

CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Fall 2007

Mid Florida Chapter



Mid Florida Chapter to Host Rain Pryor at Day of Discovery

Rain Pryor will be the featured guest speaker at the 10th Annual Day of Discovery at SeaWorld Orlando, Sunday, December 2.



Rain Pryor is the daughter of groundbreaking comic legend Richard

Pryor, whose relentless battle against MS ended in 2005. An accomplished actress and comedienne who enjoys success on stage and television, she wrote the autobiography, "Jokes My Father Never Taught Me: Life, Love, and Loss with Richard Pryor" (HarperCollins).

Rain considers her work as an MS Lifelines Ambassador (sponsored by Serono Biotechnologies) to be her most important role. Rain's commitment to fight for a cure for MS has her speaking around the country to educate people about treatment options and therapies.

Due to the popularity of the program, a lottery system for participant selection has

been instituted. The 10th Annual Day of Discovery will begin at 8 a.m. at SeaWorld Orlando Ports of Call, 7007 Sea Harbor Dr., Orlando, FL.

Please check our website, www.nationalmssociety.org/flc, to enter your family in the lottery. Click on the icon SeaWorld Lottery. The Lottery deadline is November 2.

walkMS 2008

walkMS 2008 is just around the corner. Visit www.midfloridamswalks.org for more information.

CONTINUED ON PG 3

INSIDE THIS ISSUE:



Get Walkin' Page 9



Doris Oram Page 12



Community Events Page 17



William Oliver Page 20

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PRESIDENT'S IMPRESSIONS

I believe that people affected by MS are often eager to help others. Visit our offices in Tampa or Maitland and you are likely to meet **Bob, Connie, George, Grace, Nayda, Judith or Shane**. These caring volunteers use their special talents and skills to help others.



Tami Caesar
Mid Florida Chapter
President

Throughout our Chapter's 23 counties we have amazingly warm and compassionate volunteers like **Bud, Kevin, Gabie, Jeff, Rodney and Kelley**, who turn their time and precious energy into a labor of love for others by leading self-help groups and building local MS communities.

There are also many volunteers who put their own personal stamp on how to help the cause. They host golf tournaments, dances, masquerade balls and auctions in their home towns and donate the proceeds. **Paul, Steve, Mark, Beth, Valerie, Tammy, Tommy, Carol and the Felder Family** have fun while they contribute to our mission.

Day after day I meet people who want to stop MS. They ask, "How can I help?" Barbara Bush put it best when she said, "Some people give time, some money, some their skills and connections, some literally give their life's blood. But everyone has something to give."

We know that there are many ways that people living with MS and their loved ones can channel their energy, enthusiasm and talent. What is your passion? How do you want to contribute? What is your personal brand of MS activism?

I can envision a cadre of thousands of **MS Activists** making significant progress in the fight against MS. We have a spot for you. **Join The Movement!**

A handwritten signature in black ink that reads "Tami".

Rain Pryor cont. from cover

“It’s important to me to be out there and be an advocate for families and loved ones dealing with MS, because there are treatments and resources available.”

Actress, Singer, Writer, Producer and MS LifeLinesSM Ambassador. The daughter of legendary comedian Richard Pryor, Rain Pryor is an acclaimed actress, singer, writer and producer in her own right. She currently is touring her highly praised one-woman show “Fried Chicken & Latkes,” which shares her view of growing up as the conflicted daughter of a celebrated black father and a Jewish mother. Rain completely wrote, created, and co-produced the show, adding in her own original music and lyrics to the production.

Critics have hailed her singing voice and sense of timing as rare gifts. Rain was honored as a Los Angeles Times “Critics Choice” and won the 2005 NAACP Theater Award for best female performer equity. She was named recipient of the 2005 Invisible Theatre’s Goldie Klein Guest Artist Award, and in 2004 was nominated for best solo performance in the Los Angeles version of the Tony Awards called the Ovation Awards.

