



Make a Low-Stress Season Your New Holiday Tradition

by: Shelly Stein MSW, LCSW

The holiday season brings with it the promise of joy, but it's a promise that falls short

for many. When fatigue and frustration overshadow seasonal cheer, stress becomes an unwanted holiday tradition. How can you change that tradition to a healthier, happier one?

Banish unrealistic expectations –of yourself and of others – as they only breed conflict and disappointment. Focus on the few things that are most important to you. It's okay to say "no" and to renegotiate long-standing traditions.

Use your "inner voice" to express yourself effectively. Express what you *really* feel and what you *really* think. State your message clearly, being as honest and constructive as possible. Making "I" statements is a great strategy to keep listeners from feeling defensive and to maintain open communication channels. (Don't say, "You're stressing me out." Say, "I'm feeling stressed out.")

Listen effectively. At this time of year, time and attention spans are pulled in

every direction and that can lead to miscommunication. It's easy to lose focus when someone is talking to you. Being a good listener requires concentration, tolerance and sensitivity. Stay focused, but if you find your concentration has drifted away, don't hesitate to ask the speaker to repeat himself.

Set aside dedicated time to spend with family and friends. These connections can ease holiday tension. Time spent talking with those closest to you is invaluable, whether it's enjoyed over a meal or while doing household chores.

Take even better care of yourself. Self-care is more important than ever during this stressful season. Get plenty of rest, eat a healthy and nutritious diet, drink lots of water and limit your alcohol intake.

Pace yourself. Recognizing and accepting any limitations you have is vital. You owe it to yourself and those around you to enjoy the holidays at whatever level you're capable of *comfortably* maintaining.

Shelly Stein is a licensed psychotherapist in Sarasota. She is a preferred provider for mental health counseling with the National MS Society.



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PRESIDENT'S IMPRESSIONS

Not too long ago, I sat in on a wellness workshop presented by the Mid Florida Chapter in collaboration with the Jimmy Heuga Center. It was a Saturday and I was practicing stretching motions next to friends I've known for years and some new ones I met just that morning. Some of us were seated in chairs, some in wheelchairs, some in scooters. Together we stretched. What struck me at that moment was how good it felt to be in slow motion. Present in time, breathing, and slowing down to stretch muscles that I apparently ignore far more often than I realize. I wasn't the only one in the room to acknowledge that simple actions can make a difference to the body, soul and mind.



Tami Caesar
Mid Florida Chapter President

I know the drill. I can't be there for others if I can't take care of myself. Yet, when asked about my personal wellness plan I stuttered a response peppered with nervous laughter. Are you the same? Do you manage the symptoms of MS but don't make time for exercise and recreation?

In this issue of the MS Connection you will find information about personal wellness, including articles about therapeutic recreation, maintaining mental health and yoga. We also have an update about the results of our Needs Assessment and the programs and services we will offer in response, many of which are aimed at personal wellness, symptom management, recreation and emotional support.

As we head into 2008, please join me in taking a few minutes to slow down and take a breath... and stretch. We have a busy year ahead of us and I hope you'll be ready to join the movement.

Wishing you peace and wellness throughout the holidays and the New Year.

Tami

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?

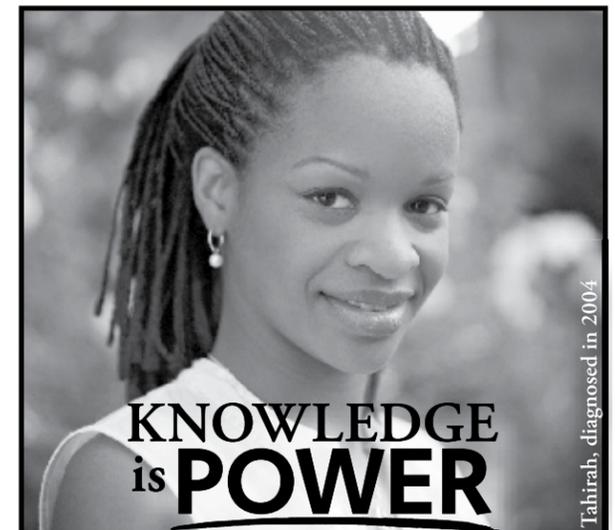
"If started early in the appropriate person, these medications can be important in slowing down the progression into classic MS," Dr. Phillips said. "But who is the appropriate person? Do I know that this single event will evolve into MS?" Disease-

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.



