Walk MS: If Not You, Then Who?

You’ve seen it, the ripple effect you get when you throw a stone in a pond. Such small, easy movements, but those little waves eventually reach all the way to the edge of the pond. Just as stones in a pond, the simplest of efforts can have powerful and far-reaching effects…

So this year, we’re calling on everyone (and that means you!) to put their passion into action and join the movement to end this devastating disease by walking, fundraising, and spreading the word about Walk MS. With walks across the country, there are plenty of opportunities for everyone to get involved in whatever way is best for them. How?

• Join us at a Walk MS event near you as a walker or a volunteer and experience what happens when thousands of people who share our vision let the light of hope shine.

• Take it a step further and form a team through your church, school, club, or place of employment and recruit others to walk and fundraise with you.

• Can’t be on site that day? Register anyway and commit to raising funds that just may lead to a breakthrough therapy.

• Ensure the word about Walk MS ripples through your community. Talk about the walk with colleagues, send information out to your network of contacts, post registration brochures at your gym, or on your community bulletin board.

Registration is open, teams are being formed, and fundraising progress is already underway, but there's still plenty of time to organize and plan how you'd like to participate in this year’s activities.

(continued on page 2)
MS Connection is the quarterly newsletter of the National Multiple Sclerosis Society, Blue Ridge Chapter. For address changes or to be added to the mailing list, please contact us at 1-800-FIGHT MS; by e-mail at vab@nmss.org; or at One Morton Drive, Suite 106, Charlottesville, VA 22903; (434) 971-8010; FAX (434) 979-4475.

Multiple sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system. The progress, severity and symptoms of MS in any one person cannot be predicted. Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with MS. If you or someone you know has MS, talk to your health care professional or contact the National MS Society at www.nationalmssociety.org or 1-800-FIGHT MS to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

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

No matter what you decide, the National MS Society offers the tools you need to make it easy including fundraising aids and a fully functional online system that tracks personal as well as team fundraising progress.

Of course it would be great if the entire community came out to support the Walk MS event in their area, but the ripple effect has to start somewhere. We hope it’s with you.

Go ahead. Jump in.

Because if not you, then who?

To register, or for more information on how to get involved visit http://www.walkmsva.org/ or call 1-800- FIGHT MS.
Many heartfelt thanks to the community focused honorees, in addition to the many generous attendees, who made the 2007 Dinner of Champions exciting, successful, and moving events. On November 13th in Roanoke, the 17th annual dinner was held and honored Dr. Charles W Steger, president of Virginia Polytechnic and State University.

Carter Beauford, LeRoi Moore, and Boyd Tinsley, philanthropic and socially active members of Dave Matthews Band, were honored at the 16th annual dinner in Charlottesville on December 12th.

Dr. Charles Steger, Carter Beauford, LeRoi Moore, and Boyd Tinsley received the Society’s highest honor, the Silver Hope Award for their contributions to making this world a better place.
What is CIS?

A person diagnosed with CIS, or Clinically Isolated Syndrome, typically has experienced a single neurological symptom, such as partial vision loss, vertigo, double vision, or weakness. The symptom lasts at least 24 hours and may even continue for weeks, but then goes away, often without treatment.

“[CIS] typically occurs out of the blue in an otherwise healthy person,” said J. Theodore Phillips, MD, PhD, director of the MS Center at Texas Neurology in Dallas. “It appears to be occurring in an isolated fashion.” To be diagnosed with CIS, all other explanations for the symptom have to be ruled out.

Is CIS an early sign of MS?
The big question with CIS is whether it indicates early development of MS. The second question is whether early intervention can help slow down that development. In three large clinical trials, early treatment appeared to delay a second episode. The results were so positive, the FDA extended the labeling of Avonex and Betaseron to include people who have had just one clinical episode if they have multiple MRI-detected lesions consistent with MS.

Is early intervention necessary?
“If started early in the appropriate person, these medications can be important in slowing down the progression into classic MS,” Dr. Phillips said. “But who is the appropriate person? Do I know that this single event will evolve into MS?” Disease-modifying drugs are expensive, inconvenient, and do not cure MS, he pointed out.