Rain wrote a book about her life called “Jokes My Father Never Taught Me,” and currently is in pre-production for the film version of “Fried Chicken & Latkes.”

Rain has been a working actress all her life. She started on stage and made her television debut in 1989 as series regular T.J. on the hit

ABC series “Head of The Class.” Rain also starred for several years opposite Sherilyn Fenn and Lynn Redgrave on the Showtime series “Rude Awakening.” She has guest-starred on hit shows such as “The Division” and “Chicago Hope” (with her father), and has been a guest on “The Tonight Show with Johnny Carson,” and, years later, on “The Tonight Show with Jay Leno,” as well as on “The Late Late Show with Craig Ferguson.” She also has appeared on the big screen in “The Grinch Who Stole Christmas,” “Panther” and numerous independent films.

On stage, Rain performed in the Los Angeles production of “The Vagina Monologues,” and she has showcased her talents in plays all across Los Angeles, including: “Cookin’ With Gas,” with the Groundlings improvisation troupe; the Who’s “Tommy;” the starring role of Joan in “West Side Story” and “Runaways.” Rain received acclaim for her singing and acting in Michael Jackson’s “Sisterella,” which earned her a nomination in 1994 from the NAACP Theatre Awards for best supporting actress in a musical. She is married and lives in Los Angeles.

Rain serves as an MS LifeLines Ambassador, traveling the country to share her experiences with her father’s battle with multiple sclerosis.

MS Activist—a vigorous advocate dedicated to bringing an end to the devastating effects of multiple sclerosis.

Ask medical questions on Curbside.MD

There's a new medical search engine—Curbside.MD—that lets you enter medical information, details about a condition, and full questions—even paragraphs. The more the better! You don't have to limit a search to one or two words or phrases.

The site searches the best medical databases for articles. What you get is a "Results Summary Page" organized into user-friendly categories. **Quick Consult** lists articles that give a broad overview of the topic (good if you want to learn more). **Best Evidence** provides in-depth articles for experts. **Best Hits** presents the most relevant results resources. Try www.curbside.md. It's free.

Virtual gathering for "Real Talk. Real Answers."

- Trying to have a normal social life without MS getting in the way?
- Wondering what to do when you're tired and your friends don't get it?
- Thinking about telling people at work that you have MS?



living with ms in your 20s and 30s

Join us—for real!

If you're young and living with MS, take part in some candid conversation at the upcoming sessions of **Real Talk. Real Answers. Living with MS in Your 20s and 30s**. The series, sponsored by the Society and MS LifeLines, will be broadcast live on the Society's Web site.

Relationships: family, friends, and significant others

Tuesday, September 25 at
7:00 p.m. ET; Live in Atlanta, Georgia

Building a career path with MS

Saturday, November 3 at 10:00 a.m. PT;
Live in Los Angeles, California

Each event will have a moderator, an expert presenter, and a group of young adults with MS for an interactive panel discussion. Viewers who register for the webcast can send in questions and get answers in real time.

Attend—no matter where you live!

Visit RealTalkRealAnswers.com to learn how to join the discussion wherever you are. Registration is free. Can't make the event? The webcast will be posted on realtalkrealanswers.com.

This program is sponsored by the National MS Society and MS LifeLines, a free resource sponsored by EMD Serono and Pfizer.

OnStar needs you

The National MS Society and General Motors are looking for lost people with MS! Or rather, people who would have been lost but used the OnStar safety and security service to help them out while on the road. The story may be used by the Society and/or General Motors to highlight how innovative products like OnStar touch the lives of people with MS. To share an experience, please e-mail Virley Gottfried at virley.gottfried@nmss.org.

General Motors has a longstanding relationship to the Society, including the GM National team (participating in multiple events), which last year raised \$144,420 for Society services and research.

