



CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Fall 2008 Mid Florida Chapter

Help Us Put a Face to MS

By Jenna Labadie, Director of Public Policy

It is crucial that we put a face to MS to personalize the MS experience and make it better understood in our communities at large. As we build our statewide advocacy program, we are building a "story bank" of personal connections to MS because we each have a story to tell. Will you share yours with us?

We want to capture your enthusiasm and desire to see positive change in the MS community. Please take a few minutes and tell me your "story" to be used during visits with legislators, in marketing materials, on the website and more.

Below are some thought-provoking questions you might use to come up with your brief paragraph. Feel free to use one or start one of your own.

You may reply by email or mail and please include your photo with your contact information (full name, address, phone). Make sure you share this request with

friends and family in the MS community. The more the merrier.

Questions to get you started---

- How might you describe MS to someone on the street? What does it feel like?
- What challenges do you face in the morning? Afternoon? Evening?
- What are your experiences with doctor visits, injections?
- How does the future look for you and how can you improve your current health?
- If you had a personal meeting with the incoming U.S. president tomorrow, what would you ask for? (be specific)
- How has the MS Society provided you a better quality of life?

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Chuck Norman
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President's Impressions

Please accept my personal invitation to join us for our

**Above and Beyond –
The Journey to End MS
2008 Annual Conference
& Research Symposium
Saturday, December 6, 2008
11:30 am – 2:30 pm
At Fantasy of Flight in Polk
City, Florida**



**Tami Caesar
Mid Florida Chapter
President**

We are excited to host our Annual Conference and Research Symposium at Fantasy of Flight. Just off I-4 in Polk County, it is a central location within our chapter territory AND a fun, family attraction. In fact, the "world's greatest aircraft collection" will be open to our guests at the end of the conference.

Dr. Tariq Bhatti will be our feature guest speaker at the Research Symposium. Dr. Bhatti specializes in neuro-ophthalmology and will be helping us keep an eye on MS.

In addition to the Research Symposium, we will be honoring the special men and women who have gone "Above and Beyond" to join the movement against MS. Nominations were submitted by a wide variety of friends, family members and co-workers who wanted to acknowledge the extraordinary efforts of their favorite volunteer for the cause. A selection committee reviewed the nominations and selected this year's honorees.

Please join us on December 6th as we present the "Above and Beyond" Awards and give our honorees the recognition they so richly deserve.

Best regards,

A handwritten signature in black ink that reads "Tami Caesar". The signature is fluid and cursive, written in a professional style.

Learn how to make medical decisions

A diagnosis of MS brings with it a mountain of information, many decisions to make—and many questions to ask. How to sort through it all? A new Society program called **My Life, My MS, My Decisions** takes you step-by-step through the process of making decisions about your medical care.

The program features a DVD and four online courses that cover the following topics:

- Teaming Up with Your Health-care Providers
- Navigating the Medication Maze
- Considering Clinical Trials
- Achieving Optimal Wellness

The courses can be accessed online wherever there is Internet access, whether at home, a community center, public library, or chapter. The DVD is also available separately if Internet access is unavailable.

Registering for better health

Three of the courses are now available and the fourth (“Achieving Optimal Wellness”) will be available in winter 2008. The DVD includes three separate segments, each featuring a different person journeying through medical decision-making:

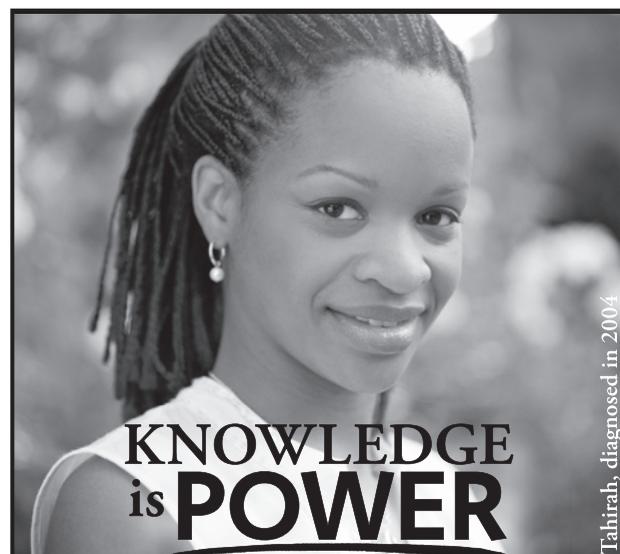
- Annie is a recently diagnosed 20-something who is a bit reluctant to begin taking disease-modifying medication.
- Diagnosed 10 years ago, James, who is in his 30s, finds that his MS is affecting his walking and his physical relationship with his partner.

- Joann is in her 40s and uses a wheelchair to get around. She feels her MS is getting worse and would like to change doctors.

The DVD follows Annie, James and Joann through the decisions they make and how they arrive at them, including researching medications, communicating with their doctors, and exploring clinical trials.

For more information, visit **nationalMSSociety.org/mydecisions**. To register, call 1-800-344-4867, or e-mail **programsonline@nmss.org**.

My Life, My MS, My Decisions is partially funded by an unrestricted educational grant from Biogen Idec, Bayer HealthCare Pharmaceuticals, Genentech, EMD Serono/Pfizer Inc., and Novartis Pharmaceuticals Corporation.



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**.

