your tax consultant or visit www.nationalmssociety.org.

#### **DeBenedictis receives MS Hope Award**

n Friday, September 16, over 600 people attended the 7th MS Dinner of Champions in Philadelphia. Nicholas DeBenedictis, President & CEO of Aqua America was given the Hope Award in recognition of his outstanding dedication to the community.

Governor Ed Rendell congratulates Nick DeBenedictis on receiving the 2005 MS Hope Award



#### CALLING ALL VOLUNTEERS:

# The National MS Society wants you!

Thank you to the more than 2400 volunteers who generously donated their time to the MS Walk, the MS 150 City to Shore Bike Tour, MS PA Dutch Bike Tour and the MS Challenge Walk.

Assistance is still needed in our Lending Library on an ongoing basis and we are always looking for help with projects in the Philadelphia and Allentown offices.

To learn more about how you can lend a hand, contact Kathie Cronk, 1-800-548-4611, or Kathie.cronk@pae.nmss.org.



MS 150 City to Shore volunteers working at the finish line.

# UNITED WAY AND OTHER WORKPLACE GIVING OPTIONS

Give to the Greater Delaware Valley Chapter of the National MS Society through United Way's Donor Option Program.

It's easy! Complete your United Way pledge form and mark the section for Donor Choice or Donor Option. For the United Way of Southeastern Pennsylvania, our agency code is #00243

If you work in the public sector or for a branch of the military, you can support the National MS Society through the Combined Federal Campaign (CFC) by selecting the designated code number: 0549.

In the Public and Private Sector Campaigns, you will find the Society listed under Community Health Charities.

Thank you for thinking of the National MS Society when you contribute through your workplace campaigns!





## Thank you

to the more than

6,500 cyclists

and all of our Pedal Partners.







25th Anniversary of the MS 150 City to Shore Bike Tour on Sept. 24th and 25th

an enormous

success and a

celebration to

remember!



MARK YOUR CALENDAR FOR THE 2006 TOUR ON SEPTEMBER 16 & 17.

- ms connection

## Disease Researchers Report Cell Transplants Protect Brain Tissues in Mice with MS-Like Disease

esearchers at the San Raffaele Hospital in Italy published unexpected results in which immature nerve cells (adult mouse neural stem cells) injected into the blood of mice with MS-like disease were able to suppress the immune attacks that damage the brain and spinal cord tissues.

The study is reported by Drs. Stefano Pluchino, Gianvito Martino and colleagues in the July 14, 2005 issue of Nature.

Dr. Pluchino injected neural stem cells, taken from the brains of adult mice, into the blood of mice with a relapsing-remitting form of EAE, an MS-like disease. Some mice were injected at the onset of disease, and others at the onset of the first relapse.

Mice in which neural stem cells were injected at disease onset started to recover between 30 and 60 days, and experienced a twofold reduction in relapses compared with untreated mice. Mice injected at the first relapse started to recover later, but showed a threefold reduction of the relapse rate between 60 and 90 days, compared with untreated mice.

Both groups showed a significant reduction in the extent of myelin damage and nerve fiber loss compared to untreated mice.

These surprising findings, if confirmed, suggest that neural stem cells that reside in the adult brain may not only serve as

replacement cells for tissue repair, but in some circumstances may also protect the brain from inflammation. Further research is needed to confirm these results and to address multiple issues involved in translating such experiments into finding ways to fight the immune attack and protect and repair brain tissues in people with MS.



#### **Research Highlights**

The Summer/Fall 2005 issue of "Research Highlights" is available on the National MS Society Web site at nationalmssociety.org, or by calling the Chapter at 1-800-FIGHT MS.

Articles from this report include:

- Stepping Up the Pace of Rehabilitation Research
- Toll-Like Receptors: Newly Discovered Molecules Play Possible Role in MS
- Spotlight on Childhood MS
- Progress by Collaboration: Dr. Charles Stiles

## Study Asks, "What can I do to help my MS?"

aking care of one's health is important for all women, but particularly for women with MS. The purpose of this study is to identify the range and extent of health promoting behaviors (as well as barriers to these behaviors) for women with MS. In addition, the relationship between these behaviors and quality of life and participation in life roles will be explored. More research is needed to understand the actual lifestyle practices of women with MS.

Women 18 years or older who are diagnosed with multiple sclerosis can participate. Questionnaires will be sent to you to fill out at your convenience. If assistance is required, a phone interview can be scheduled. The questionnaires will take approximately 20 to 30 minutes to complete. Confidentiality of all participants will be maintained.

Study results will help researchers gain a clearer understanding of the degree and ways in which women with MS maintain health promoting behaviors and how these may effect their quality of life and role participation.

