

# CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Summer 2008

## bike MS: Bike to the Bay 25 years and counting!

### bike MS

bike to create a world free of MS

Introducing 25K route starting at Uncle Ted's rest stop in Milton

Back when Theodore Stuchlik still worked at Diamond Electric Company, he was approached one day with an interesting question: Would he allow some enterprising bicyclists—fund-raising for MS by pedaling 150 miles from Dover to

Rehoboth Beach and back—to set up a rest stop on his property? Located on Route 88 in Milton, Delaware, the grassy stretch lay only 25K from Rehoboth, which made it the perfect rest stop.

“Tommy Hartley rode with about 50 folks in those early days,” remembers Stuchlik’s widow,

Pauline, “and Tommy’s father owned Diamond Electric, where my husband worked as the office manager. Of course, my husband said yes. And that’s how this rest stop became known as Uncle Ted’s.

“I love it,” adds Mrs. Stuchlik about her continued participation. “It’s my little contribution. It’s amazing to me just how much people are willing to donate and how much they are willing to do. And the most amazing thing about it all is that, on Monday morning after the event, my grass is a little trampled, but in two or three days, you’d never know anyone was here at all. They are the cleanest, most polite people!”

For more on Bike to the Bay, turn to page 7.

## *A typical teen gets on with her life*

In the year before receiving an MS diagnosis, Heather Marshall experienced what her mother thought were typical teen-aged growing pains, not knowing they would get progressively worse. Then, one day, Marshall lost her vision.



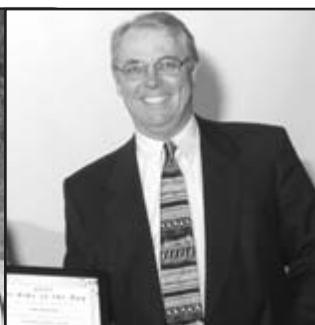
Heather Marshall’s graduation photo was taken shortly after the MS diagnosis.

“We saw a lot of doctors over that weekend,” notes Marshall’s mother, Kitty Fletcher, “before we found out it was optic neuritis [an inflammation of the optic

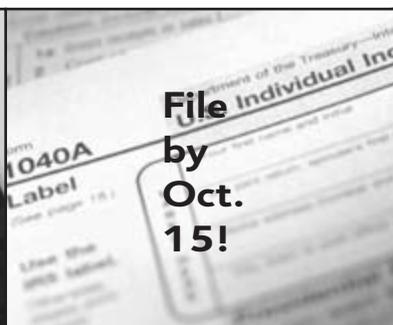
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Tax rebate includes low incomes Pg. 12



Get budget-smart Pg. 17



## President's impressions **Why I ride**

**President of the Delaware Chapter, Kate Cowperthwait**

Each year, when the Bike to the Bay rolls around, I find myself asking the same questions:

Why would any woman in her right mind don those tight, little spandex shorts with the added padding? Or the skintight jersey—skintight in places that shouldn't be! Or the bike helmet

that sculpts your hair into a mushroom! And why would any woman pedal off on a 75-mile trek downstate?

Putting aside any doubt about my sanity, I can list a number of perfectly good reasons why I ride. See if you agree.

• I ride to set an example to my family, my children, and my neighbors. As the president of the Delaware Chapter and long-time advocate in the fight against MS, I need to set an example.

• I ride because 2008 marks the 25th running of the Bike to the Bay, and I feel like celebrating.

• I ride because I spent a lot of money on my bike, and I had better get some use out of it—*or I will never hear the end of it.*

• I ride because I want the sausage sandwich at Uncle Ted's rest stop.

• I ride because I have a team of extraordinary women who ride with me, and I don't want to let  
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## *MSConnection, Spring 2008*

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### **Delaware Chapter Officers**

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### **The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS.**

Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve the quality of life for many people with MS. To learn how to help manage MS as well as about the current research that may—*one day*—reveal a cure, talk to your health-care professional. Then, contact the National MS Society at (800) 344-4867, or visit [www.nationalMSSociety.org](http://www.nationalMSSociety.org).

The information provided by the Society is based on professional advice, published experience, and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The Society recommends that all questions and information be discussed with a personal physician and does not endorse products or services. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any mentioned products or services.

## Free individual counseling



Do you experience a sense of sadness or loss? Do you think your partner

doesn't understand? Do you have MS-related work issues? Have you told your employer yet?

MS can be very hard to accept sometimes. Whether your issues are personal or work related, use the tools that can help you resolve them. Talk to one of the counselors that the Delaware Chapter has under contract specifically to help you through the "rough spots."

**Am I eligible?** Yes, if you are a chapter member with an MS diagnosis. This program is open to anyone with MS and is not need-based.

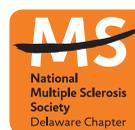
### How much does it cost?

Payment for your sessions is covered by the chapter, so they are free for you.

**Where is it located?** Sessions are one-hour long and available at a location near you.

### How do I make an appointment?

Call Debra. In New Castle County, call (302) 655-5610. In Kent and Sussex counties, call (800) 344-4867.



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## Lending library offers new titles

The Delaware Chapter maintains a significant lending library for your use. Here is a sample of some of our newest titles:

- *101 Accessible Vacations: Travel Ideas for Wheelers and Slow Walkers*
- *Caring for Loved Ones with MS: A Guide for Families*
- *Employment Issues and Multiple Sclerosis*
- *Health Insurance Resources: A Guide for People with Chronic Disease and Disability*
- *Multiple Sclerosis: A Self-Care Guide to Wellness*
- *Multiple Sclerosis: Your Legal Rights*
- *Social Security Disability Benefits: A Guide for People Living with Multiple Sclerosis*



### How long may I borrow materials?

Three weeks. Pre-paid return envelopes are included—at no cost to you!