MS activists ready to move

More than 90% of people responding to a survey by the Society's Public Policy Office last May said they would like to be more involved in MS advocacy activities. The survey was sent 14,000 people who have signed up for the MS Action Network. About 2,100 people—one in seven—responded.

The survey asked respondents about issues they found most important, tools they could use to be more effective activists, and their level of participation in MS activism.

Ready to move

Many said they would attend a town hall meeting, a rally, or write a letter to the editor.

Nearly a quarter said they were willing to post information about MS issues on their blog, in chat rooms, or on a Web page. Many MS activists already do.

These are all easy ways to join the movement. Anyone can be an MS activist without leaving town, or even without leaving home.

About the MS Action Network

The MS Action Network is a nationwide group of thousands of MS activists who stay informed on MS issues and take action when necessary. To find out about getting involved, visit nationalMSSociety.org/advocacy.

The ultimate in advocacy: Vote!

General elections will be held November 6, 2007. Get ready **now**:



1. Visit the U.S. Election Assistance Commission's Web site (www.eac.gov) to access the national voter registration form and information about voting regulations in every state.
2. Contact your local board of elections to find out if your polling place is accessible and what devices are available for people with low vision, poor manual dexterity, or anything else that could interfere with voting.
3. If your polling place lacks accommodation, request changes or ask for reassignment to a place that meets ADA guidelines. These guidelines are online at www.ada.gov/votingchecklist.htm.
4. Some voters with disabilities opt for an absentee ballot. Some states have deadlines for these applications. Go to www.vote411.org and click on **Absentee Voting** for information.

No Internet? Call **1-800-344-4867** and ask for an MS Navigator.

Get your word out

Every day, MS activists all over the country are at work educating policymakers about public policy of great importance to people with MS. Now you can read about what these activists are doing, and add comments and links of your own, at MSActivist.blogspot.com.

The blog is updated frequently. Visit often and let your voice be heard.

Society funds major clinical trial of sex hormone

Neurologist Dr. Rhonda Voskuhl (UCLA) is leading a team of researchers at seven medical centers to conduct a two-year, controlled clinical trial of estriol, a female sex hormone, added to standard therapy with Copaxone (glatiramer acetate, Teva Pharmaceutical Industries Ltd.) in 130 women with relapsing-remitting MS. The trial is currently recruiting participants.

This study is being funded by the Society in partnership with the Society's Southern California chapter and the National Institute of Neurological Disorders and Stroke.

The role of hormones in MS

MS affects women two to three times as often as men. This and other gender differences spurred the Society to launch a research initiative into gender in 1998. Fifty projects supported through this \$10 million initiative followed.

Among the findings was the possibility that estriol may help protect against the immune attacks that underlie MS. Estriol levels rise significantly during pregnancy, when disease activity declines in most women with MS.

"We are very enthusiastic about this new agent," Dr. Voskuhl said. "Estriol has decades of human safety experience throughout Europe, and it will be given as a pill, not a shot."

For more information about this trial, visit nationalmssociety.org/EstriolTrial. To read about the Society's gender initiative, visit nationalmssociety.org/Gender. If you don't have access to the Internet, call us to have the information sent to you.



Major trial for secondary-progressive MS treatment launched

BioMS, which makes MBP8298, launched a phase III clinical trial this June to test the drug in more than 500 people with secondary-progressive MS. Positive results from a phase II trial and long-term follow-up were recently published in the **European Journal of Neurology**.

MBP8298 is a synthetic myelin basic protein fragment, or peptide. Researchers believe it may make the immune system of people with MS tolerant of myelin.

For more information about the trial, including information on participating, visit clinicaltrials.gov/ct/show/NCT00468611.

True or False?

The National MS Society only provides grants to support research of already successful therapies.

FALSE. Research is about discovering things we don't know—as much as it is about verifying what we think we know. The Society is funding clinical trials of experimental treatments for MS, such as sex hormones (see page 6), and more, including 30 special “high-risk/high-reward” pilot grants to explore new and untested ideas. For more information on Society-funded research, visit nationalmssociety.org/FundedResearch.