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.

This is why we're here.



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.



Christina Fitzsimmons (top photo); the Mike Dugan Scholar, Andrew Carpenter (bottom photo); and the Stitzer Family Memorial Scholar, Natasha Spedalle.

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**.

Medicare Part D 2008 Sign-Up or Switch

The annual enrollment period for Medicare's Part D prescription drug plans is **November 15 to December 31, 2007**. With a few exceptions, beneficiaries can only join or change plans in this period.

- Don't assume that your current plan will continue covering the same drugs at the same cost in 2008. There may be another plan that better suits your needs.
- If you already have a Part D drug plan, you should receive a notice by October 31 listing any changes in coverage or costs for 2008.
- Compare this new plan with others offered for 2008. Are there higher premiums, deductibles, or co-payments? Has coverage during the donut-hole period changed? Most importantly, does the plan cover **all** your medications? If you have questions, contact your plan.
- If you want to stay with your plan, do nothing.
- If you are signing up for the first time or want to switch, find out what's available in your area and compare plans by using the Medicare Prescription Drug Plan Finder at www.medicare.gov. Or call Medicare at 800-633-4227.
- For more help with choosing a plan, use the link www.shiptalk.org to find your State Health Insurance Program, or SHIP.

For assistance, call us at 1-800-344-4867 or go to nationalmssociety.org/Medicare.

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.)



Congressman Russ Carnahan



Congressman Michael Burgess

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 who 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, D.C., 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

MS 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.

Some plain talk about life insurance

Kim Calder, MPS

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.



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

Make a Gift Before Year's End

Now is the time to maximize 2007 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 year-end 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. You must make gifts before December 31.

■ 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 in 2007 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 on or before December 31, 2007, directly to the MS Society.

For more information about the year-end 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

TAMING HOLIDAY STRESS ←

Think about past holidays and choose two or three of your most cherished rituals. Cast off others that are just habit or obligation. That way you won't burn out trying to do everything.

Community Partner Spotlight

Quantum Leap Farm Helps Riders Overcome Hurdles

by: Edie Ebbert Dopking Phd. and Executive Director of Quantum Leap Farm

The therapeutic value of horseback riding has been recognized since the 1940s, when a polio epidemic affected many children in Europe.

A physiotherapist realized that the rhythmic movement of horses models the normal human gait. She began putting polio-stricken children on ponies to re-educate the youngsters' bodies. Children who underwent "hippotherapy" (hippo – Latin for horse) experienced better outcomes than those who did not ride.

Hippotherapy offers many benefits for people with MS. Whether you're a novice or an experienced equestrian, it's a safe and fun way to make friends and fight the

progression of MS symptoms. This therapy can stimulate numerous bones, muscles and neural networks involved in normal walking. Riders can see improvements in leg strength, muscular coordination, balance, posture, and overall gait quality and stability – ultimately gaining more functional mobility.

Hippotherapy is performed by a licensed physical or occupational therapist certified through the North American Riding for the Handicapped Association or another certifying body. Therapists appropriately pair horses and riders. For example, horses that produce slow, smooth, rhythmic movement can help patients with high

muscular tone relax and stretch muscles and joints, thus improving their flexibility and increasing their range of motion. Horses with a more choppy gait produce more movement in their riders and can help those who have low muscle tone tighten up the core muscles.



What a great day for Hippotherapy.

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QUANTUM LEAP - CONTINUED FROM PG 11

Hippotherapy offers psychosocial benefits as well, as riders engage with volunteers, horses, and other participants in the Therapeutic horseback riding offers multiple benefits to participants with MS. It's a great exercise for helping preserve balance. Gradual increases in the duration and intensity of sessions can result in improved muscle tone, stamina, posture, and trunk stability. And as riders work to develop independent control of seat, legs and hands to cue their horse more effectively, they're able to improve muscle coordination.

As with any other form of exercise therapy you'll want to check with your doctor before beginning. Most therapeutic riding programs screen potential participants before accepting them into their programs.