### How do I borrow materials?

Visit MSdelaware.org. In the left-hand directory, click on "Library & Literature." Or call Debra at (302) 655-5610.

## Research survey

# The emotional experience and quality of life with MS

This survey requires the participation of both a person with MS and someone who knows them [that person] well and who has regular contact with that person.

The study involves a 15-minute survey via the internet. The survey begins with a brief explanation of the study and a consent

document. If you agree to participate, you will proceed to a survey that asks questions of the individual with multiple sclerosis and concludes with questions for the person who interacts with them on a regular basis. All questions concern the health, quality of life, and emotional experiences of the individual with MS. The study requires the participation of both the individual with MS and someone who knows them well.



Study participation is voluntary and anonymous. No identifying information will be collected. Both participants must be 18 years of age or older. E-mail [rspencer@umbc.edu](mailto:rspencer@umbc.edu) if you have any questions about this study.

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nerve that causes loss of vision with the swelling and destruction of the myelin sheath covering the optic nerve]. Heather has had complete loss of vision in both eyes, but after steroid injections for a week, she has been lucky enough to regain all her vision; however, she does still continue to lose her vision every now and then.”

“It just happens sometimes,” adds the Frederica teen who celebrated her 19th birthday in January. “One minute I can see; the next I can’t. I have a photographic memory, though, so as long as nobody changes anything, I’m fine.

“When I found out I had MS,” continues Marshall, “it was very bad for me because I saw it as people in wheelchairs—always—and I thought it was going to be me in a wheelchair. Then, the doctor said it was hereditary. I said ‘What?! No one else in my family has this!’ I live across the street from my step-sister. She has a one and a half year old, and I help with her sometimes. It’s hard to think that I won’t be able to walk—that I can’t have kids. I can’t subject my kids to this!

“I’m sorry,” says Marshall, calming herself. “My MS has limited me in what I can do. I can’t stand or sit for a certain period of time, can’t walk long distances, can barely run. I used to work at a factory-retail outlet but just lost my job because of my disability.”

“Heather has lost several jobs,” adds her mother, “because she has episodes at work that scare people. They don’t understand what is happening. It also poses some safety issues when she doesn’t know when she will lose her vision.”

“Still, I function in society,” notes Marshall with determination in her voice. “I say to myself ‘If this happens to me and I can’t do anything about it, I have no one to blame but myself.’”

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*One minute I can see; the next I can’t. I have a photographic memory, though, so as long as nobody changes anything, I’m fine.*

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“I read a lot when I can. And I’ve written my own book, a fantasy called *The Scrubs*. It’s 407 handwritten pages. Now, I’m writing a sequel called *Angel Stand*. It’s about one of the original character’s sons, goes into more detail—the teenager who turns into the man and the wacky things men do!” laughs Marshall.

“Reading and writing keep my mind from wandering, keep me focused. I’ve got a dog, too. I got him for my birthday. He’s only seven months old, an Australian shepherd-cattle dog mix, and he’s always running around like a kid.

“He’s my momma’s boy,” croons the smitten teen.

### **What helps?**

“For me,” says Marshall, “the information I get that explains MS is great, especially the hard information that’s easy to understand and easy to get others to understand. My mom went on the internet for me when I was diagnosed and got lots of information. The MS newsletter, I’ve read it I don’t know how many times!

“And I went to MS camp one year. It was nice to see other kids my age with the same problems. It was a fun experience. I had a good time.

“But it’s hard for me to reach out to people I don’t know. Besides, I have all the support I need. I’m surrounded by people who love me, my fiancé, friends, my sister,” smiles Marshall.

### **Ready advice**

With typical teen-aged energy, Heather Marshall readily volunteers her advice for getting on with life.

“Exercise! If you have MS and can’t get around easily, go outside! Plant a garden! (I have a garden with two red rose bushes. Roses are my favorite.) Get a dog! A dog will keep you on your toes! A dog is ‘man’s best friend.’ With a dog, you can play with him and love him forever. It’s good to have a companion if you don’t have anybody else.

Continued at top of next page

“You can’t think about the past or the future,” adds Marshall. “Think only about what you do today. And if your family doesn’t understand what you’re going through, give them a piece of paper explaining why you’re so tired all the time. Write it by hand if you need to. Just explain in ways they will understand.”

“It makes life easier,” muses Marshall, “to think of someone else, something besides your MS.”

## MS READaTHON

### Promote reading!



Would you like help promoting reading in your family, your child’s school, or local library? The Delaware Chapter has a program for you.

It’s called the MS READaTHON, and its goal is to promote reading and community involvement among elementary and middle school students throughout the year. For more info, call Jenna at (302) 655-5610, ext. 15.

## Information specialists

### Ready to meet your needs



In March, the Delaware Chapter added several new members to the Program team: information specialists. Also known as

professional navigators, these men and women with master’s degrees in social work plus other home health professionals have been trained to meet your specific needs as a Delawarean with MS. They will work with you discreetly and quickly. Plus, they are available Monday through Friday from 9:00 A.M. to 5:00 P.M. EST. Simply call the chapter office as usual. We’ll do the rest.