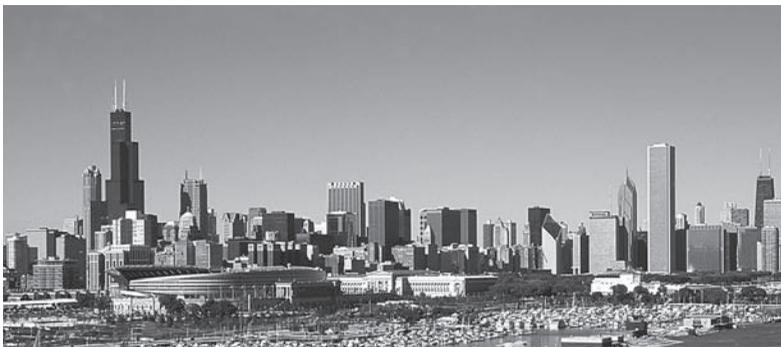
Join the movement.



Society's National Conference offers something for everyone

Every leader in the MS movement will find something of value at this year's National Conference.

Those of a scientific bent can ask about MS research at two open panel discussions. The first session features Marcia L. Finlayson, MSc, OTR, PhD, Stephen D. Miller, PhD, and Anthony T. Reder, MD; the second session features Howard Lipton, MD, David C. Mohr, PhD, and Betty C. Soliven, MD. At the MS Fellows Poster Session, people can meet many of the "best and brightest" new MS researchers attending the first ever Research Fellows Conference, being held in conjunction with the National Conference.



Those looking for inspiration will hear keynote speaker Malcolm Gladwell, author of **Blink, The Tipping Point**, and a new book, **Outliers: Why Some People Succeed and Some Don't**.

Many workshops will discuss advocacy issues, including what the election's outcome may mean for the Society's Health Care Agenda. Other workshops address how to get our message out to a wider range of people with MS, reaching communities diverse in both culture and geography.

Bold Moves by our Hispanic/Latino Advisory Council

Under the leadership of noted neurologist Victor Rivera, MD, the Society's National Hispanic/Latino Advisory Council has established bold goals for the next three years. They include:

- Promoting more participation by Hispanics and Latinos in clinical trials
- Promoting studies on the experiences of Latinos and Hispanics with MS
- Developing more resources to educate health-care professionals about this community
- Increasing the number of Hispanic/Latino volunteers on chapter boards or as participants in Society fund raising, programs and events.
- Including Hispanic/Latino outreach dimensions in the proposed federal study of MS prevalence by the CDC.

The Council has already created the Spanish-language glossary of MS terms on our Web site and been instrumental in developing the national telephone support group, Café con Leche.

Currently, Dr. Ron Duran, a council member and a professor at the Alliant International University, is doing field work in collaboration with the Society to identify the unique challenges faced by Hispanic/Latino families living with MS. And Dr. Debbie Victor, an occupational therapist and recent graduate of the University of Illinois at Chicago, developed a set of action steps for outreach to Hispanics and Latinos to be distributed to all chapters in the new year.

An invitation to join a national discussion

by Weyman T. Johnson, Jr., chair, National Board of Directors

This coming January a new federal administration will begin asking questions about how to address our national health-care crisis. The major presidential candidates may hold different views on how to fix the current system, but almost every voter in the country agrees without reservation that the status quo is unacceptable.

We at the National MS Society certainly agree. The impact of under-insurance, uninsurability, lack of coverage for maintenance or off-label therapies, disparities in quality and availability of care—especially of long-term services—and the consequences of inconsistent and expensive medical record-keeping are all harmful to those of us in the MS world.

Last May, the National Board unanimously adopted a set of health-care reform principles to guide our active participation in the national discussion. Our board leads a movement that seeks a world in which we may live as powerfully and productively as possible, despite what MS may do. Based on that, we agreed on seven principles, listed in the box.

The full principles are, like MS itself, complex. You can find the complete text at nationalMSSociety.org/healthcareprinciples or by calling us at 1-800-344-4867. I urge you to get it, read it, talk about it with family, friends and associates, and to send copies to your elected officials.

Fixing our health-care system will involve federal, state and local action. We will need all your voices to ensure that these priorities are taken seriously when reforms are in planning stages. Times are not easy, and the economy may take time to regain momentum. People with MS can and should contribute to a renewal. But we know that productivity of all kinds hinges on enabling people with chronic illness or disabilities to live their best lives. This in turn requires having access to high-quality medical care.

To learn more about the Society's health-care reform activities and to join in, call your chapter or go to nationalMSSociety.org/advocacy.

National Multiple Sclerosis Society
National Health Care Reform Principles



We believe meaningful health-care reform must involve these seven principles:

1. Accessible health-care coverage
2. Affordable health-care services and coverage
3. Standards for coverage of specific treatments
4. Elimination of disparity in health care
5. Comprehensive high-quality health care available to all.
6. Increased value of health care
7. Access to high-quality long-term supports and services

Chasing the blues away

Depression strikes an estimated 47% to 54% of people with MS—but a new study suggests that you can lift your mood by taking positive actions.

The study was an outgrowth of a longitudinal MS quality of life study conducted at the University of Texas at Austin, funded by the National Institutes of Health and conducted by Dr. Lorraine J. Phillips, PhD, APRN, BC, FNP, and Dr. Alexa Stuijbergen, PhD, RN, FAAN.

Stuijbergen started the study by surveying 443 people with MS yearly, asking how often they felt depressed, and to describe the symptoms they experienced. But one of the participants, Doris Varnell, a 57-year-old retiree, told Stuijbergen she found the questions “depressing.”

“I wanted to know what people were doing to make themselves feel better,” said Varnell.