The Society is currently working across borders with researchers in Canada and other countries.

TRUE. The movement to end MS is global, and the Society has long been involved on an international level funding research projects all over the world including, most recently, Australia, Cyprus, France, Germany, Israel, Italy, and the UK. To learn more about research the Society is funding worldwide, visit nationalmssociety.org/InternationalResearch.

The National MS Society's Web site only reports research conducted in the USA.

FALSE. As part of its global outlook and commitment to the bigger picture, the Society posts MS-related study results from all over the world at nationalmssociety.org/Bulletins.

The National MS Society's Web site doesn't report information about research into alternative and complementary medicine.

FALSE. Whether yoga classes, ginseng supplements, or acupuncture, recent studies

show that about 75 percent of people with MS use some form of alternative or complementary medicine. For that reason, the Society reports on the latest results of studies on stress management, herbal and nutritional supplements, reflexology, and other complementary and alternative medicines.

The Society does not support research into progressive MS.

FALSE. Since its inception, the Society has been actively involved in supporting studies related to progressive MS. The more than 380 research projects currently funded by the Society explore virtually every aspect of MS, as well as more basic research into nervous system development and repair and the workings of the immune system. To read about projects specifically focused on progressive forms of MS, go to nationalmssociety.org/ProgressiveMS, then scroll down and click on **Current Funded Research and News**. Or call us to have the information sent to you.

CLINICAL TRIALS

101



For information about clinical trials currently testing MS treatments, go to nationalmssociety.org/ClinicalTrials. This page includes a link to trials currently seeking participants as well as an explanation of trial phases, and news of results.

Call 1-800-344-4867 if you have no Internet access.

Adapted from “ADAPTING: Financial Planning for a Life with Multiple Sclerosis”

Here are some ideas to help get spending under control:

- Apply for all available programs for which you may be eligible, including VA benefits, Medicare, Medicaid, food stamps, state programs for low-income individuals, and pharmaceutical assistance programs offering lower-cost medications. (An MS Navigator can help. Call us.)
- Find a doctor you like and stay with him or her. Frequently changing doctors wastes time and money. (We can send names and our brochure, **Choosing the Right Health-Care Provider.**)
- Ask your doctor to write prescriptions for items you may need, such as a brace or a special bed. A prescription shows medical necessity, which makes it more likely that your insurance will reimburse you.
- Put away the credit cards—and only bring them out to pay for emergencies.
- Call your local housing authority or talk to your hospital social worker if you are having trouble paying your rent. Ask about “Section 8” programs, in which you pay part of the rent based on income, and the government pays the rest.
- If you do not make very much money, you may be able to use the Earned Income Tax Credit. This will reduce your taxes and may even result in a refund. You can claim this credit on IRS Form 1040. (Call the IRS for more information. The number is in the blue, or government, pages of the phone book.)
- If you have many medical expenses, you may be able to deduct them from your

income for tax purposes. Keep all of your medical bills, and all receipts for other expenses related to MS. These include mileage if you drive to doctor appointments and the cost of modifying your home. Show these receipts to your tax preparer.

For the entire 72-page book—*Adapting: Financial Planning for a Life with Multiple Sclerosis* visit www.nationalmssociety.org/financeguide or call us for a free copy.

Relationship Matters A Program for Couples Living With MS

Minimize the impact of MS on your life
Free classes for couples:

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

Each couple makes a personalized education plan with an MS Navigator. Options include:

Facilitated on-line chats
Topic-based teleconferences
Audio files for computer or iPod

Contact us:
1 800 FIGHT MS (1-800-344-4867)
or at couplesprogram@nmss.org

Relationship Matters when MS moves in.



Funding for this project was provided by the United States Department of Health and Human Services, Administration for Children and Families, Grant: 90FE009001.