## Calendar of Events

June 9 MS Golf Tournament, White Clay Cr. CC

June 24 Dinner of Champions Kick-off

June 28 READaTHON Night, Frawley Stadium

July TBA bike MS Bicycle Expo

Sept 25 bike MS: Bike to the Bay Pre-reg Night

Sept 27–28 bike MS: Bike to the Bay 2008

Oct 29 Dinner of Champions with Joyce Nelson

## Advocacy Alert

We know that all three of Delaware’s legislators support people with chronic illnesses and disabilities. However, we want to ensure that people with MS have our legislators’ support when and where it counts—when it’s time for them to vote! They are much more likely to vote and act in your favor if they hear from you personally. (For details on the House MS Caucus and the Senate MS Caucus, see the top of page 13.)

### Call (877) 224-0041.

**Ask for Sen. Joe Biden.** Urge him to join the Senate MS Caucus.

**Ask for Sen. Thomas Carper.** Urge him to join the Senate MS Caucus.

**Ask for Rep. Mike Castle.** Thank him for joining the House MS Caucus.

## In memory of

### Clarissa M. Booth

From: Joan & David Hitchens  
Loretta & James  
Keenan  
St. Mark's High School  
cafeteria staff  
Dolores Scarfi  
Patricia M. Saienni  
Scott & Millie O'Hara  
Dennis & Henrietta  
Cook  
Robert & Sandra  
DiEmedio  
Marie V. Dally  
Sandra & Michael  
Mensingher  
Lori & John Demanczyk  
Mary & Mike Moxley  
Mary & Bob Lightcap

### Clarissa M. Booth (cont'd.)

From: Anthony & Carol  
Brazen  
Kim, Kate & Wil  
Duggan

### Diane Beenick

From: Construction  
Professionals Inc.  
Michael & Ligia Skyer

### Albert Lore

From: Dolores & William  
Stewart

### Donald Bartlett

From: Dolores A. Gilston  
& family

### Charles W. Meyers

From: Olen & Sandy Boyce  
Thomas & Wave  
Starnes  
Bessie Shockley

### Virgil A. Chaffinch, Jr.

From: Kay & Mark McMahon

### Lynde Harper

From: Claire O'Hanlon  
Michael Pagano

### Beverly Gail Taylor

From: Michelle Hamza  
Jane & James Bristow  
Earl & Betty Brown  
Anna Long Freese

## In honor of

### Christine Ingordo

From: Jennifer Ingordo

### Laura Kananen's birthday

From: Carol Mateja

### Mr. & Mrs. John Spadaccini

From: Ursula Guerino

### Anonymous

From: Suakim Court # 54,  
Daughters of Isis

### Stephanie Hall-Berman on her birthday

From: Rosemary & Richard  
Engle  
Fletcher Plumbing,  
Heating & Air  
Conditioning, Inc.

## A gift that gives back

A National MS Society Charitable Gift Annuity not only helps find a cure for this devastating disease but also creates great benefits for you right now. Benefits include an immediate income tax charitable deduction, attractive rates of return, and lifetime payments that are partially tax free.

For more information, call (800) 344-4867. Or visit [www.nationalMSsociety.org](http://www.nationalMSsociety.org).

# A symbiotic relationship becomes greater than its parts

“Why don’t you start at a school?” The question was innocent enough. As the founding father of Bike MS: Bike to the Bay, Eugene “Gene” Mayhew had been trying to figure out how to make the 150-mile bike ride for MS easier on the growing number of participants. Mayhew and a small group of volunteers had wrought an accessible bike route out of the rural Delaware countryside, beginning in an Odessa farm field and ending at the Henlopen State Park, where the cyclists stayed in the old army barracks—if a cot was available! In the Odessa field, there were port-a-potties and registration tables set up, but they shared space with the cyclists, their bikes, their cars, and the crows. And Gene Mayhew was hearing a lot of not-so-nicely-made suggestions for indoor plumbing, clean sheets, and entertainment at the end of the ride.

Hearing her husband trying to work out the route’s start for the umpteenth time, Carol Mayhew asked “Why don’t you start at a school?” With a blink of understanding, Mayhew began hunting for a school that would accommodate the cyclists’ needs. The next year, the participants and volunteers that make up the 150-mile Bike to the Bay gathered inside Smyrna High School.

“That was 1987 or ‘88,” says Mayhew, “when we came up with

the route we have today. Uncle Ted’s became a rest stop that year. And the finish line moved to Dewey Beach.

“I knew the owner of the Rusty Rudder, Jay Prettyman.

He was so generous with his support of community efforts. When I approached him, he opened the Rusty Rudder to us, let us use the kitchen, and never charged us for it. Sheila Barr was the bike coordinator at the time. Her husband Brian ran the kitchen crew. And Sheila and I got every hotel we approached to agree to house the cyclists for the night. We were now able to register indoors and have access to clean bed linens and indoor plumbing.

“Women like their own showers!” adds Mayhew with a chuckle.

Meanwhile, the small group of volunteers and cyclists began to expand exponentially. As the founding father and the only person to have cycled in the event every year since its inception, Mayhew drew a wide range of individuals into the effort. In the process, he says a symbiotic relationship developed that was greater than its individual parts.



**Bicyclists await the start of the 1997 two-day bike ride**

“Do you know how we got Patterson-Schwartz to sponsor us?” asks Mayhew. “Becky Wolhar approached me one day at the gym and asked if she could ride. I knew she’d been fighting cancer, but of course, I said yes. And she rode one way to Lewes on her first try. She worked at Wilmington Trust at the time but knew Dick Christopher at Patterson-Schwartz and that the company was looking to be involved in a family-friendly event.”

Thanks to his job as a U.S. probation officer, Mayhew drew in Tracy Walls-Pulling and Captain Richard “Rick” C. Pulling, Jr., of the Delaware State Police.