Varnell wrote up a list of positive actions she engaged in to lighten her mood. She sent her list to Stuijbergen who, to Varnell’s surprise, began to ask study participants if they tried similar things. The results were dramatic. People who checked off the most items on Varnell’s list for a given week were the least depressed. Actions included:

- Saying “thank you” and meaning it
- Phoning a friend
- Visiting a friend



Bill Stanton

- Saying something pleasant to someone else who didn’t expect it
- Crossing off something on your to-do list because you finished it
- Learning something new
- Volunteering or agreeing to become a volunteer
- Going to the library and checking out a book to read
- Going shopping and buying something for yourself
- Taking a nap
- Pampering yourself with a manicure, massage or relaxing bath

Although the study does not prove that the actions alone were responsible for boosting the participants’ mental health—

Vote for your insurance!

There's another election looming: the annual coordinated election period. Every year, from November 15 to December 31, people eligible for a Medicare prescription drug plan can enroll or elect to switch plans.

Your current plan may change in 2009

Carefully read the **Annual Notice of Change** that you received in October from your current prescription drug plan. (If you haven't yet received it, call and ask for it.) Any changes will take effect on January 1, 2009. Look for changes to your plan's:

- monthly premium
- annual deductible
- co-pays or co-insurance increases
- list of covered drugs (also known as the plan's "formulary").

If you are on an MS disease-modifying drug, pay special attention to the tier that this drug is on. The lower the tier, the lower

your out-of-pocket expenses.

Special request?

If your doctor made a special request in 2008 to your plan, such as a preauthorization or exception request that allowed coverage for a specific drug, call and ask what you can do to maintain coverage for that drug.

Help!

Overwhelmed? Give us a call at 1-800-344-4867 and ask to speak to an MS Navigator® about your Medicare Part D coverage.

But don't wait too long—Medicare advises making any changes well before the December 31 deadline to allow for processing.

Chasing the blues away (cont.)

people who were happiest could have just been born that way—it does suggest that incorporating more positive actions into the day may improve quality of life even for a person with severe limitations.

"People who suffer from ongoing depression should always consult their doctor," Stuijbergen added.

"The Influence of Positive Experiences on Depression and Quality of Life in Persons with Multiple Sclerosis" is in **The Journal of Holistic Nursing**, V. 26, #1, March 2008, pp. 41-48.

Treatment update— Betaseron only

Bayer HealthCare Pharmaceuticals will launch a very thin (30-gauge) needle and a new autoinjector (BETAJECT LITE) at the end of October. The new autoinjector will replace all previous autoinjectors for Betaseron. The use of any autoinjector other than this latest version may result in people not receiving their full dose of medication. Go to betaseron.com/thinner or call 800-788-1467 for more information and to request the new autoinjector.

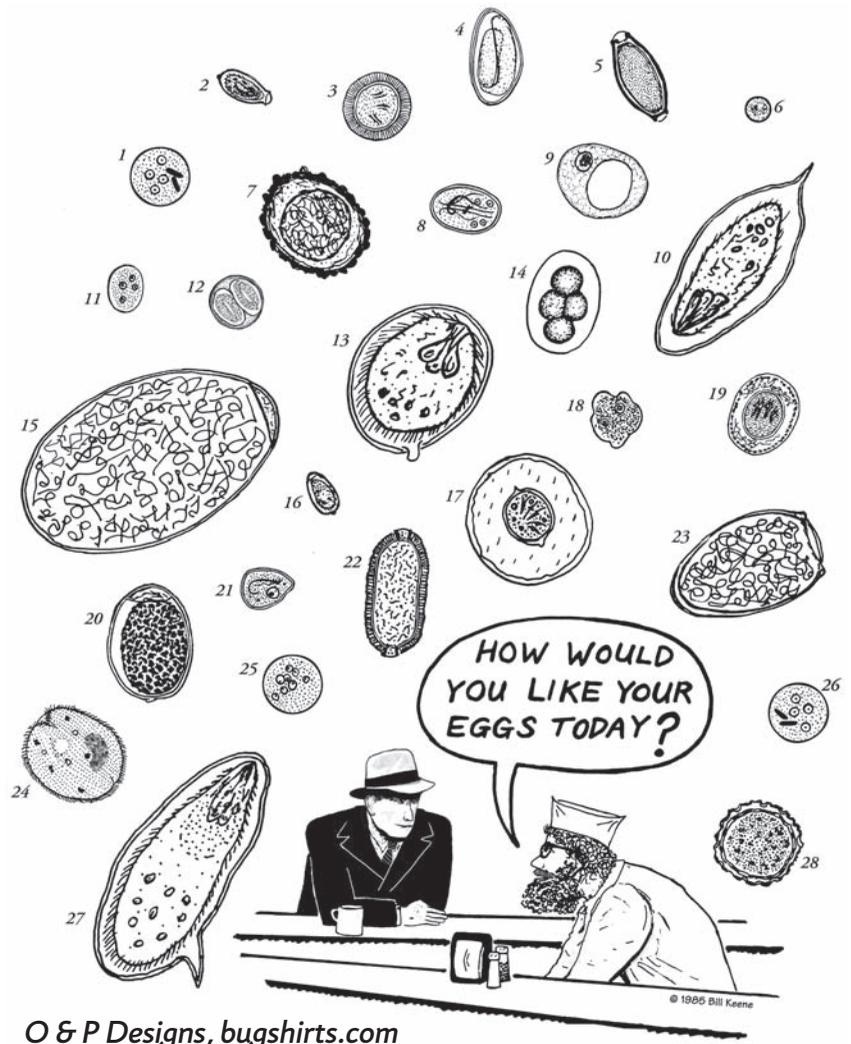
The “Yuck” Factor

John Fleming, MD, calls it the “yuck factor.” But people with MS might happily drink parasitic worm eggs if it meant a reduction in disease activity.