Get Walkin'

by Dana Bard

Autumn: The kids are back in school and the crisp weather has set off your inner alarm clock: time to get out and get walkin'!

It's all about commitment—First things first: Decide how many times a week you'll walk and for how long—start small and stick with it. Fifteen minutes, twice a week for the first month; half an hour, three or four days a week after that. Write up a short contract, sign it, and hang it somewhere prominent.

Get the right shoes—The right shoe fits! It should provide arch support, cushioning, and compensate for any stride problems you may have. If you're buying walking shoes for the first time, test them out in the store. Make sure they're flexible (can you bend and twist the shoe?), with a relatively flat, unflared heel. Walkers strike with their heels first.

If MS has made your gait less steady, consider shoes with leather rather than rubber soles, which may cause you to trip. If you have difficulty finding shoes with leather soles, your shoe repair shop may be able to add one on to an existing shoe, or sand down part of the sole.

It's not the destination—but a destination helps. Today I'll walk to the video store to return the Harry Potter DVD. Later in the week I'll walk to the convenience store for milk rather than driving to the supermarket. Mix it up!

Techniques to remember—Start and finish with a few minutes of gentle stretching. As you walk, keep your chin up and your shoulders back. Swinging your arms will increase the intensity of your walking.

Play it safe—Avoid paths with uneven pavements/sidewalks. If you need balance

(continued on page 10)



Face of MS is a winner

The Society's **Face of MS** Web site has won a **2006 INSIGHT Award of Excellence** from the National Association of Film and Digital Media Artists. The annual award is given to individuals, businesses, and organizations that have increased public awareness—through film and digital media—about issues that affect our world.

Visit **FaceofMS.org** where people share their MS experience and others learn about what it means to live with MS. If you haven't sent your story, do so! You can submit text, photos, and video. Easy how-to instructions are on the site. Or "post your thoughts" (on the top menu bar). Check in regularly and tell others about it. New stories are posted daily.

("Get Walkin' continued)

support, talk to your physical therapist—and walk easy with a cane or walking stick.

Never forget—Water, personal identification, a cell phone, keys to the house.

Always wear—Sunscreen! Consider a hat with a brim.

Sorting it all out—For me, walking alone is the perfect time for meditation, contemplation, or to work out problems I don't have time otherwise to think about.

Walk with a friend—Occasionally I'll walk with Joyce, who lives across the street. She has a spring in her step, a smile on her face, and a positive attitude—valuable traits in a walking partner. Walk buddies keep each other motivated.

Discover a trail—Visit TrailLink.com and search their online database to find a trail near you.

Join a walking club—Visit the American Volkssport Association's Web site, www.ava.org, to find walking events, clubs, workshops, and special programs. Or call **800-830-WALK**.

Mall walks rule—When there's rain or sleet, or blistering heat, I drive to the Ridgemont Mall for a temperature controlled environment. No stops at the food court.

Keep walkin' and you'll be ready for next year's 2008 MS Walk. Call us for details or visit nationalmssociety.org/Walk to register, learn about setting up your own Walk team, or sponsor someone with a pledge.

JOIN THE MS MOVEMENT WITHOUT LEAVING YOUR DESK.

The National MS Society has been at the core of virtually every major breakthrough in treating and understanding the disease during the last 60 years....while supporting those affected by multiple sclerosis.

Show your commitment to a world free of MS through workplace giving. Donations can be automatically deducted from each paycheck and sent directly to the National MS Society. Just designate the National MS Society in the Combined Federal Campaign or ask about supporting the National MS Society through your company's employee giving program.

Designate CFC #11409 and join the movement.

A Proud Member of
 Community
 Health Charities®
 WORKING FOR A HEALTHY AMERICA

CFC #11409


 National
 Multiple Sclerosis
 Society

My Decisions workbook

Teaming up with your **Healthcare Providers** is available on our Web site at nationalmssociety.org/mylifeworkbook or by calling us for a copy. This is the first segment of four **My Life, My MS, My Decisions** workbooks—for newly diagnosed people and everyone else. The need to make decisions can occur at any time in life with MS.