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**With a thumbs up, Gene Mayhew starts the ride—just as he has for 25 years.**

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“Gene recruited me,” begins Walls-Pulling. “I was working in the federal building with him, and he came to me and asked ‘Would you like to volunteer?’ I first helped with the event in 1986, doing whatever they needed me to, and over the years have changed roles to organizing the volunteers as well as the finish lines at both ends.

“I told Rick he was volunteering the first year we were dating,” laughs Walls-Pulling. “I told him it was mandatory.”

“I did the parking lot the first year,” says Captain Pulling, “drawing on friends and co-workers to pitch in to get the job done.”

Since 1990, Pulling has served on the Planning Committee and



**Sheila Barr and Rick Pulling face the camera at the 1997 two-day event.**

worked with Mayhew as the event’s co-chair. Pulling assumed the chair after Mayhew retired, and he and Walls-Pulling continue to be guiding forces for the two-day bike event.

“I have had a wonderful time over the years,” adds Pulling, “and every year poses new challenges. The core group of volunteers who continue to come back year after year makes the job easy.”

Continued from page 2



**Kate (standing, far left) and some of her team, Fifty Exquisite Women, at last year’s event**

them down.

- I ride because I can. So many people would gladly trade

places with me and ride—if only their MS would let them. I ride for all of my neighbors who can’t.

- I ride because this year’s fundraising just might help make the difference in finding the cause and the cure.

- I ride because I believe I can make a difference.

Join me!

The 25th anniversary of Bike MS: Bike to the Bay is September 27 and 28. You can choose from a number of routes. Depending on your ability or inclination, you can opt for the two-day 150-mile route, the one-day 75-mile or 45-mile route, or the new 25K that begins at Uncle Ted’s rest stop—where I’m headed for the sausage sandwiches!

*Cycle on!*

*Kate*

## Georgetown Couples Support Group

Having a healthy relationship is hard work even in the best of times. MS can make it even harder.



The Georgetown Couples Support Group provides couples with three types of support: emotional, informational, and affirmation. The group allows couples who are experiencing the MS journey to share the joys, sorrows, fears, successes, and failures that they are all living with. In the group setting, open communication is encouraged and, in turn, creates a common bond that many find indispensable in dealing with the emotional issues that come with MS.

Participants report that, by attending this support group, they see a positive effect on their coping skills, confidence level, outlook on life, and spousal relationships.

This group is led by a licensed professional. (For place and time, see “Support groups” on page 9.) For questions, contact Kathy Finkle, L.P.C.M.H., at (302) 422-8026, ext. 146.

# Support groups

## Dover

### Kent Lunch Bunch

Fourth Thursday of the month

11:30 A.M.–1:30 P.M.

Accessible restaurants in Dover

**Leader:** Regina at (302) 734-8749

### Men with MS

First Saturday of the month

10:30 A.M.–12:00 noon

Comfort Suites Hotel

**Leader:** John at (302) 947-1556

## Georgetown

### Shore Group Two

Second Wednesday of the month

1:30 P.M.–3:00 P.M.

CHEERS Community Center

**Leaders:** Kay at (302) 422-9584

or Jamie at (302) 684-4513

### Couples Support Group

Third Wednesday of the month

7:00 P.M.–9:00 P.M.

Easter Seals, Room 218

**Leader:** Kathy Finkle, L.P.C.M.H.,

at (302) 422-8026, ext. 146

## Harbeson

### Sussex County MS Shore Group

First Wednesday of the month

6:00 P.M.–8:00 P.M.

St. George's Chapel, Parish Hall

**Leaders:** Jamie at (302) 684-4513

or Kay at (302) 422-9584

## Newark area

### Middletown Lunch Group

First Thursday of the month

12:00 noon–2:00 P.M.

McGlynn's Pub & Restaurant

**Leader:** Karen at (302) 378-2573

### Main Street Circle of Friends

Second Wednesday of the month

5:00 P.M.–7:00 P.M.

Newark Senior Center

**Leader:** Sara at (302) 737-4694

### Couples Support Group

Third Wednesday of the month

(No meetings in July and August)

6:30 P.M.–8:30 P.M.

Newark Senior Center

**Leader:** Gail at (302) 299-4123

## Wilmington

### Coffee & Conversation at Sunrise

First & third Thursday of the month

10:30 A.M.–12:00 noon

Sunrise of Wilmington

**Leaders:** Fran at (302) 764-4335

or Mary at (302) 633-1080

[The support group] is like a family to me. I always look forward to our monthly meetings and feel so comfortable speaking about any subject, knowing that I am with friends and whatever we discuss stays within the group.

—anonymous member of Coping with Life and MS

### Coping with Life and MS

First Tuesday of the month

4:00 P.M.–5:30 P.M.

St. Paul's United Methodist Church

**Leader:** Sue R. Crichton, M.S., L.C.S.W., at

(302) 475-4957

*Thank you! Thank you! Thank you!*

*Thank you!*

*Thank you!*



*To all who helped to make the Spring 2008 fundraising season a success—whether by walking, riding, or volunteering—many, many, many heartfelt thanks.*

*Thank you! Thank you! Thank you!*

## Welcome to new staff

The Delaware Chapter is pleased to welcome two new staff members to the Development team.



As the new team coordinator, Karen Shore recruits individual event participants as well as works with teams. Before joining the chapter staff, Shore served as the nature director for Camp Lenape, taught English as a second language in Japan, and fulfilled internships with Blue Cross Blue Shield of Delaware, *The Harrington Journal*, and United Cerebral Palsy of Delaware.

The new event coordinator, Jennie Welch, is responsible for organizing walk events and Bike to the Bay as well as other fundraising events. Welch's most recent experience includes a stint at JP Morgan Chase, where she served as a senior lead operations analyst. Welch also has experience organizing third-party fundraising events in Delaware and working with nonprofits in the U.S. and abroad.