In a study run by Dr. Fleming, five people with MS will ingest the eggs of the whipworm, or *Trichuris suis*, a virtually harmless organism, to see if they will divert the immune system from attacking myelin. If the experiment shows promise, Dr. Fleming hopes to enroll 15 more people with MS and follow them for a year.

The study is based on the “hygiene hypothesis,” which theorizes the low incidence in MS in developing countries may be due to early exposure to infectious agents. “Modern sanitation is of course an important advance for public health,” explained Dr. Fleming, a professor of neurology at University of Wisconsin, Madison, “but it is possible that autoimmune diseases may be an unanticipated consequence of extremely hygienic environments.”

A recently published study involving a small number of people with MS underscores the potential of the worm egg approach: Investigators from the Raúl Carrea Institute for Neurological



O & P Designs, bugshirts.com

Research in Argentina found that helminth-infected people with MS showed evidence of anti-inflammatory immune activity,

compared to uninfected people with MS and those with a different infection. The investigators also found that immune cells isolated from the helminth-infected individuals produced nerve growth factors, which may translate into beneficial nerve protection.

Researchers need you! ←

Scientists are testing new medications for MS in clinical trials across the country. Some will result in groundbreaking new treatments for the disease. Clinical trials depend on volunteers—people like you—who want to participate. For information on clinical trials taking place in your area, visit nationalmssociety.org/clinicaltrials.

What's Your Financial I.Q.?

by Natalie Karlin

Can medical expenses reduce my taxes?

- **Specific rules must be met** on what percentage of income went to medical expenses for tax deductible status. See IRS publication 502 or visit www.irs.gov/publications/p502/index.html.
- An **air-conditioner** can be a medical expense according to the IRS!
- Before purchasing a **wheelchair**, check with a tax adviser about your medical plan's specific restrictions and deduction status.

Answer: Yes, if you meet requirements.

Does it make sense to transfer medical debt to a credit card?

- It only eliminates the debt to the **medical provider**.
- The **debt still exists** to the credit card company but isn't considered "medical."
- **Medical expenses can be used to offset income** in many states which could make you eligible for Medicaid or other assistance programs based on a "medically needy" status.

Answer: The best option is to negotiate a payment plan with the medical provider.

Is it wise to take a loan from a 401k to pay off debt?

Some 401k plans do allow loans against funds already contributed to the plan.

Factors to consider

- How much is in the 401k?
- How enormous is the debt?
- Can it be paid off without the loan?
- What is the person's cash flow?

Answer: Once that money is taken out, it is not growing for future benefits.

Is it possible to reduce education loan payments?

- **Contact the agency or organization** that provided the loan. Qualifications exist for some forms of payment relief. Take action before late fees are charged.
- Under the U.S. Department of Education, a **completely disabled individual can qualify for a loan to be forgiven**. But strict rules apply. Visit <http://www.ed.gov/index.jhtml>.

Answer: It's worth trying.

Where to turn for help: The Society has enlisted 600 volunteer financial advisers nationwide to give free advice through The Financial Education Partners Program. Call us.

Guidestar.com verifies a nonprofit's legitimacy regarding credit counseling services.

Bankrate.com can figure how much of a monthly credit card payment goes to pay down the original debt.

Natalie Karlin is a freelance reporter who was diagnosed with MS in 2005.

Join the Movement—without leaving your office

Designate the National MS Society in your employee giving campaign

Every year, over 1.5 million employees support important non-profit organizations nationwide through employee giving campaigns. If you are a federal government employee or your private employer offers a charitable giving campaign, you can help move us closer to a world free of MS by designating a contribution to the National MS Society.

Most charitable giving programs offer employees the opportunity to make an annual pledge, which means a portion of their donation is automatically deducted

Combined Federal Campaign (CFC)

If you work in the public sector or you are in the military, contributions can be made through the CFC by selecting the designation number 11409. If you work in the private sector, look for us listed under Community Health Charities or ask your campaign coordinator about designating a gift to the Society.

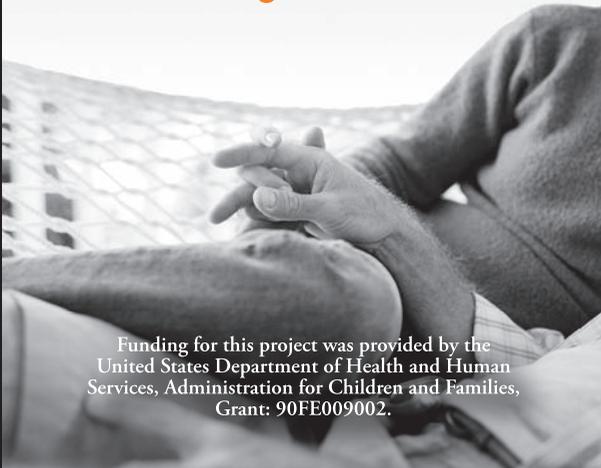
from each paycheck. Donations can also be made as a one-time contribution by writing a personal check. When you choose the National MS Society your donation comes directly to our chapter.

Your company doesn't offer an employee giving program? Talk to your benefits administrator about starting one. And call us. We can give you the resources you need.

Participating in a charitable giving program is an easy way to help provide vital services, spark public policy advocacy, and fund cutting-edge research.

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

Relationship Matters when MS moves in.

Send your stories and photos to:
Jenna.Labadie@NMSS.ORG

Or

Attn: Jenna Labadie, Director of Public Policy
4919 Memorial Highway, Suite 160 • Tampa, FL 33634

If you require assistance, please call Jenna Labadie at 813-889-8363.