Based on experience

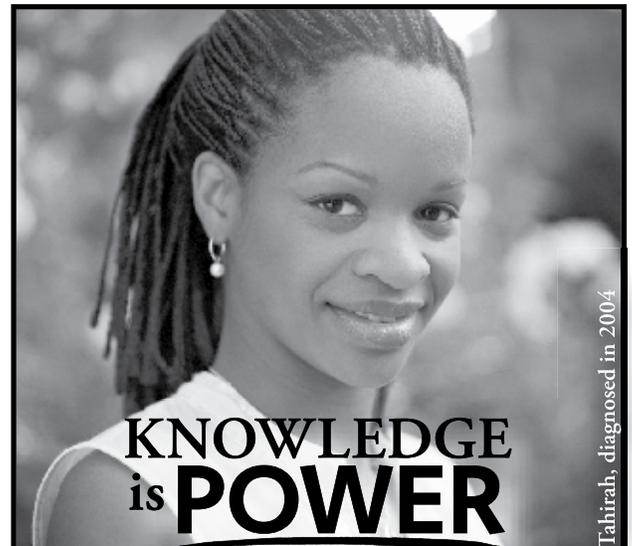
This workbook, focused on how to work with physicians and therapists, was written by Karen DeJoe, DO, a doctor who has had MS for over 10 years. She blends her experiences as a professional and a person with MS in discussing practical techniques for getting the best out of these important relationships.

The workbook presents case histories of real people with real problems giving users an opportunity to work out solutions to their issues. It also has sample letters, record-keeping forms, and an impressive list of resources for trustworthy information on MS.

Future segments in the **My Life, My MS, My Decisions** series will focus on treatments, clinical trials, and wellness.

Dr. DeJoe is a physician consultant for the National MS Society and the Central New England Chapter and is writing a book about the lessons she has learned through having MS.

Biogen Idec, Novartis Pharmaceuticals, EMD Serono and Pfizer, and Genentech provided unrestricted educational grants to support this program.



KNOWLEDGE is POWER

Tahirah, diagnosed in 2004

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.



National Multiple Sclerosis Society

Time to tell your boss you have MS?



Stop; breathe! Before your meeting ... get technical advice. There is much at stake. You need facts about the ADA (Americans with Disabilities Act) and advice about the kinds of accommodations that have worked well for other people with similar problems.

We also think you'll need some psyching up—just as you do for telling people in your personal life. The National MS Society wants to be your ally in this process. Call us.

Excerpt from **Disclosure: the Basic Facts**, a National MS Society brochure available on our Web site at nationalmssociety.org/Disclosure, or call us.

Scholarship Winners

In June, the Mid Florida Chapter awarded scholarships to 12 college-bound recipients.

Though these 12 recipients are diverse in many ways, with different goals and backgrounds, they all share something in common: they have all been affected by multiple sclerosis. Each student has a parent living with MS, and has spent most of his/her childhood accommodating the effects of this disease. The Mid Florida Chapter congratulates these remarkable students and wishes them all the best in their future academic endeavors. To read more about our scholarship winners, please visit the Mid Florida Chapter's website at www.nationalmssociety.org/flc and click on the scholarship icon.



Wendy Piesco, Palm Bay

University of Central Florida, Pre-Med (Doris Oram Memorial Volunteer Scholarship)

As a child, Wendy Piesco considered her mother a real-life Wonder Woman. Despite her busy schedule as a Registered Nurse, Wendy's mom had energy to spare. All that changed when Wendy was 10 years old and her mom was diagnosed with MS. Suddenly taking on adult responsibilities, Wendy dedicated herself to help her mom's recovery in every way possible. The two are now active MS volunteers.