### Help wanted **A few, good volunteers**

Are you interested in sharing your skills or learning something new?

Would you be willing to put in long hours with no pay but lots of fun?

Are you interested and willing because you want to make a difference in the lives of your neighbors with MS?

Call (302) 655-5610.

# Team Cyc-O honored as 2007 top fundraising team



For raising an impressive \$64,912 during the 2007 Bike MS: Bike to the Bay, team Cyc-O

“I ask everybody for money,” explains Bonkowski about his top-fundraising technique. “And then, I ask everybody I ask for money to ask everybody they know for money.”

To build camaraderie with team Cyc-O, Bonkowski organizes training rides and sends out periodic newsletters. “On the newsletters, I use the logo from team Cyc-O’s jersey with our team motto: ‘Nothing great is accomplished without madness,’” laughs Bonkowski. “And I let everyone know ‘Here’s where we

are, and here’s where we want to go.’

“Every year,” says Bonkowski, “we’ve done better than the last. The team has been fantastic. I never expect it—am astounded by it really—but each year the Cyc-Os have done it. There’s no magic to it. We try to have fun while encouraging each other. The Cyc-Os are great that way. And it catches fire. I guess you could call it ‘contagious enthusiasm.’

“This year,” adds Bonkowski, “the team is aiming for \$75,000. ‘Nothing ventured...’—you know.”

was honored by the Delaware Chapter at the event’s Awards & Kick-off on March 11. Accepting the 2007 Top Fundraising Team Award was the team captain, Mike Bonkowski.

## Awards for Bike to the Bay 2007

	Corporate	Friends & Family	Club or Organization
<b>Top fundraising team</b>	Wilmington Trust: \$42,260	<i>Overall</i> <b>Cyc-O: \$64,912</b>	Wheeltors: \$33,270
<b>Top fundraising cyclist</b>	<i>Overall</i> <b>Dick Nenzo: \$15,370</b>	Mike Bonkowski: \$13,125	Richard Barros: \$8,174
<b>Best team name</b>	Boxwood Roadies	Team TaTonka	Gear Jammers
<b>Top pledge-average team</b>	Team Endo: \$240	PNC Pedal Pushers: \$160	EMTs: \$243
<b>Most-improved fundraising team</b>	ING Direct	The Rose Group	Gore Bike Wear
<b>Largest team</b>	Bank of America: 76	<i>Overall</i> <b>Y’s Guys: 103</b>	Wheeltors: 41
<b>Best team shirt design</b>	Astra Zeneca	<b>Sept. 27 &amp; 28—bike MS: Bike to the Bay 2008</b> with a choice of 25K and 45-, 75-, and 150-mile routes  <b>Sept. 25—Pre-registration Night at Saturn of Newark</b>	
<b>Top rookie team</b>	Team Gustafson		

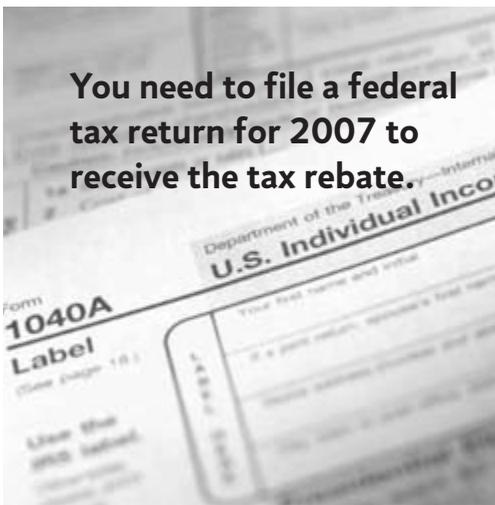
## Tax rebate includes people with low incomes

This May, the IRS begins sending out economic stimulus rebates—to everyone who filed a 1040A tax form for 2007.

Even if you do not owe anything, be sure to file by October 15, 2008. (While the tax-filing deadline is April 15, there is no penalty for filing late.)

Individuals on Social Security, vets with disabilities, and those folks who have incomes of \$3,000 or more a year will receive \$300—couples will receive \$600—even if they have not filed before.

**You need to file a federal tax return for 2007 to receive the tax rebate.**



For more information and a copy of the 1040A form, visit [irs.gov](http://irs.gov). Or call (800) 829-3676.

## Research needs brain tissue

**B**rain tissue research has the potential to tell us more about MS—from what causes it to how to prevent it. But less than one percent of people with MS make arrangements for a posthumous donation of brain tissue. And that is not enough for researchers to work with. (Researchers also need tissue from non-MS-affected brains.) The Society is supporting a number of tissue and DNA banks throughout the U.S.

In February, the Society convened the first MS Tissue and DNA Banks Investigators Meeting. Sue Strauss, a marketing expert in the field of organ donation who helped facilitate the meeting, summed it up: “As a person with MS, I’m excited to be working to speed up the process of gathering information about the disease, its causes, and its manifestations.”

Two important points arose:  
1.) Tissue must be taken within hours of death to be of use to researchers, so arrangements must be made in advance.  
2.) There is no disfigurement of the body, and funerals can take place promptly.

If you want to make this generous gift, discuss your wish with several family members, and sign up with a tissue bank as soon as possible.