Jackie's Story

Truthfully, describing MS to others is a difficult task, especially because MS is so individualized. I am quite fortunate that at this point the only thing I feel is utter exhaustion. The best way that I can describe that exhaustion is to compare it with the late stages of pregnancy. I take an injection three times per week and although it is NOT something I look forward to, it is just something that I do. It's become just as natural as brushing my teeth. The mornings after my shots, I face the potential of getting sick to my stomach, so I do not venture too far from home those mornings. And yet, I feel fortunate.

While I may feel fortunate, so much still needs to be done about MS. There is absolutely NO reason why ONE of my medicines should cost anyone \$1,800 per month and that there are so many people in this country who can not fill their prescriptions because of the cost. Health care reform is needed and it's needed NOW. My future is tomorrow and it looks great. I will NOT allow MS to define who I am or what I do. I live my life as if every day were my last, because you just never know.

by Emily Noble

How do you describe the unknown to someone? Just when you think you've figured it out, MS throws you a curveball. Shortly after 9/11, I developed a numb spot on the left side of my scalp that eventually spread to the

side of my face. For almost a year, I underwent tests too numerous to count (but I can tell you how many spinal taps I had - three!). On the eve of the one-year anniversary of 9/11, I got the call - "You have MS."



I am one of the lucky ones diagnosed with a chronic illness. I had medical insurance that paid for all of my visits, tests and medications. If only every person with MS could say the same thing. I always made it a point to speak with someone in the doctor's waiting room to find out how long they had lived with MS, what medications they were on, and how they coped. It was devastating to hear how many people were uninsured or underinsured! My mouth dropped when a woman, about 24 years old, told me how her insurance would only pay a portion of her treatment. Her out-of-pocket expense was over \$300 a month, which her parents paid for. Or the 40-year-old-man, whose marriage deteriorated because of his illness and who put off treatment because he couldn't afford it. How does this happen in today's day and age?

February 2007 marked a turning point for me. My husband's job relocated us to the Tampa Bay area from New York City. It took me seven months to find employment, but thankfully, I was able to get medical coverage under my husband's plan. I will admit to complaining how much more expensive everything has been (office visits, deductibles, medications), but then I remember that I have insurance!

Volunteer Spotlight

It's a Family Affair

When it comes to volunteering, three isn't a crowd, at least not in the Fleischer family. Paul, Patricia and Taylor Fleischer have all joined the movement to end MS. Patricia was diagnosed with MS nine years ago. At first, she was in a slump and didn't know how to get out of it. So five years ago, she decided to register for walkMS and she's participated each year since.

The first year her fundraising was just a personal donation. "The walk inspired me to change my life and help those with MS who are worse off than me," she said. She felt that she wanted to help in anyway she could and she wanted to teach her daughter about giving back. "It's great to meet new people and see familiar faces. Everyone is so friendly and helpful. It's really a great experience every year," Patricia added.

The family's involvement doesn't end there. Patricia's husband Paul has ridden in bikeMS for four years and Patricia and Taylor volunteer at the event. He said it's heartwarming to see his wife and their 11-year-old daughter Taylor when he crosses the finish line. "It's great to see Patricia standing there, knowing that I accomplished something for her," Paul said.

Paul and Taylor volunteer at the walk where, at age 5, Taylor was one of the youngest volunteers to ever help out at the event. Patricia has even gotten her Girl Scout troop to volunteer at the walk in the past.

"I hope we've encouraged more families to get involved. There's a way for everyone to support the movement. Regardless of how young or old you are, or whether you have MS or not, there's a way for you to join the movement to create a world free of MS and make a real difference," Patricia said.

The Teen Summit Hit the Heights

Our first-ever Teen Summit was a huge success! Participating in this exciting weekend retreat were 38 teens from across the north and central Florida area. They enjoyed a weekend of horseback riding, canoeing, rock climbing and ziplining in the company of new friends. Thank you to the Ryan Todd Lacey Foundation for funding this incredible retreat!

Thanks as well to the Circle F Dude Ranch, Metropolis Transportation, and Rich Killian for their contributions. The Mid Florida Chapter has a number of ways to get teens involved. From the Teen Summit Retreat to Teen Outings, we offer programs of all kinds for teens with MS and those whose families have been affected by MS. They can attend programs, participate in special events, volunteer or be decision-makers on the Teen Council.

If you'd like more information about teen programs, contact: Gabriela Casado, Family Programs Manager at 1-800-344-4867 or via email at gabriela.casado@nmss.org



Teen Summit

Community Partner Spotlight

Many Opportunities to Get Moving are Waiting for You

MS isn't a reason to sit on the sidelines. With some modifications, people at all levels of disability can enjoy the benefits of exercise. Almost everyone can find some form of healthy physical activity that is appealing enough to be challenging and fun.

Moderate exercise for 20 minutes or so every day yields the same benefits as rigorous workouts. Start by talking with your physician or physical therapists about the types of exercise most likely to benefit you. Some options include swimming or water aerobics, joining friends for a walk around the mall, playing an adaptive sport, chair stretching, aerobics, Tai Chi, Pilates, therapeutic horseback riding and yoga.

Locally, there are several venues that offer exercise programs appropriate for people with MS.

In Tampa, the Bob Sierra Family YMCA hosts a Flexercise Water Workout class three times a week. The class has several participants with MS, Parkinson's disease and arthritis. Sandy Elmore teaches the class and was certified by the MS Society to teach water aerobics for people with MS.

Throughout Brevard County, Ruby Saunders of Mind, Body, Health Yoga offers gentle yoga classes. Classes are held weekly in various

locations. In addition, Ruby is interested in starting a class specific for people with MS if there's enough interest in the community.