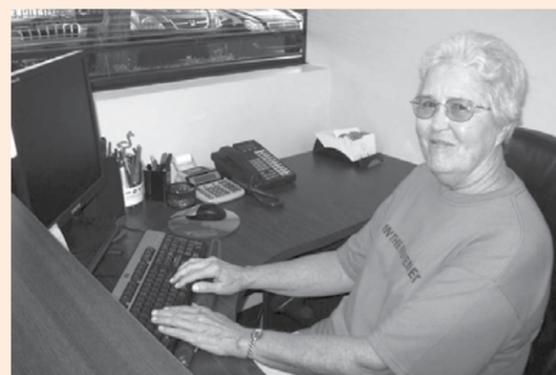
The Mid Florida Chapter's Quality of Life Grant covers exercise and wellness programs that can help you enjoy the many benefits of hippotherapy. Quantum Leap Farms in Odessa (just northwest of Tampa) offers a number of programs, an experienced staff of therapists and a stable of horses ready to help you Join the Movement. For more information, call (813) 920-9250 or visit their website at www.QuantumLeapFarm.org.

Volunteer Spotlight: Grace Vallier

Grace Vallier's personal involvement with MS began as many people's do – with a loved one who was diagnosed with MS. In Grace's case, it was her nephew, followed by her twin brother. Her awareness of the disease followed her into retirement as she moved to Florida in 2004. After becoming an active member of her Lakeland church, she contacted the Mid Florida Chapter office and offered to volunteer her time and talents to the National MS Society.

Are we ever glad she did! Grace is truly committed to our organization. Once a week, she braves I-4 and travels from her home in Lakeland to our Maitland office. Grace was a key part of the April MS Bike Tour's success, helping us communicate with the thousands of riders who would go on to raise over \$1 million dollars. Whether it's stuffing envelopes or entering information in our database, she never shies away from the task at hand and always seeks ways to help the National MS Society do more for people with MS. Grace has Joined the Movement and is doing something about MS Now.

Join the Movement like Grace. Contact the Mid Florida Chapter of the National MS Society for more information on how you can volunteer, www.nationalMSSociety.org/flc; 1-800-344-4867, option 2.



Grace proudly wearing her Join the Movement T-shirt while volunteering at the Maitland office.

You Asked for It, We're Doing It

Moving Programs and Services Forward for People Living with MS

The goal for programs and services for the Mid Florida Chapter has always been to provide equal access to high-quality *local programs and services that meet the needs of people living with MS throughout the chapter territory.*

As our new fiscal year kicks off, we are guided by a wealth of new information that relates specifically to *you*. In late April, the Mid Florida Chapter completed a Needs Assessment of people living with MS in our territory. Our goal for this in-depth survey was to learn which programs and services our MS community needs most.

Details on survey results have been explained in town hall meetings that continue to be scheduled throughout the Chapter territory. Here is what we heard and how the Mid Florida Chapter is responding to the needs of people with MS in Central Florida.

WE ASKED HOW WE CAN IMPROVE OUR PROGRAMS AND SERVICES.

Your answer:

The Mid Florida Chapter must begin to meet the needs of people living with MS by offering more programs and services that are more easily accessed.

Your input:

- 32% of total respondents and more than 50% of people under 35 want online programming
- 44% of people stated lack of convenient times/location the reason for not attending programs
- 25% of people feel unsupported emotionally in their area
- 46% of people have not attended a Chapter event in the past two years.

The Chapter's response:

- Offering an online support group and/or community for people living with MS through MS Learn Online
- Increasing the number of support groups and educational programs in underserved rural areas
- Offering more programs at night and on the weekends

TO ENSURE EFFECTIVE OUTREACH, WE ASKED HOW AND WHERE YOU GET MS INFORMATION OTHER THAN THROUGH THE MID FLORIDA CHAPTER.

Your answer:

People rely on the NMSS website, their healthcare professionals and printed literature for sources of information about MS.

Your input:

- 70% NMSS Website
- 53% Healthcare Professional
- 51% Printed Literature
- 41% Other MS Organizations
- 38% Other Websites/Forums
- 31% Local Chapter Website
- 23% Friends Who Have MS

The Chapter's response:

Providing healthcare professionals who serve people with MS with information on program and service delivery throughout the Chapter's 23 counties. Outreach will include:

- Educating healthcare professionals as part of a continuing, comprehensive treatment plan.