### Donations for genetic studies

How do we find the genes that make

someone susceptible to MS? Investigators at the meeting agreed on the need for DNA, especially from Latinos, Asian Americans, African Americans, and Native Americans. A simple blood donation is all it takes. To donate, contact one of the following:

UCSF MS Genetics Group  
**Phone:** 866-MS-GENES (866-674-3637)  
**Web site:** [ucsf.edu/msdb](http://ucsf.edu/msdb)

Accelerated Cure Project  
**Phone:** (781) 487-0008  
**Web site:** [acceleratedcure.org](http://acceleratedcure.org)

### Tissue banks

Rocky Mountain MS Center  
**Phone:** (303) 788-4030  
**Web site:** [MScenter.org](http://MScenter.org)

Human Brain and Spinal Fluid Resource Center  
Neurology Service  
**Phone:** (310) 268-3536  
**Web site:** [loni.ucla.edu/uclabrainbank](http://loni.ucla.edu/uclabrainbank)

MS Tissue Repository at University of Illinois at Chicago  
**Phone:** (312) 996-5763

## Congressional MS Caucus builds on achievements

**T**he Congressional MS Caucus in the U. S. House of Representatives, which was founded in July 2007 to give the MS movement a greater presence on Capitol Hill, is already impressing Beltway insiders. By November 2007, the caucus had helped MS researchers gain access to a \$50 million Department of Defense medical research fund previously restricted to other diseases.

Now, members of this bipartisan group—along with

other members of the House—are signing on to a letter requesting that \$15 million be provided to fund MS research through the Congressionally Directed Medical Research Programs. As of this writing, some 80 representatives have signed, including Rep. Mike Castle (D-DE).

Jill Allen Murray, the policy director for Rep. Russ Carnahan (D-MO), helped the Society set up the caucus. Carnahan and Rep. Michael Burgess, M.D. (R-TX) co-chair the House MS Caucus.

### In the U.S. Senate

Co-chairing the newly formed Senate MS Caucus are Sen. Byron Dorgan (D-ND) and Sen. Orrin Hatch (R-UT).

Urge Sen. Joe Biden (D-DE) and Sen. Thomas Carper (D-DE) to join the Senate MS Caucus. Call (800) 828-0498, and ask for Biden's and Carper's offices.

### Tips for phoning legislators

For tips on how to phone legislators, visit [nationalMSSociety.org/advocacy](http://nationalMSSociety.org/advocacy).

## MS activists visit Washington

**O**n May 6, the Delaware Chapter's Government Relations Committee joined more than 400 MS activists from around the country in Washington, DC, for the 2008 MS Public Policy Conference. Craig Crawford, a popular commentator who appears regularly on *The Early Show*, was the keynote speaker.

Our members met with Rep. Mike Castle, Sen. Joe Biden, and Sen. Thomas Carper to discuss these priority issues:

- increasing federal investment in MS research through funds made available by the Department of Defense
- eliminating the 24-month waiting period before Social Security Disability beneficiaries are entitled to medical coverage
- conducting accurate assessments of the incidence and prevalence of MS in the United States.

Join the movement! Become an advocate!  
Call Marie at (800) 344-4867.



# What's Cooking?

**C**indy Gackle, O.T.R./L., M.S.C.S., a staff therapist at the University of Minnesota Medical Center, Fairview, in Minneapolis, has ideas on conserving energy while creating great meals.



## Plan ahead

“If you have help to carry your groceries you might be able to do a week’s worth of shopping,” Gackle says. “If you don’t have help, see what you can cut out and save for next time.”

## Shop smart

- Create a master shopping list and make copies. Circle items as you need them, and you won’t have to make a new list each time.
- Shop when your energy is highest and your market is least crowded.
- Go to markets you know the layout of, or take a friend until you learn the layout.



- Choose a market that has motorized carts for you to ride on if you get tired.
- Buy foods that can be frozen or kept in the pantry for times when you just can’t get to the store.
- Choose pre-skinned garlic, frozen chopped onions, and pre-washed and pre-cut veggies to cut prep time.
- Make big meals so that leftovers can be frozen and heated up when you don’t feel like cooking.

- Investigate online or phone shopping, especially for buying in bulk.

## Make your kitchen work

“Design a work area that meets your needs,” Gackle says. “Arrange items close enough to you so that you don’t strain yourself or lose balance.”

- Keep your most-used ingredients for everyday cooking out on counter-tops.
- Keep your kitchen well lit with clip-on task lighting.
- Make a cutting surface you can use while sitting down. Pull out a drawer, drape it with non-skid fabric (like drawer liner), and stick a cutting board on top.

## Invest in labor savers

- Clip-on fans help keep you cool in the kitchen. Try ANTONline.com. Or keep a supply of cooling products to beat the heat, such as neck coolers from bodycooler.com.



- Non-skid rolls: This webby rubber material, sold as “drawer liners,” is multi-purpose. Use it under cutting boards, on serving

carts, or anywhere you don't want objects to slip.

Available at many home goods stores and at [housewares.hardwarestore.com](http://housewares.hardwarestore.com).

- Over-the-stove mirrors let you see what's cooking without craning your neck. Available at [sammonspreston.com](http://sammonspreston.com).

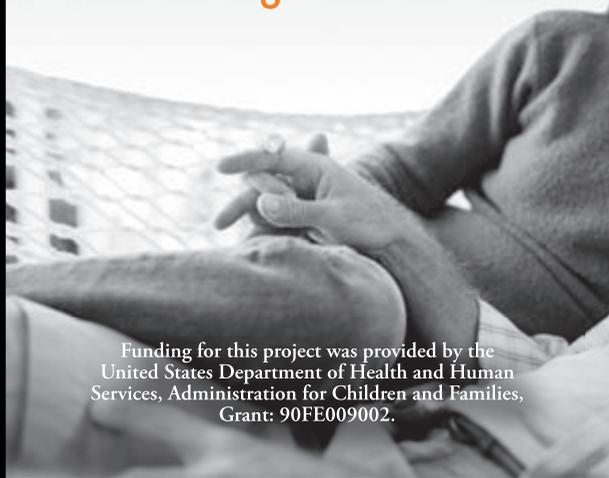
- Knives with big handles decrease the amount of effort needed for cutting. Sammons also has an L-shaped knife for less strain.