Exercise is part of the overall wellness plan. Visit your local YMCA, health clubs, or yoga studios and ask about their classes. The Mid Florida Chapter's Quality of Life Financial Assistance Program will cover exercise and wellness programs. For more information on exercise, the programs listed above, other appropriate recreation/exercise venues in your community, or about the Chapter's Quality of Life grant, visit our website at www.nationalMSSociety.org/flc.

Above and Beyond—

The Journey To End MS
2008 Annual Conference and
Research Symposium

Saturday, December 6, 2008
11:30 a.m.- 2 p.m.

Fantasy of Flight- Polk City
For more information, or to register,
call 1-800-344-4867 or visit our
website at
www.nationalMSSociety.org/flc

2009 Teleconference Series

December 9, 2008
Spirituality

Research supports the idea that people heal faster when they are at peace, relaxed, and connected to a power greater than the body and mind alone. Spirituality can provide that connection. Enjoy hearing John Jordan, MSW, LCSW, Vice President of Clinical Services at United Family Services, and gain tools to better understand your spirituality and grow comfortable with your own humanity.

January 13, 2009
Diet and MS:

The Nutrition Connection
 Join us to learn about meal preparation, eating healthy to manage fatigue as well as nutrition facts that can affect MS. Speaker: Denise Nowack, RD, Executive VP National MS Society Southern California Chapter.

February 10, 2009
Relationships Matter

Having a satisfactory relationship is hard work even in the best of times. MS can make it even harder. The National MS Society Relationship Matters program exists to help you and your partner minimize the impact of MS on your lives. Enjoy an overview of this great free program by Manager, Lara Rezzarday.

TO REGISTER for any teleconference or receive additional information about a specific speaker or topic: Please call: 1-800-344-4867 All calls are free! Supportive materials will be mailed to registered participants prior to the call date.

The Gala's Just Around the Corner!

The Mid Florida Chapter of the National MS Society is

celebrating 50 years of serving people living with multiple sclerosis and the progress made to develop better treatments and the eventual cure for this disease. We have many exciting initiatives planned for the year. One of the most anticipated is the 50th Golden Anniversary Gala that will be held on January 30th at Ports of Call, SeaWorld Orlando.



This evening will not be your typical Gala. The attire will be cocktail or business attire so the people attending can plan on lots of fun and no 'stuffy' dinner program! Great prizes will be available to lucky and skilled participants while everyone enjoys music from the past five decades. The 'Golden Anniversary Gala' will feature plenty of great food and drink along with unique 'gold' theme games for the guests. The top game of the Golden Anniversary Gala will be the 'Ounce of Gold' Giveaway and our "Gold Diggers" only have 500 tickets available to win a real ounce of pure gold. There will be a "Golden Wheel" to can spin for prizes. Guests can purchase chocolate bars and receive "golden tickets" to win wonderful prizes. There will also be "Golden Scavenger Hunt" quest for treasures and a "Golden Casino" including a celebrity poker tournament.

To purchase tickets, visit the Mid Florida Chapter website, www.nationalMSSociety.org/flc, and click on the Golden Anniversary Gala link or contact our office at 407-478-8882 for more information.



National
Multiple Sclerosis
Society

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but *do not* represent therapeutic recommendations or prescription. For specific information and advice, consult your personal physician.

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

Did You Know....

Studies show that early and on-going treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with multiple sclerosis. The National MS Society's medical advisors recommend that people with MS talk with their health care professional about using one of these medications and about strategies and effective treatments to manage symptoms. The National MS Society is committed to ensuring that people with MS have the information and quality care they need to live healthy, productive and independent lives.

If you or someone you know has MS, please contact the National Multiple Sclerosis Society today at 1-800-344-4867 or www.nationalmssociety.org to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

Donate Your Used or Unwanted Vehicle to Create a World Free of MS

The end of the year is a popular time for new car shopping and making contributions to the National MS Society for tax deductions. Here's how you can do both! Instead of trading in your car, or if you have a spare vehicle you no longer need, consider donating it to the National MS Society's AUTOS-4-MS program.

Through this program, individuals and organizations can donate their unwanted cars, trucks, trailers and motorcycles to help those with multiple sclerosis. We also accept recreational vehicles upon inspection. The Society sells them at used vehicle auctions and uses those funds to serve people living with MS and fund research to create a world free of MS.

Unlike other vehicle donation programs, AUTOS-4-MS does not use a third-party, for-profit company

Community Events

Join The Movement. Host your own community event. Numerous volunteers host fundraising events throughout the year to benefit the local programs and services offered by the Mid Florida Chapter and to fund research to create a world free of MS.

If you are interested in hosting your own community event, please contact Phil Deal at phil.deal@nmss.org or 1-888-950-9080 ext. 22.

Upcoming Community Events

February 16, 2009

MS Cure Classic, Valrico, 12:30 p.m.

This golf tournament will be held at River Hills Country Club on Monday, February 16, 2009. Contact Co-Chairmen Paul Tynan at 813-625-0546 or pltms2002@yahoo.com or Steve Backhaus at 813-727-2965 or steve@eptampa.com

We'd like to thank the following individuals and organizations that recently hosted a community event.

Thank you to the residents of SunLake Estates and members of the SunLake Christian Fellowship for supporting a dinner event hosted by **Lois Spohr** as part of the 50 Celebrations in 50 Days to celebrate the 50th Anniversary of the Mid Florida Chapter. Lois' community raised over \$1,500 with their

event. Congratulations and thank you for your support.