MRI evidence makes the case
Long-term studies show that what a person’s MRI looked like at the time of a CIS largely indicated whether they went on to develop MS.

“If the MRI is completely normal with the exception of abnormality associated with the CIS, then that person has a relatively low risk of MS even 15 years out,” said Dr. Phillips. “But if there are multiple lesions consistent with MS, that person has a pretty high risk.” When that’s the case, many neurologists recommend early intervention with a disease-modifying drug. Insurance coverage for Avonex or Betaseron shouldn’t be a problem, since the FDA now includes CIS as an indication for both drugs.
2007 Scholarship Program biggest yet

This year the National MS Society Scholarship Program has awarded 332 scholarships to college-bound high school students and graduates. The program has grown exponentially since it was launched five years ago in 2003.

Three four-year scholarships of $10,500 each were awarded to the Society’s Presidential Scholar, Christina Fitzsimmons (top photo); the Mike Dugan Scholar, Andrew Carpenter (bottom photo); and the Stitzer Family Memorial Scholar, Natasha Spedalle. The complete list of recipients, with excerpts from their personal essays, is available at nationalmssociety.org/scholarship.

Eligibility for 2008
High school seniors or graduates who have MS or a parent with MS and who will be attending an accredited post secondary school for the first time next fall are eligible.

Applications and information can be downloaded at nationalmssociety.org/scholarship. Or call us at 1-800-344-4867 to receive a copy by mail. Completed applications are due January 15, 2008.

For help with filling out the form, contact Scholarship America, a non-profit organization that receives and screens the applications, at 1-800-537-4180, extension 471.

2007 Blue Ridge Chapter Annual Meeting & Team Rally Report

This November’s Annual Meeting and Team Rally, held in both Roanoke and Charlottesville, drew people from all across the Blue Ridge Chapter territory. Honored at the meetings were volunteers, fundraisers, and community partners. These honorees helped to make programs, services, and events a success in 2007. Listed below are the 2007 award winners.

National Hall of Fame Award
- Lisa Eorio

Norman Cohn Hope Award
- Meg Haymans

Terry Phelps Volunteer Hall of Fame Award
- Wayne, Louise, Lori & Patrick Hall
- Ken Shafer - Skyline Bicycle Tours
- Blue Ridge Bicycle Club

Above and Beyond Volunteer Award
- Jane Adair - David Bailey
- Teens Give - Patricia Stevenson

Advocacy Award
- Scott Waskey

Alex Sawyer Client Services Award
- Ann Howard

Bike MS Team Award
- Easy Riders - Winchester Wheelmen

Clinical Programs Award
- Shelley Post

Community Partner Award
- Bayer Healthcare Pharmaceuticals
- Biogen Idec - Cargill
- CK Courier - EMD Serono / Pfizer
- James Q. Miller Consultative MS Clinic
- Martha Jefferson Hospital
- Pepsi Cola Bottling Co. of Central VA
- Virginia National Bank

Diamond Community Partner Award
- Atlantic Bay Mortgage Group
- Petroleum Marketers, Inc.
- Teva Neuroscience

(Continued on page 11)
MS Caucus gains power

This summer the Society announced the new Congressional Multiple Sclerosis Caucus in the U.S. House of Representatives. This Caucus is the first of its kind, and provides the MS movement with champions in Congress to support MS issues. Congressmen Russ Carnahan (D, Missouri) and Michael Burgess (R, Texas) are co-chairing. As of late September, 38 members have joined. (For the current list, visit msactivist.blogspot.com.)

Keep the momentum building

The MS Caucus gives the movement to end MS an effective presence on Capitol Hill. If your U.S. Representative has not yet signed on, encourage him or her to do so. Go to nationalmssociety.org/advocacy, click on Announcing New Congressional MS Caucus, and enter your ZIP Code.

The push for new MS research funding

For the past year, the Society and thousands of MS activists have been aggressively pursuing a new avenue of federal funding for MS research: Legislation that would designate $15 million for MS research through the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense.