This knowledge can contribute to more comprehensive treatment planning for women with MS and can provide valuable information to newly diagnosed women who struggle with the questions, "What can I do to help my MS?"

If you are interested in participating in this study and/or have questions, please contact: Andrea Carr Tyszka, OTR/L at 609-254-3923 (atyszka@temple.edu) or Ruth S. Farber, PH.D, OTR/L 215-707-4880 of Temple University, Department of Occupational Therapy.

## MS Clinical Trials Features Updated Site

here are several updated features on the National MS Society Web site relating to Clinical Trials in multiple sclerosis.

- The list of "Agents in Clinical Trial for MS" has been updated for 2005. This document lists approximately 130 ongoing, planned, or recently completed studies of agents under study for MS. www.nationalmssociety.org/pdf/ research/agents.pdf
- An expanded version for health care professionals has also been updated for 2005. This version contains extensive information on possible mechanisms of action for each agent, as well as study results, if these are available.
   www.nationalmssociety.org/pdf/ research/clinicaltrials.pdf
- The section on "Trials Recruiting Patients" contains information about trials indexed by state that are recruiting people with MS. Studies are currently listed in 43 states, as well as 15 countries.

www.nationalmssociety.org/Research trialsrecruiting.asp

#### Subjects Needed for "Mothering With MS" Study

eing a mother is an important role for many women, yet relatively little is known about mothering in special circumstances, such as having MS, from the perspective of the mother.

Dr. Ruth S. Farber from Temple University's Department of Occupational Therapy has been doing research to understand the experience of mothers diagnosed with MS. This study explores the mothers' participation in parental activities, their satisfaction with this involvement and their sense of well-being. In addition, the influence of social support and perceived health will be examined. More participants are still needed.

Mothers actively parenting a child or children ages 12 and younger can participate in this study. Women will be mailed a set of four questionnaires, some background questions and a selfaddressed stamped envelope. These

should take approximately 45 minutes to complete. The confidentiality of all participants will be maintained.



If interested in participating in this study or if

you have questions, please contact Ruth Farber, PhD, OTR/L at 215-707-4880 or msmoms@temple.edu.

#### A NEW SELF-HELP GROUP IS FORMING IN WEST CHESTER, PA

The Chester Let's Talk MS group will meet on the first Thursday of each month from 6:45 p.m. to 8:45 p.m. at the West Goshen Township Building, 1025 Paoli Pike, West Chester, PA.

To learn more about this group contact Pamela Berretta at 1-800-548-4611 ext.168 or pamela.berretta@pae.nmss.org

To place a classified ad in "MS Connection," 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: 1994 Ford Econoline Conversion Van, Hydraulic Lift, handicap accessible, 35,000 miles, Best Offer. 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. 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:**

- 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: 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.
- 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.

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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 device 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. It's 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: I/glide Manual Assist Wheelchair. Never used. 16 1/2 w x18 d. Asking \$2000. Call 610-258-8880.

FOR SALE: Beautiful home in Rydal designed and built 8 years ago for easy, gracious living. First floor completely accessible. Open flow of spacious rooms, large master bedroom, oversized master bath. Gorgeous kitchen, great room, dining room, den, powder room, fireplaces, builtins, many other lovely features. Additional bedrooms and bath on 2nd floor. Set on one acre of private, fenced grounds. Unique, special house for a variety of

lifestyles and needs. In absolute move-in condition. For more information, call Lynne Berman 215-576-6321

FOR SALE: Indi-Care Wheelchair with adjustable legs, swing away arms - like brand new! \$350. For more information contact Max at 610-461-1787

FOR SALE: Power Wheelchair, Invacare Storm Series. Very food condition. Newer batteries. Battery charger. Jay2 cushion. Manual included. Right-hand controls. Asking \$1100.00 For more information call 215-257-9428.

FOR SALE: JET 3 ULTRA Electric Wheelchair, virtually brand new condition-barely used, multiple foot rest options, on board battery charger, removable basket, highback seat with headrest, owners manual included. Original cost \$3,000, best offer. Call Nick at 215-945-7370.

FOR SALE: Ever Rest manual wheelchair, good condition. \$100 or best offer. Contact Rosalie at 215-477-8878.

FOR SALE: Victory Electric Scooter. Only driven once (6 months old) - easy to operate. Brand-new condition. Can be taken apart easily - instructions included. Very comfortable high-back chair. Plug into wall overnight to charge batteries. Asking \$1000.00.

Contact Steve at 215-203-0767 or email stevieb@starlinx.com.

FOR SALE: Jazzy power chair and lift. Hardly used, great condition. Both for \$2000. Call Grace 610-698-1020.

FOR SALE: Electric Craftmatic Scooter. One year new. Good condition. \$200. Call Debbie at 609-499-2303.