Thanks to the **MS Comprehensive Care Center** in Orlando for hosting a celebration as well. In conjunction with Dr. P. Phillips Hospital, Dr. Rosenberg and Dr. Venkatarmana and their staff hosted an educational program and raffle to benefit the local chapter.

The **Felder family** in Tampa hosted the 7th Annual MS MaSquerade, on September 13, and raised more than \$16,000 this year. Thanks to all who attended, the event committee and the outstanding sponsors.

RedCarpetMonday.com hosted their second annual silent auction to benefit the National MS Society. RedCarpetMonday.com is a sophisticated business network of Orlando professionals with a new group forming recently in Tampa. The silent auction generated over \$1,200. Special thanks goes to Michelle Hires and Ryan Totka for their support, and to all the auction prize contributors and bidders.

The Fifth Annual Pasco County MS Silent Auction Extravaganza hosted by Beth Cohen, Tammy Carr, a local volunteer committee, and the Crab Shack in Port Richey took place on October 3-5 and raised \$11,000- topping last year's record-breaking year. Thanks to all the hundreds of attendees, bidders, and the event committee for making this event such a huge success!

Please check the Mid Florida chapter's website often for a current list of Community Events in your area. Due to publication deadlines and delivery dates, the Chapter is unable to provide a complete up-to-date list of Community Events in the MS Connection.

Are Your Boots Made for Walking?



Friends of Hope 2008, Team Friends of Hope in Sarasota was the #1 Team in 2008, raising over \$30,000! Congratulations!!!

Do you want to be part of one of the largest fundraising events aimed toward creating a world free of MS? Do you want to do something about MS now?

Well, this is your opportunity! walkMS is kicking off 2009 RIGHT NOW! Don't miss it! This is a fundraising event in which everyone can participate. The ways to get involved are endless and we make it easy for you. Whether you prefer to walk, ride, stroll, or cheer, this is the event for you! Everyone can participate and everyone can raise money to support local services and research to find a cure.

walkMS is about family, friends, co-workers, and neighbors coming together to raise money and show support for everyone in Central Florida living with MS. If walking isn't your thing...no worries, we have a spot for you at our finish line. Come cheer on the hundreds of people who cross the finish lines in celebration.

In 2008, 3,200 people pledged to raise funds and show support. Together they raised \$617,000. In 2007, 2,600 people raised \$564,964. What does that mean? It means the more people who participate, the more money we raise to help our communities.

Don't let this opportunity pass by. Here is your chance to make your personal mark against MS. You can visit the walkMS website at midfloridaMSwalks.org for details on each of the walks. If you're unable to attend any of the locations listed, please check out the on-line "We Will" Virtual Walk and register today. Information is also available to assist you with your fundraising journey.

Register sooner rather than later so you can check this off your "to do" list and start making your mark now.

Help us Keep Our Promise:2010

When new MS research concepts come to light, or emerging technologies open up new opportunities, the National MS Society attracts researchers who conduct targeted research on specific topics in need of exploration. The Promise:2010 campaign offers hope to people living with MS by funding vital research in four promising research areas. To learn more, visit our website at www.nationalMSSociety.org/flc or call 1-800-344-4867.

To fund MS research through the Promise: 2010 Campaign, please mail your contribution to: Promise:2010, National MS Society, 2701 Maitland Center Pkwy, Suite 100, Maitland, FL, 32751. Please note on your check the gift is for the Promise:2010 Campaign. Also, feel free to contact us at 1-888-950-9080 if you have any questions. Thank you for your support.

A bikeMS Tale with “Moore” to Tell

Dottie Moore is an amazing woman. She is an MS activist and a volunteer. And she has MS. In 2008, her husband Jim participated in his first bikeMS ride. We thought we would share with you the words of Dottie, speaking of her family’s experience with their first bikeMS ride.



GETTING IT TOGETHER

We have this thing we do in our family. When my husband and I hug, our Beardie mix, Ginger, stands on her hind legs to get in on the act. We call this our “group hug.”

We don’t do this much, though, because when Jim isn’t working, he is off biking. So, I shouldn’t have been surprised when he announced that he was going to do the 2008 bikeMS: Bright House Networks MS Ride with several of our friends. I was thrilled and PROUD. You see, I have MS and he was riding for ME and my disease. How cool is that? Except for one little thing. I had promised myself that I was going to “become an MS activist” in 2008. So now what? I can’t ride a bicycle. The last time I rode a bike, I did a “Laugh-in.” Remember Johnson stops his tricycle and falls over sideways? That would be me, and it is not pretty.

PREPARING FOR THE RIDE

The team needed money and they were busy training. Eureka! I would raise the money and surpass ALL expectations. I e-mailed/solicited/BEGGED family/friends.

The team and I received some nice donations but we needed more. I called the MS Society and brain-stormed ideas. I had NO idea what I was doing but I wanted to blow the team’s \$1,200 goal out of the water. While at Ginger’s groomer, he suggested a raffle. I had NO clue how to do a raffle but I would have to make it up as I went along. I hit up the owner of my hair salon, my wine guy, restaurants...you get the idea. Before you knew it, I had over \$1,200 worth of really good stuff. I was on my way to the raffle of champions!!!!

We raised over \$4,000, which was great. But the type “A” personality in me was disappointed because I knew I could have done better. But MS forces us to compromise that type “A” sometimes doesn’t it.

On the morning of the ride I watched the MS Society staff with their tireless energy and felt the tears well up. They were jumping up and down, blowing horns. This is what it is about, you silly goose! These people had worked so HARD, and here I was grouching in my self-absorption and misery. The finishers came trickling in. They were riding for MS. They were riding for me. I thanked the bikers over and over. Ginger worked the crowd, sitting on her hind legs and smiling (for real!). Here comes the team!!! I am beaming with pride. And feel so blessed.