CONTINUED ON PG 14

- Hosting three professional education programs in 2008 to target Mental Health Professionals, Nurses and Physical Therapists in order to provide education for the care and treatment of people they serve who live with MS.
- A presence in MS specialty care centers and clinics throughout the Chapter in order to provide face-to-face service coordination and resources to people affected by MS.
- Informing members of the latest educational programs and services as well as research information via the web.

WE ASKED WHAT ARE THE MOST DIFFICULT CHALLENGES FACED BY YOU AS AN INDIVIDUAL, SO WE CAN PLAN MEANINGFUL PROGRAMS TO MEET YOUR NEEDS.

Your answers:

- Among *all* people living with MS, *fatigue* and problems with *cognitive functions* are the most widely experienced challenges faced in the past year.
- People with more *severe symptoms* mentioned struggling with more *basic day-to-day* functions such as eating, bathing, toileting and getting out of the house.
- *Younger people (under age 35)* are the most likely to have had difficulty dealing with *sadness and other emotional issues*.

The Chapter's response:

- Symptom management programs*
- Long-term care planning and direct service coordination**
- Emotional support services

* See New Symptom Management Programs are Meant to Empower, Page 15 for details.

** See Three Tiers to Better Support, Page 14 for details.

WE ASKED WHAT ARE THE MOST DIFFICULT CHALLENGES FACED BY YOU AND YOUR FAMILIES/CAREGIVERS.

Your answer:

- Available activities
- Financial limitations
- Communication About MS

The Chapter's response:

- The "Strengthening MS Families" program (see "Strengthening MS Families" through stronger support, page 15 for details)
- Overall, the Needs Assessment process helped the Chapter identify gaps, better understand your expectations of the organization and move toward providing even more relevant programs and services. Thank you to everyone who participated in the survey. Your input was invaluable!

Three Tiers to Better Support

The Chapter will soon introduce "MS Navigator," a new three-tiered approach to support and care management services. This approach is designed to help people understand the resources available and to access them more easily to help better manage their MS.

The Fast Lane – People affected by MS will be able to contact the Chapter at 1-800-344-4867 and press Option One to talk with Information and Referral Specialists who can guide and support you as well as answer all your questions about MS.

The Co-Pilot's Seat – This new level of care provides service coordination from "MS Navigators" who work directly with you. Together, you'll be able to set achievable goals, then reach the resources and services needed to keep or regain independence. These resources include in-home health care, transportation, counseling, family support/education, Quality of Life Grant Assistance

(financial support), equipment loan, and/or healthcare services. The Chapter partners with service providers in the community to offer the best services at the best prices. For a complete list of preferred service providers, call the Chapter or visit www.nationalmssociety.org/flc.

Destination: Future – Coming in Fall 2008 is a level of care management that goes beyond short-term goal setting. This level of care will provide long-term care managers who will be able to assist in long-term care planning, crisis management needs and counseling services. In the meantime, if you need assistance with long-term care management, please call the Chapter to be linked with someone in your community who can help.

New Symptom Management Programs are Meant to Empower

Being able to learn more about the symptoms of MS and how they are best managed can help ensure independence and empowerment for people affected by MS. Based on the response from the Needs Assessment, the Chapter is planning and implementing teleconferences, in-person, and online programs to help you learn more about symptom management and to meet and talk with people who share similar experiences.

Look for these exciting programs over the next 12 months:

- North American Education Program – Nervous System Repair & Cognitive Functions
- Planning for a Life with MS – Financial Planning Teleconference
- MS Legal Eagles – Get your Legal Questions Answered
- Fatigue: Take Control!
- Living Well With MS – A Look at Exercise, Wellness and Therapeutic Recreation

Strengthening MS Families through Stronger Support

Through the new "Strengthening MS Families" program, the Mid Florida Chapter provides services that meet the needs of the entire family – both adults and children. The goal of this program is to improve the quality of life for families affected by multiple sclerosis by offering information on MS and available treatment options, dispelling myths about the disease, providing support and offering much-needed respite activities. The program is designed to help meet the following areas of family support, as asked for in our recent Needs Assessment:

Your input:

Recreation/Social Activities	38%
Web Based Programming	28%
Counseling	26%
Retreats/Respite	24%
Caregiver/Couple Support	24%

In 2008, a number of "Strengthening MS Families" programs will be offered. These will include:

- 10th Annual Day of Discovery at SeaWorld Orlando
- MS Journey Club for Families
- MS Kids Camp
- Youth Against MS Teen Summit
- Relationships Matter Couples Weekend

Visit www.nationalmssociety.org/flc or call the Chapter and speak with Family Programs Manager, Gabriela Casado, ext. 34, for more details about how to be involved in the "Strengthening MS Families" program.

Just Diagnosed? We're Here for You

When first diagnosed with MS, a million questions go through your mind. It's not uncommon to experience fear, uncertainty, confusion and frustration. The National MS Society has a number of programs and services in place just for those newly diagnosed and their families. The National Multiple Sclerosis Society offers the following programs:

At-Home Educational Program

The Knowledge Is Power (K.I.P.) program is a free at-home educational series for people newly diagnosed with MS and their families. Written by Dr. Rosalind Kalb, a highly regarded author and psychologist, K.I.P. is delivered to your email address or postal address each week. The program uses up-to-date information to address the effects of MS on your life and the lives of people who care about you.

K.I.P. helps you deal with one of the greatest challenges presented by MS – the unpredictability and uncertainty of what lies ahead. Weekly topics include:

- Taking the First Steps: What is MS?
- Dealing with Your Diagnosis & Disclosure
- Disease-modifying Treatments for MS
- Maximizing Your Employment Options
- Treating Yourself Well
- Maintaining Healthy Relationships: Family, Friends, and Colleagues
- Working with Your Doctor

Visit www.nationalmssociety.org or call 1-800-344-4867, option 1 to register for this empowering educational series.

Retreat Workshops

In 2008, the Mid Florida Chapter will host two in-person retreats in early spring and late summer. These workshops will bring those newly diagnosed together with their peers for an informative session during which they can get questions answered and learn more about MS.

Peer Support

Not the group workshop kind? No problem. Call the Chapter to learn how you can chat with a peer in your area. The Mid Florida Chapter is also introducing "MS Coffee Chats", peer support for people who are newly diagnosed. "MS Coffee Chats" will be hosted quarterly beginning in January throughout our 23-county area.

Visit www.nationalmssociety.org/flc for up to date information on all programs for the newly diagnosed. Call 1-800-344-4867, option 1 to schedule your coffee chat.

Southeast Chapters Offer Year-Long Teleconference Series

The Mid Florida Chapter has partnered with other Chapters in the Southeast to help you join the movement from the comfort of your own home. A year-long teleconference series offered to people living with MS will help them better manage their MS. These toll-free teleconferences will be held on the second Tuesday of every month from 7:30 to 8:30 p.m.

Register now for the topics that are of interest to you. Worried that you may forget the call by registering so far ahead? We'll mail you a confirmation postcard and/or email after we receive your registration. After you register, you'll receive the call-in number and hand-outs that correspond to the topic the week before each call.

Dates and brief summaries of the upcoming teleconferences are as follows:

December 11, 2007

Staying Well with MS: Preventative Healthcare

Presenter: Mary Hughes, MD
Information on MS and wellness including nutrition, exercise, yoga, aquatics, emotional wellness, fatigue and depression.

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January 8, 2008

Mood, Memory & MS

Presenter: Kristine Herfkens, Ph.D
Cognitive problems that are common with MS and how to manage them.

February 12, 2008

MS and Sexuality

Presenter: Megan Weigel, MSN, ARNP, FNP-BC
Answering your questions about intimacy for men and women with MS during an upbeat, open conversation.

March 11, 2008

MS 101

Presenter: Jayne M. Ness, MPhD
Basic information on MS, symptom management, coping with MS, talking with others about MS, treatment options and current research.

April 8, 2008

Understanding Social Security Disability Insurance

Presenter: Winnie P. Pannell, Esq.
Critical information needed to understand and apply for SSDI and to undergo the appeals process.

May 13, 2008

Affecting Change: Getting What You Need

Presenter: Dorothy Northrup, MSW, ACSW
Learn how to be your own best advocate when working with community, health and government agencies to break down barriers and get what you need.