Unfortunately, the bill that passed in the House on August 5, 2007, did not include funding for MS research. But MS activists did not give up. In late September, Congressman John Murtha (D, Pennsylvania) finally agreed to fight for at least $10 million for MS research during the conference committee, which came after the Senate voted on the bill.

When the Senate Defense Appropriations Subcommittee approved their FY 2008 spending in mid-September, the bill included language to support MS research. Even though it was not in the program we requested, it will provide a new avenue for funding. We will continue pursuing CDMRP.

About the funds

The CDMRP provides funding for research through the Department of Defense as directed by members of Congress. Activists believe that MS research would be an appropriate target of these funds: A study published in 2004 identified more than 5,000 cases of MS among veterans that were deemed “service-connected.”

In late 2006, the Society began a nationwide petition drive urging Congress to support funding for MS research through the CDMRP. The petition garnered more than 100,000 signatures.

In March 2007, MS activists who attended the annual MS Public Policy Conference in Washington, DC, brought the issue to Capitol Hill in person.

What’s next

For the latest, go to msactivist.blogspot.com, and to learn how to help, join the movement at nationalmssociety.org/advocacy.
Society-funded researchers discover two new “MS risk” genes

M

S is not a single-gene disorder. Researchers have already concluded that the disease involves many genes interacting with some environmental trigger or triggers.

Locating the specific genes that are associated with a higher risk for MS can tell scientists more about how the disease works—and may lead to new therapies.

For more than a decade, the National MS Society has taken the lead, aggressively funding MS genetics research. It helped launch the International Multiple Sclerosis Genetics Consortium (IMSGC), a collaborative group of researchers with expertise in genetics, database design, and immunology who pool the large amounts of data needed for genetics studies.

New findings
This year, the IMSGC completed the largest genome scan for MS to date. Using a DNA chip that maps 500,000 individual genetic locations they found two genetic variations strongly associated with MS.

The variations were found in the genes for interleukin-2 receptor-alpha and interleukin-7 receptor-alpha, both of which control cytokines—the messenger proteins that regulate immune cells. Interleukin-2 and -7 have been associated with T cells that have the power to turn off an immune attack. Research has shown that interleukin-2 is involved in other autoimmune diseases, including type 1 diabetes.

The IMSGC published these findings in an early online edition of The New England Journal of Medicine (July 29, 2007). The study was jointly funded by the Society and Harvard University. All of the data from the gene scan is being made publicly available to aid future research.

Two studies confirm findings
Two papers published online in Nature Genetics on July 29 reported similar findings associating interleukin-7 with MS.

In the first, an international group of collaborators funded in part by the Society explored three genes that had earlier been associated with MS. The group was able to confirm an association with the gene for interleukin-7.

The second paper—by collaborators in Sweden, Denmark, Finland, and Norway—followed up an earlier study and also identified interleukin-7.

The road ahead
The findings of all three studies suggest possible new targets for better MS therapies. One therapy is already being tested. The monoclonal antibody “daclizumab” (PDL BioPharma and Biogen Idec) targets interleukin-2 receptor-alpha.
Can a person with MS purchase life insurance?

This is one of many insurance-related questions that may arise after a diagnosis of MS. The facts provide a somewhat mixed outlook for those who hope to include life insurance in their personal financial plans.

A survey of Society members living with MS conducted last year revealed that nearly 70% have a life insurance policy, although most of them obtained it prior to diagnosis. Slightly more than half of those who tried to get life insurance for the first time after diagnosis were turned down. But among those who obtained it after diagnosis, 70.1% reported no difficulty in purchasing it. About 16% reported being charged a higher rate because of MS and 20% said their coverage was limited due to their disease. (It is not known if the applicants who were turned down were different from those who were accepted. Were they older, for example, or more severely disabled?)