- Immersion blenders (pictured here at right): Anything from soups to smoothies can be pureed in the pan they were prepared in—without heavy lifting. Visit [kitchenaid.com](http://kitchenaid.com).



## Relationship Matters

### A Program for Couples Living with MS



Funding for this project was provided by the United States Department of Health and Human Services, Administration for Children and Families, Grant: 90FE009002.

**Take charge. Get smarter. Live better.**

**A positive approach to MS and your relationship.**

**Free classes for couples:**

- Communication and conflict resolution skills
- Financial planning • Career decisions
- Intimacy • Having fun together

**When you know how to take charge as a couple, MS doesn't have to rule your relationship.**

**Contact us:**

**1 800 FIGHT MS (1-800-344-4867)**

**or [couplesprogram@nmss.org](mailto:couplesprogram@nmss.org)**

**Relationship Matters when MS moves in.**

## Report suggests ways to improve MS treatment

A landmark report by the National MS Society in partnership with Teva Neuroscience suggests that greater collaboration among health-care professionals may hold the key to more effective management of MS. It also suggested that collaboration could stem the tide of neurologists who are leaving the field of MS care.

### About the report

Last year, the Society surveyed nearly 2,000 people with MS, along with neurologists, case managers, specialty pharmacists, and managed care professionals. The survey asked about quality of life, cost and reimbursement for MS health care, and ongoing treatment of MS and its symptoms.

Among the findings:

- More than 90 percent of people with MS said they rely heavily on their neurologist for treatment. A majority would welcome a disease-management program involving other professionals.
- More than 60 percent of the neurologists said that they are reluctant to take on

new MS patients because there are so many administrative barriers. Many said they would welcome an increased role by specialty pharmacies to help provide patient education and support.

- Some 90 percent of managed care organizations now use specialty pharmacies to distribute the MS disease-modifying drugs, and nearly 60 percent of the specialty pharmacies said they routinely have contact with people with MS.

Nicholas LaRocca, Ph.D., associate vice president of Health Care Delivery and Policy Research at the Society and the report's chair, told *MS Connection* "The results suggest that people living with MS could more effectively manage the disease through greater collaboration with managed care organizations, neurologists, and specialty pharmacies. We will be setting up meetings with managed care organizations in the coming months to discuss the findings and ways to move forward."

Read *The Multiple Sclerosis Trend Report* online. Or call us and ask for a copy.

## Energy management proven to fight fatigue

It seems that fatigue—the most commonly reported MS symptom—can be reduced by using one's energy more efficiently. And a Society-funded study has found that people with MS gain long-lasting benefits from learning energy management.

Led by Virgil G. Mathiowetz, Ph.D., O.T.R./L., at the University of Minnesota, the study first led 169 people with MS through a six-week energy management course. The students learned to balance rest and work, how to position their bodies for certain activities, and when to delegate tasks to others. The participants reported an immediate reduction in their fatigue and a substantial increase in their ability to function at home and at work.

Even better news comes from the follow-up study that reevaluated the participants a year later: Fatigue was still significantly reduced, and people reported a better quality of life.

# Get budget-smart: Develop a monthly spending plan

by Gary Sullivan

“MS is not a one-size-fits-all disease,” Helen Kim Bass, C.S.A., told *MS Connection*. Bass is a MetDESK Specialist at New England Financial who volunteers as a legal and financial advisor for the Society’s Southern California Chapter. “But it makes sense for all of us to economize.”

## Taking the first step

Bass recommends a bare-minimum savings cushion to cover six months to a year’s worth of bills. “Above that, you should plan to save 10 to 20 percent of your income every month.”

How do you do this? Create a budget. Use software such as Quicken or an Excel spreadsheet, if you use a computer. Or write the whole thing out on paper in longhand. Accurately detail your monthly income and your monthly expenses.

Break down your expenses into two categories: “fixed expenses” and “other.” Fixed expenses include rent or mortgage payments, groceries, prescriptions, transportation, utilities, insurance, and outstanding credit card or loan debts.

If you pay any of these in annual or semiannual payments, break them down into what they cost per month.

“Everything you spend beyond your total fixed expenses—other than unplanned emergencies—can be saved,” Bass says.

## Learning to save—more!

- Dine out less. Take a sack lunch to work. Control grocery costs by shopping around.
- Can you get a more economical cell phone plan? Cheaper internet service? Do you really need cable TV?
- Shop for low-cost entertainment (community centers, local colleges, libraries), and ask about free passes for people with disabilities.
- Many utilities and telephone companies have programs for people unable to work full time because of a disability. Ask!



- Do you have a large car payment? Consider selling and buying something affordable but reliable. Then, scale back your car insurance to liability only.
- Pay down credit card debt as quickly as possible to avoid all that interest. If the minimum monthly payment is \$100, pay \$150 or \$200. If you have more than one card, use the one with the lowest interest rate, and put the others away.
- Loan and credit card payments can sometimes be negotiated. Call the bank, and tell them you have a medical condition. You may have to ask to speak with a manager.
- If you have a profound disability, check with your county property tax board. You may be eligible for a tax break.

## MS Awareness bling

As MS Awareness Week 2008 kicked off this March, Christopher & Banks launched its second limited-edition MS Jewelry line.