June 10, 2008

The Way We Were – The Changing Face of Relationships

Presenter: Shelley Peterman Schwarz
How to tell people in your life what you're going through, how to accept changes in relationships, and how to build a circle of care and support.

July 8, 2008

Clear Thinking about Alternative Therapies

Presenter: Emily Riser, MD
Become an informed consumer through tips for clear thinking about alternative therapies.

August 12, 2008

Targeted Research & Clinical Trials

Presenter: Patricia O'Looney, PhD
The V.P. of Biomedical Research for the National MS Society will provide an update on targeted research projects as well as clinical trials currently underway.

September 9, 2008

Be in Command of your Bladder!

Presenter: Heather Simpson, PT
A major contributor to bowel and bladder incontinence is weakness of the pelvic floor muscles. Explore available rehabilitation and treatment options.

To register for any or all of these teleconferences, call 1-800-344-4867, option 1 or email programs.rsvp@flc.nmss.org. Visit the website at www.nationalmssociety.org/flc for more details.

Intro to Yoga Class Scheduled for December

Yoga is a non-competitive activity that includes a series of movements done slowly and mindfully with breath awareness. Yoga creates an internal environment that lets you find your own balance for an optimum state of health and well-being.

Mind Body Health Yoga and the National MS Society will be hosting an Intro to Yoga program on Monday, December 3 at the Unity Church of Merritt Island from 5:30 p.m. to 6:30 p.m. Join us and discover the benefits of gentle yoga as part of your overall MS wellness plan. (As always, be sure to consult your physician before starting any exercise or wellness regimen.)

Intro to Yoga

Monday, December 3
5:30 p.m. - 6:30 p.m.
Unity Church of Merritt Island
4725 North Courtenay Parkway
Merritt Island
Refreshments will be served.

Please RSVP by calling 1-800-344-4867, option 1 or email programs.rsvp@flc.nmss.org

The Equipment Loan Closet Needs Your Donations

Medical equipment can be very costly and often presents a financial challenge to people with MS. To help ease that burden, the Mid Florida Chapter operates an Equipment Loan Closet. Through this program, durable medical equipment is available on loan to people with MS who can't afford it, are under-insured or have surpassed their insurance benefits. Equipment availability is based on inventory. The Loan Closet depends on donations from the community and we're currently in need of the following items:

- Lift Chairs
- Hoyer Lifts
- Scooters
- Power Chairs (No Hoverounds please)
- Manual Wheelchairs

Donations must be in good condition and patient-ready. A letter acknowledging your donation for tax purposes is available.

To donate an item to the Equipment Loan Closet, or to request a piece of equipment, please contact the Mid Florida Chapter of the National MS Society at 1-800-344-4867, option 1.

Living with MS Webcasts and Podcasts



The National MS Society offers a variety of educational programs on multiple sclerosis. Read about MS at home with your family and watch our online webcasts. Log on to www.nationalmssociety.org, click on "Living with MS" and then explore our webcasts and podcast for more information.

The Many Faces of Generosity

Throughout our 23-county territory, individuals and businesses alike put their resources, time, and talent to work to raise money for the National MS Society. We're always amazed at the creativity and commitment shown by these supporters and their networks of friends, families and business associates. We thank them one and all for joining the movement!

Here are just a few of the recent Community Events to benefit the National MS Society:

RedCarpetMonday.com, a sophisticated business network of professionals in Orlando, hosted a silent auction during one of their recent networking functions. The auction generated more than \$1,000 for the Mid Florida Chapter. A special thanks goes to Michelle Hires and Ryan Totka for their support, and to all the auction prize donors and bidders.

The MS Masquerade, an annual event hosted by the Felder Family in Tampa, was held on September 8, and raised more than \$20,000! Thanks to everyone who attended, the sponsors and the event committee.

The Fourth Annual West Pasco MS Silent Auction Extravaganza hosted by Beth Cohen, Tammy Carr and the Crab Shack in Port Richey took place on September 21-23 and raised \$10,044 – tripling last year's total. Thanks to all the attendees, bidders, and committee for making this event such a huge success!