Risk is a complicated concept, because it relies on averages. A few people with MS who develop very progressive disease die prematurely of its complications (such as respiratory infections, for example). Thus overall life expectancy in MS is considered to be 95% of normal. Insurance companies give their best policy terms to the “best bets”—to people who are in perfect health. But that doesn’t mean a person with MS can’t obtain a policy, as our research showed. Here are some general tips for shopping for life insurance:

- Maximize your opportunities to obtain life insurance through your own or your spouse’s employer. (Your spouse should do the same!)
- An insurance broker could save you a lot of time and frustration. Call an MS Navigator at our chapter to help you find one.
- Apply for life insurance as early in your disease process as possible, before MS has a chance to impair your functioning any further.
- Never try to hide your diagnosis from an insurance company or a broker working on your behalf. Failure to disclose any requested information is fraud, which could bring very severe (even criminal) penalties.
- If you are not satisfied with the offers you receive, keep searching.

If you are ultimately unable to purchase the life insurance coverage you are looking for, a good financial planner may be able to suggest other strategies to help you reach your financial goals and provide protection for your future. Ask your MS Navigator to help you identify a financial planner with whom you can review all the issues.
Valentines Day Dinner in Harrisonburg

Enjoy dinner, music, and dancing!

A time for anyone with MS to come and have fun on Valentines Day. All are welcome (families, children, couples, singles, friends).

February 14, 2008 at 5:30 pm
Traditions Restaurant
625 Mount Clinton Pike
$5 per person (financial assistance available)

Enjoy a great dinner at Traditions Restaurant and music entertainment provided by professional DJ Scott Lowe. Eat, relax, socialize and, yes, even dance if you’d like!

RSVP required by February 5, 2008
1 800-344-4867 or (434) 971-8010

Blue Ridge Chapter Lending Library

MS and Your Feelings: Handling the ups and downs of multiple sclerosis
Allison Shadday, LCSW

Author Allison Shadday, LCSW has lived with MS since 1994. In this volume, she identifies the multifaceted emotional responses to MS and shares insight into these feelings. She also presents methods to strategically cope with emotional responses, and uses patient stories to demonstrate her strategies at work. The book features a chapter for caregivers as well as a forward by neurologist Dr. Stanley Cohan.

Materials may be checked out for two weeks and are mailed with a postage paid return envelope. To check books out or to obtain the complete list of the books, CDs, and videos contained in the Chapter’s lending library contact the Chapter office at 1-800 FIGHT MS (344-4867).

Air Mask: Poems of Passion, Love, Life, and Survival
Vanita Oelshlager

This compilation of poems vividly chronicles the author’s experiences as a caregiver for her husband, Jim, who has multiple sclerosis. The poetry is paired with photographs, which serve to reinforce the themes and images evoked by the text.
National MS Society Orientation:
Learn how we can serve you!

Orientation sessions to the programs and services of the National MS Society, Blue Ridge Chapter will be:

Walk-in’s welcome. RSVP’s appreciated. (434) 971-8010 or 1-800 FIGHT MS

February 5, 2008 @ 12 pm
May 6, 2008 @ 12 pm
August 5, 2008 @ 12 pm

These free orientation opportunities will last for approximately one hour and will be held at the UVA Healthsouth Rehabilitation Hospital, 515 Ray C Hunt Drive in Charlottesville, VA. The orientation will be in the first floor conference room—please remember to sign in at the front desk. Call or email the chapter office with questions at 1-800 FIGHT MS or vab@nmss.org.

Topics of discussion will include:

Information & Referral Services—Looking for MS specific services in your area? Let the Blue Ridge Chapter help you locate them.

Financial Assistance—What’s covered? What’s not? How do you apply?

Recreation Programs—Get Fit Stay Fit Wellness Scholarship, exercise classes in your area

Education Programs—Learning and Living Series, CARES, Knowledge is Power, Relationship Matters

Social Programs—Family Days, Respite Camp

Lending Library—What’s in the lending library? How do you request materials?

Emotional Support Programs—What is a self-help group? Where’s your closest group? And what is a Peer Supporter?