This year, the MS Collection includes

- a lavalier-style quartz and pewter necklace for \$20,
- an elasticized pearl, quartz, and crystal bracelet for \$24, and
- pearl and crystal earrings for \$14.

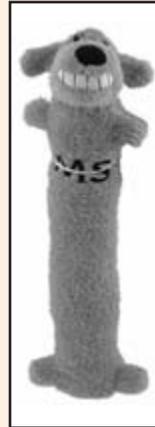


Half of the proceeds will benefit the National MS Society. Last year, Christopher & Banks raised more than \$120,000 through MS Jewelry sales.

The collection is available in nearly 800 Christopher & Banks and CJ Banks stores nationwide as well as on the Banks Web site. Visit [christopherandbanks.com](http://christopherandbanks.com), and type “MS” in the search field.

## MS Research Loofa Dog

Got a pooch who loves to play?



Dogs and dog-lovers alike will love this exclusive orange plush toy with its super-wide grin and MS Awareness message. Loofa Dog's long (12 in.) tubular shape makes him easy to pick up and carry around—and he squeaks when squeezed or chewed.

Visit [carealotpets.com](http://carealotpets.com), and type “MS Loofa Dog” in the search field. Care-A-Lot will donate the profits of Loofa Dog sales to the Society's Promise: 2010 Campaign.

### About Promise: 2010

The Promise: 2010 Campaign is a nationwide Society effort to raise \$30 million for MS research by the year 2010. Read more about the promise at [nationalMSsociety.org/Promise2010](http://nationalMSsociety.org/Promise2010).

## Delaware Chapter announces 2008 scholars

Through the generosity of the Eolyne K. Tunnell Scholarship and the Arthur J. Stapler Memorial Foundations, five Delaware high school seniors will be receiving scholarships for their freshman year of higher education.

“These individuals have been impacted by MS in their immediate family,” says Kate Cowperthwait, the chapter president. “They deserve our financial support.”

The 2008 scholars and their high schools are as follows:

Josh T. Billy  
GLASGOW HIGH SCHOOL

Torey L. Hewett  
CAESAR RODNEY HIGH SCHOOL

Anthony J. McGuire  
ST. MARK'S HIGH SCHOOL

Alex R. Hahn  
CAESAR RODNEY HIGH SCHOOL

Jacob A. Markiewitz  
THE CHARTER SCHOOL OF WILMINGTON

For photos and individual statements from the scholars, visit [www.MSdelaware.org](http://www.MSdelaware.org).

# The Art of Asking for Help

by Allison Shadday, L.C.S.W.

**W**hen I first learned I had MS, I was a medical social worker. It was my job to care for people who were ill. I knew how to give others my help but not how to receive it.



- When folks come through for you, show your appreciation.
- Find ways to reciprocate. Let people know that you're there for them as well.

## The benefits of asking for help

- Others gain a better understanding of what you're experiencing.
- It can help you to feel less alone.
- You will have more time for the things that can only be done by you.
- You may have energy for things you would really like to do.

Requiring assistance, at any level, can radically alter our sense of independence. It makes us feel so vulnerable! These tips may make reaching out a little easier:

- Explore how you feel about needing and asking for help.
- Ask yourself how it feels to help others.
- Recognize that, when you ask for assistance, you're

giving someone a chance to feel useful.

- Plan on what to ask for when someone says "Is there anything I can do?" Requests could be as simple as asking someone to go with you to a doctor's appointment.
- Identify at least three people to call. Do not rely on one person for all your needs.

## Information in Spanish

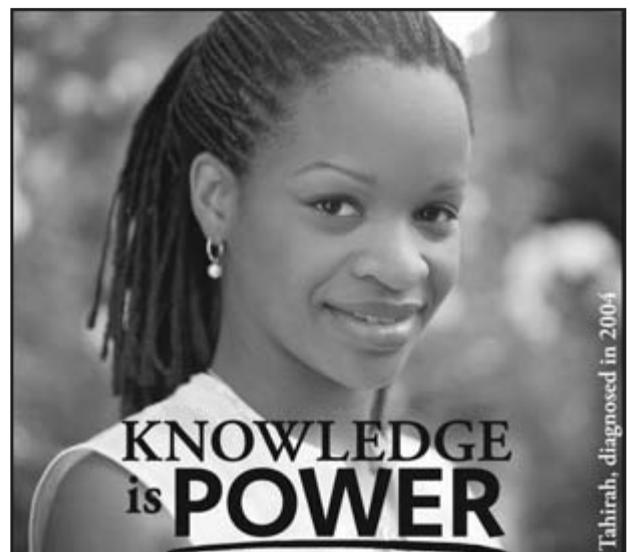
Are you more comfortable reading in Spanish?

Do you know someone who is?

Dozens of the Society's most popular brochures, videos, and Web casts are now available in Spanish—free!—including *Saber es Poder (Knowledge is Power)* for folks who are newly diagnosed.

For a complete list and instructions in Spanish on downloading or ordering, call (800) 344-4867, and press 1.

Or visit [nationalMSSociety.org/Spanish](http://nationalMSSociety.org/Spanish).



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

Join the movement.



REGISTER NOW!

# Celebrate 25 years of Bike to the Bay! Ride the new 25K!

Join us as we celebrate the 25th anniversary of Delaware's premier bicycling event.

In addition to the 75- and 150-mile routes starting in Dover and the 45-mile route starting in Milford, a new 25K route is now available starting at Uncle Ted's rest stop.

**Date:** September 27–28, 2008

**Starting time:** Depends on where you start!



[www.MSdelaware.org](http://www.MSdelaware.org)



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Delaware Chapter

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handicapped**