Many thanks to **Gucci at the Mall at Millenia** in Orlando for hosting a private benefit reception in their store on September 27. The reception was well-attended, and the National MS Society will receive 10% of the evening's purchases. Special thanks to Cellan and Michael Lehman and Susan Brown from BOBOSART, along with the other committee members, for helping organize this wonderful evening.

The Crop for Hope, a scrapbooking weekend with auctions and raffles, was led by Jackie Durning in Tampa. Taking place September 28-30, this year's event raised more than \$5,000. Many thanks to Jackie and her committee for their fantastic efforts!

The Honors Congress at the University of Central Florida hosted the first annual "Olympics at UCF" on Saturday, October 6. Fun was had by all as UCF students joined the Movement by participating in field day Olympic events and generated over \$1,200. Special thanks to Mara Campbell and her committee for their hard work.

Upcoming Event: MS Cure Classic River Hills County Club in Valrico, FL Monday, February 18, 2008 at 12:30 p.m. Contact Co-Chairmen: Paul Tynan at 813-625-0546 or pltms2002@yahoo.com or Steve Backhaus at 813-727-2965 or steve@eptampa.com

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.

Mid Florida Chapter Community Events

The Chapter invites you to attend events near you and support the MS Society!

If you are interested in hosting your own community event, please contact Phil Deal at phil.deal@flc.nmss.org or 1-800-344-4867, option 2, ext. 22.

Put on Your Walking Shoes

Walk Season 2008 is Right Around the Corner

We're committed to finding a cure for MS one step at a time and we hope you'll join us. In March and April of 2008, we'll hit the streets to raise more than \$700,000 for the Mid Florida Chapter. This year we have six walkMS locations to select from over the course of three weekends.

Below, you'll find the dates and locations of the six upcoming walkMS events. If you'd like to join a walk but there's no location convenient to you, consider our new "We will" Walk. Select from any date listed, recruit a team and walk together in your own community. All "We will" Walkers will receive the same online and fundraising benefits offered to walkers at the main sites.

March 15, 2008

Orlando – Lake Eola at Thornton Park
Tampa – Tampa's Lowry Park Zoo (PM Walk)

March 29, 2008

Cocoa – Riverfront Park at Cocoa Village
Lady Lake – The Villages Polo Fields
St. Petersburg – North Straub Park

April 5, 2008

Sarasota – JD Hamel Park at Main Street

Team captains, start rounding up your teams! Register now by visiting the website at www.midfloridamswalks.org. You can start your fundraising before the New Year arrives. For questions about walkMS or registration, please email Jamie Elasick at jamie.elasick@flc.nmss.org or call 407-478-8880, option 2, x 29.

This is going to be the biggest year yet and we hope to see you there!



TeamMS Ken's Kuties from the 2007 Walk in Orlando at Downtown Lake Eola.



MS walkers receive their medals after crossing the Cocoa Beach finish line.

Put the Wheels in Motion to Find a Cure

Join the Bright House Networks MS Bike Tour

Everyone who participates in the Bright House Networks MS Bike Tour helps the Mid Florida Chapter support people living with MS, and helps fund research to find a cure. Some of our cyclists do it for the love of riding. Others do it for a friend or loved one. And there are those who join with co-workers. Among these cyclists are a number of inspirational stories, such as this one told by D. Bradley Romp.

In 2006, at the age of 45, my life changed forever. I was diagnosed with MS. The fact that I was diagnosed frustrated and angered me. Like many of us that are living with MS, I'm plagued with daily fatigue, vertigo, numbness in my legs, and pins and needles in my left arm. Due to my symptoms, my active lifestyle started to change.

I needed an immediate personal goal that I could attain. I simply couldn't imagine a better way to enhance my health than on my bike, and enjoying the benefits and enormous satisfactions of riding my bike under my own power speaks for itself. In April 2007 I participated in – and FINISHED – my first MS Bike Tour. The experience I had impacted me so powerfully that I'm determined to ride in many more MS Bike Tours for years to come. My experience with the MS Bike Tour has totally changed my attitude and has fueled me with hope, inspiration, and a purpose!

It is amazing how many people who know me come up and ask, "How can you even think about riding 50-100 miles a day with your health?" I just laugh and say, "Having MS is like running multiple marathons every week. Surely I can handle a few miles on a bike for the MS Bike Tour!"