Online Resources—Web-casts, Information, Calendar, Fundraising Events

Volunteer Opportunities—CSI’s, MS Ambassadors, Self-Help Group leaders, Peer Supporters, Friendly Visitors

You’ll have the opportunity to ask questions and find out what programs and services would benefit you and your family!
January 22: Ask the Right Questions, Get the Answers You Need
Presented by Dr. Lori Trefts

January 29: Cognitive Issues and Compensatory Strategies
Presented by Dr. Jeff Wilkin

February 5: Carepartners: Working Together
Presented by Dr. John Griffith

February 12: Sexuality and Intimacy
Presented by Cally Bell, Nurse Practitioner

February 19: Spirituality
Presented by Dr. Tom Graves

February 26: Managing Difficult Symptoms: Bowel and Bladder
Presented by Pat Kennedy Nurse Practitioner

March 4: Social Security Disability Insurance: The Ugly Truth
Presented by Richard Neuworth

March 11: Research Updates
Presented by Dr. Ben Greenberg

All calls begin at 7pm

You may register for as many or as few calls as you’d like!

Call 1-800-344-4867 to register & to get call-in information.

(continued from page 5)

2007 Blue Ridge Chapter Award Winners
Frank Fesperman Self Help Group Award
- Julie Golimowski

Bike MS Volunteer Award
- Gregory Faust

MS Ambassador Award
- Paul Snead
- Julie Clevenger

Ottis Craver Fundraising Award
- Robin Maxwell

Public Relations Award
- Robin Maxwell

Walk MS Volunteer Award
- George and Janet Menassa
Everyday heroes

Last year Jeanne Clem of Kentucky wrote the national office: “What I want for Christmas is to hear from everyday heroes who deserve to be heard. You hear celebrities’ stories on the news. But you don’t hear, “Two years ago today, Jeanne Clem was diagnosed with multiple sclerosis and her employment along with bits of her life were terminated—but here she is now, celebrating small victories!”

To accommodate this universal need, the Society created theFaceofMS.org in March 2006. People have been posting stories there ever since. Here are two of them.

Tom Young, Ohio
About 10 years or so ago, I was diagnosed with “probable” MS. Later the diagnosis became more definite.... My family MD said, “expect interesting symptoms.” He was certainly right about that. Some of the interesting symptoms included a sensation of flashing lights when I was in total darkness. Of course the less interesting symptoms bother me the most. The real bummer is that I have almost no sense of balance. I can only remain upright if I can see a horizon.

The progression of the disease has been very slow because I’ve been taking a very expensive drug. I’m still working. I did, however, give up flying airplanes. If my sense of balance ever comes back the first thing I’m going to try to get is the required medical certificate and fly an airplane again.

Michele Mogck, Montana
I was diagnosed six years ago, shortly after the birth of my beautiful daughter. People look at me strangely when I tell them that I feel MS is probably one of the best things that has ever happened to me. I have always been very driven—focused—never letting anything stand in my way. I was so focused, I was never, really, in the present.

I’ve learned not to take things for granted—and to be thankful for everything that I do have. I shudder to think that had it not been for my MS, how quickly life would have passed without me taking the time to cherish, love, and just enjoy.

Visit FaceofMS.org for many many more stories—and to add (or update) your own!

TAMING WORK STRESS

Take a short break right at your desk. Mute the phone and the computer. Take off your glasses if you wear them. To help slow down your mind, inhale while thinking the word “peace,” then exhale to the word “tension.” Even five minutes of quiet breathing can bring some relief.

For more ideas, visit our brochure Taming Stress at nationalmssociety.org/TamingStress. Or call us for a printed copy.
Listen up!

The National MS Society’s Web site features a number of sound files, including podcasts and archived webcasts, offering easy listening at your convenience. And beginning December 2007, an audio version of the national magazine, Momentum (formerly InsideMS), will also be available.

I’ve never used a sound file before!

Actually, you probably have. A sound file is simply any electronic file that contains digital information to reproduce sound. CDs use very large sound files, using something called PCM coding.

Because of their large size they aren’t used much on the Internet. Instead, files on the Web are usually in the MP3 format.

What does that mean to me?

The MP3 is compressed, eliminating portions of the audio file that are essentially unnecessary. That means you can download them relatively quickly. The Society’s podcasts, archived webcasts, and the new audio version of Momentum are saved as MP3 files.

How do I listen to an MP3 file?

Let’s try one of the Society’s podcasts as an example. First, go to nationalmssociety. org/podcasts and find a podcast that interests you.