Afterthoughts

I signed the MS Wall - “30 years and still figuring it out.” You can see by this that it is true. One thing is for sure though. I am proud of the MS Society, the sponsors, the volunteers and the cyclists. They are beyond heroic in my eyes. And I am way proud of us - our family and our first RIDE - Jim, Ginger, and despite everything...I am even proud of me. *Group hug*

Research Update

Alemtuzumab Results Published: Reduced MS Relapses and Accumulation -- Phase 3 Trials Recruiting Patients

Treatment with alemtuzumab (Genzyme Corporation) reduced the accumulation of disability and the frequency of relapses in people with early relapsing-remitting MS, compared to Rebif® (interferon beta-1a, EMD Serono, Inc. and Pfizer, Inc.). Those taking alemtuzumab had a 74% reduction in the risk of MS relapse compared with those on Rebif, and a 71% reduction in the risk for sustained accumulation of disability. Those on alemtuzumab, an immune-suppressing monoclonal antibody, experienced adverse events more frequently, including immune thrombocytopenic purpura (a serious bleeding disorder), thyroid adverse events, and infections. The results, originally reported at medical meetings, have now been published (New England Journal of Medicine 2008 359;17: 30-45), and two Phase 3 trials are currently recruiting participants with relapsing-remitting MS.

Background and Details

Alemtuzumab is a humanized monoclonal antibody directed at CD52 (a protein on the surface of immune cells) that is currently approved by the U.S. Food and Drug Administration as a single agent for treatment of patients with B-cell chronic lymphocytic leukemia. Its ability to target immune cells has led investigators to test its potential as a treatment for relapsing-remitting MS.

Drs. D. Alastair Compston, Alasdair J. Coles (University of Cambridge, UK) and colleagues have now published results of phase 2 clinical trial that compared high and low doses of alemtuzumab (given by IV infusion over three to five days once a year) with Rebif, a standard MS therapy, in 334 people with early relapsing-remitting MS who had never taken any other disease-modifying therapies. The primary outcomes were the time to sustained accumulation of disability and the rate of relapse.

Those in the alemtuzumab groups were slated to receive two to three cycles of the annual infusion. However, dosing was temporarily suspended due to the occurrence of immune thrombocytopenic purpura (ITP), a rare condition in which low blood platelet counts can lead to abnormal bleeding. After the first cases of ITP occurred, one of which was fatal,

Genzyme implemented a patient safety monitoring program which includes patient and physician education and regular contacts with patients. A total of six alemtuzumab-associated ITP cases were identified and, when necessary, promptly treated.

Most of those on alemtuzumab received their second infusion cycle (207 out of 223 total), but fewer went on to receive a third cycle (46 out of 223). The results reported in this publication follow the participants out to 36 months of the study.

Results

The results were nearly the same for the two doses of alemtuzumab, so the data for patients receiving this drug were pooled for the comparison with Rebif. After thirty-six months, those taking alemtuzumab experienced significant reductions in the risk of MS relapse compared with those taking Rebif (74% reduction, with an annualized relapse rate of 0.36 for Rebif versus 0.10 for alemtuzumab) as well as significant reductions in the risk for progression of disability compared with those taking Rebif (71% reduction). Among secondary outcomes that were measured, significantly more of those on alemtuzumab remained relapse-free at 36 months (52% for Rebif and 80% for alemtuzumab). In addition, the mean disability score (EDSS) for those on alemtuzumab improved slightly (by 0.39 point) while the mean score of those on Rebif declined slightly (by 0.38 point).

Among other side effects reported in the Phase 2 study, patients who received alemtuzumab were more likely to develop thyroid disease and mild to moderate infections (i.e., infections requiring no specific medical intervention or requiring only oral medication). Thyroid problems are reported to have been easily detected and treated. Patients who received Rebif experienced injection site reactions, fatigue, flu-like illness, headache and abnormal liver function tests.

Comment

"We are pleased to see potential new treatment options move positively through the MS pipeline," said John R. Richert, MD, executive vice president for research and clinical programs at the National MS Society. "We look forward to results from the Phase 3 studies now getting underway, which will help determine if this treatment can be used safely and effectively in people with MS." Two Phase 3 trials of alemtuzumab, supported by Genzyme Corporation and Bayer Healthcare Pharmaceuticals, are currently recruiting participants.

Rebif is a registered trademark of EMD Serono, Inc. and Pfizer, Inc.

Orlando Man Climbs Mt. Rainier to Raise Awareness and Funds for People Living with MS

He did it! Chuck Norman, an emergency room nurse in Orlando reached the 14,000 foot summit of Mt. Rainier in July obtaining a goal he has worked months to achieve. In addition to his personal accomplishment, he wanted to make a difference in the lives of people living with MS. A family friend was diagnosed with MS and Chuck and his wife felt a climb dedicated to this cause would be a wonderful tribute to her.



Chuck Norman
Mt. Rainier

“I’ve been in the Coast Guard, a firefighter, a paramedic, and now an emergency room nurse,” Norman says. “I’ve been taking care of people for years and now I wanted to try to help find a cure for MS. A lot of symptoms of acute mountain sickness are similar to the symptoms people experience with multiple sclerosis.”

Chuck paid his own expenses for the climb and all the funds he raised (\$7,000 and growing) will help people living with MS and help fund research for a cure. “My original goal was \$3,000. I am thrilled with the amount of money we’ve been able to raise and the awareness we generated about MS.” To read more about Chuck’s climb, visit his website at <http://thesnowshoecub.com/>.

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