Participating in the MS Bike Tour is a positive family activity for everyone. Most importantly, the MS Bike Tour is a way to show others who affected by MS that there is hope for each and every one of us.

Bradley became a Top 10 fundraiser for the 2007 MS Bike Tour, and he recently joined the bikeMS Ride Committee for the 2008 ride. He resides in Tampa with his wife and two sons.



Giving the photographer a wave, Bradley makes riding 150 miles look effortless.

Help us Keep our Promise: 2010

Helping those affected by MS meet their day-to-day needs is a major focus and objective of the National MS Society. But our ultimate goal is to find a cure for this disease. So just as we're committed to helping those who need us today, our organization is committed to helping fund long-term research areas that may hold the key to finding better treatments and ultimately, a cure.

Promise: 2010 is a nationwide initiative established by the National MS Society with the goal of raising over \$32 million by the year 2010. These funds will only be used to support MS research. Each Chapter in the country has pledged to raise a portion of that \$32 million goal.

The Mid Florida Chapter's pledge commitment is \$250,000. We need your help to make this pledge a reality. Please consider making a donation directly to our Promise: 2010 campaign in order to help fund the following four vital research areas.

Nervous System Repair and Protection

The largest grants ever offered by the Society set the stage for translating basic lab research into clinical efforts to restore nerve function in people with MS.

The Sonya Slifka Longitudinal MS Study

This study is a repository of in-depth information about the lives of people with MS. Data is compiled to learn the effects of MS over time and what factors influence the long-term course of MS.

Pediatric MS Treatment Centers

The National MS Society is establishing regional pediatric MS centers to set the standard for pediatric MS management and care, to offer optimal medical and

psychosocial support to children and their families and to conduct research to better understand pediatric MS.

The MS Lesion Project

This international collaboration seeks patterns in the MS damage seen in brain tissue and attempts to correlate those findings with actual clinical signs, symptoms, and response to therapy.

For more information or to make a contribution to Promise: 2010, please contact Tami Caesar, President NMSS Mid Florida Chapter, by calling 1-800-344-4867, option 2, ext. 25, or emailing tami.caesar@flc.nmss.org.

Contributions can be mailed to: NMSS Mid Florida Chapter, 2701 Maitland Center Parkway, Suite 100, Maitland, FL 32751. Please write "Promise: 2010" in the memo area of your check.

WORKPLACE GIVING

Fight MS without leaving your desk

Designate the National MS Society during your workplace giving campaign.

For a full list of workplace campaigns that include the Mid Florida Chapter of the National MS Society, please visit our website at www.nationalMSSociety.org/flc or call us at 1-800-344-4867, option 2.



If You or Someone You Know Has MS

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 multiple sclerosis. Talk to your health care professional or contact the National MS Society at www.nationalmssociety.org or 1-800-344-4867 to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

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

The National Multiple Sclerosis Society is dedicated to ending the devastating effects of MS.

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SAVE THE DATE



PUT ON YOUR WALKING SHOES



walk to
create a world
free of MS

WALK LOCATION

Orlando, Lake Eola at Thornton Park

Tampa, Tampa's Lowry Park Zoo

Cocoa, Riverfront Park at Cocoa Village

Lady Lake, The Villages Polo Fields

St. Petersburg, North Straub Park

Sarasota, J.D. Hamel Park

"We will" walkMS

Visit www.midfloridamswalks.org, or call 1-800-344-4867, option 2, ext. 29 for more information, or to register.

DATE

March 15, 2008

March 15, 2008
(evening walk)

March 29, 2008

March 29, 2008

March 29, 2008

April 5, 2008

Select any date in March and walk in your community.

Address or Name Change?



If you are receiving duplicate mailings, wish to be removed from our list, or if you need to update your name and contact information, please contact Kathy Alt at (800) 344-4867, option 2, x 23 or kathy.alt@flc.nmss.org. In addition, if you are receiving an electronic newsletter through your email and wish to be sent a hard copy of the newsletter instead or if you are receiving a hard copy and wish to be sent an electronic version, please send us your email address with your preference to kathy.alt@flc.nmss.org.



**National
Multiple Sclerosis
Society**

Mid Florida
Chapter

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