To listen to it immediately, just click on the link as you normally would and the file will play automatically in your browser. Most browsers (e.g., Internet Explorer, Safari, etc.) will have the appropriate player already installed. If yours does not, you will be prompted to download it at no cost.

You can also download the audio file to your computer by placing your cursor on the link and clicking the right-hand side of your mouse (right click). (Mac users, hold down the Apple key, then click.) Choose “Save Target As …” and then choose where on your computer you want to save the file. You should be able to choose “Desktop,” for example.

Depending on whether you have a modem (telephone line) or broadband Internet connection, this will take a few seconds or a minute or so. Once the file is downloaded, you can select “open” and the file will begin to play right on your computer.

If you would like to listen on your portable MP3 player, such as an iPod, simply move the file to the subdirectory where you keep your song files, then import the file into your MP3 management software, such as iTunes or Zune.

For more help

Apple Computers
www.apple.com/itunes

Yahoo Podcasts
podcasts.yahoo.com

Zune
www.zune.net

About.com
mp3.about.com
Start thinking about planned giving in 2008!

Now is the time to plan to maximize your 2008 income tax deductions by making donations to non-profit organizations, including the National MS Society. The Society encourages you to give prudently, joyfully, and generously.

Here are a few tips to help you make the most of your planned giving:

- **Get advice**
  Before making any significant gift to the Society, have your CPA, attorney, or other advisor determine the impact on your income tax return and estate. If facing a large tax bill this year, you may want to create a larger charitable tax deduction for yourself. Calculate your income.

- **Give early**
  Gifts of non-cash assets (IRA transfers, stock, real estate, etc.) or life-income gifts (gift annuities, trust arrangements, etc.) may take a little time to arrange. Your professional advisor and the Society’s Gift Planning Office will appreciate helping you avoid the end of year rush with early gift activity.

- **Review your stocks**
  Look at appreciated stocks you have held for more than a year. It may be prudent for you to make a year-end gift using appreciated stocks—you will avoid capital gains taxes in the process. By giving the stock to the Society and allowing us to sell it, you may also receive a charitable deduction for the full value of the stock.

- **Consider a charitable gift annuity**
  Charitable gift annuities provide you with guaranteed payments for your life as well as current tax benefits. Our gift annuity administrator can assist you and your advisor with confidential personalized illustrations and printed material.

- **Transfer IRA tax free**
  Those over the age of 70-½ qualify under the Pension Protection Act to donate up to $100,000 from an IRA to charity. These gifts are tax-free and may help you meet your required IRA distribution levels. Simply direct your fund administrator to transfer a portion of your IRA directly to the MS Society.

For more information about planned giving opportunities at the National MS Society, contact our Gift Planning Team toll-free at 1-800-923-7727 or read more about making a special gift by going to nationalmssociety.org/donate and clicking on Planned Giving. You can also contact your local chapter at 1-800-344-4867.

—From the National Gift Planning Team

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### Bike MS and Walk MS

These events will be here before you know it! For more information about what will be going on in your neighborhood visit:

- [www.walkmsva.org](http://www.walkmsva.org)
- [www.mstourdevine.org](http://www.mstourdevine.org)
2008 “Make Your Mark” Contest

Submit your best photography, artwork, poetry, stories, speeches or songs that show you want to do something about MS now!

All entries will be featured in the Make Your Mark gallery at 2008 events and the top 5 entries will receive a National MS Society gift pack with a fleece jacket, lunch tote, coffee mug and MORE!

The winners will be announced during MS Awareness Week. March 10-17, 2008

Your submissions should explore these questions:

> How have I joined the movement?
> How have I moved my life forward while living with MS?
> How has the MS Society helped me?
> What am I doing to help others with MS move forward?
> What would a world free of MS look like?

There is no entry fee or age restrictions, anyone and everyone is welcome to participate!

Please mail or drop off your entry to National MS Society, Blue Ridge Chapter Attn: Contest, 1 Morton Drive, Suite 106, Charlottesville, VA 22093 or email to erin.irtenkauf@vab.nmss.org.