"It took her years to go from a wheelchair, to a walker, to a cane, and, finally, to walk without aid. Watching her recover taught me faith, hope and responsibility. Together we aided others in seeing that hope can conquer anything. It will affect my life forever, and I will never forget what I have learned. I will never take my wonder woman for granted again."

The Doris Oram Memorial Volunteer Scholarship

This is the inaugural year of the Doris Oram Memorial Volunteer Scholarship, named in memory of Doris Oram – a longtime volunteer of the Mid Florida Chapter who dedicated her life to helping others. She passed away in September, 2006. To honor her generous spirit and commitment to service, the Mid Florida Chapter will present an annual scholarship to one student who exemplifies volunteer leadership throughout their high school career.

Doris spent countless hours working on special events and programs for the Mid Florida Chapter. No matter what the task, she was there with a smile and the motivation to get the job done. Doris was driven by her heart and passion for helping people, and wholeheartedly embraced the mission of the Mid Florida Chapter. We are honored to establish this scholarship as a living memorial to her.



Doris Oram

On a family trip to New York City.

Scholarship Winners cont.



**Rani Abad, Casselberry
Valencia Community College**

Rani Abad had long been familiar with fundraising activities to combat catastrophic diseases, but didn't have a personal connection until her mother

was diagnosed with MS five years ago. Attending the 2006 University of Central Florida MS Walk, she was moved by the many people supporting those with MS.

"The people who attended ranged from moms, dads, sisters, friends, etc. It showed that nobody had to do this by themselves. I must say that my favorite part... was to see my mom cross under the finish line once again. It gave me a sense of victory because she pulled through and finished off another challenging year."



**Ashley Bartlett, Longwood
University of Georgia,
International Relations**

Ashley Bartlett's family has twice been affected by MS. Both her mother and aunt were diagnosed within a short time of each other. With

her aunt also dealing with MS, Ashley saw a positive change take place in her family, as relatives pulled together to provide support for the two sisters and their children.

"It made them, and me, realize how delicate life is, and how we take those we loved for granted. MS, I thought, would be this unbearable kind of burden, an indestructible thing, and then, after awhile, it became a blessing. I never knew something quite like this would show my family and I so many good things about each other and how to live better lives."



**Tiffany Cole,
Safety Harbor
University of Central
Florida, Biology Pre-Med**

Tiffany Cole characterized her father as "one of those people who never stopped moving," and who had

always been there for her and her two sisters. But since his diagnosis of multiple sclerosis three years ago, Tiffany and her sisters have been there for him.

As MS has made his movements more limited, she carries on her dad's can-do attitude for him – for the man who would readily help anyone who needed his help, and who would do whatever needed to be done. Tiffany has gained an appreciation for "the simple things in life that we all take for granted."



**Kristin Hall, Longwood
University of Central
Florida, Business**

Kristin Hall can't remember a time when her mother didn't have MS. That's because her mom had already been diagnosed

when Kristin was born. Going through the past 18 years has been a great challenge for the family, but has yielded the unexpected rewards that come of loving hearts pulling together to overcome adversity.

"The truth is, I feel I have learned many things from multiple sclerosis. I have honestly learned to enjoy life to the fullest, and take nothing for granted. However, most importantly, MS has taught me mostly about love."

CONTINUED ON PG 14

Scholarship Winners cont.



**Kristy Long, Spring Hill
Pasco-Hernando County
Community College**

Although Kristy was only three years old at the time her mother was diagnosed with MS, she remembered how the active, outgoing mom she loved was left unable to walk.

Becoming a caregiver at an early age instilled in Kristy a strong sense of responsibility and the drive to succeed at every endeavor.

"I feel that I have gotten to show my true potential... Life has not been easy for me, but looking back, all these struggles have been part of making me who I am and into exactly who I would ever want to be: a nice, caring, loving person who loves life and learned to deal with anything that is thrown my way."



**Alicia Mossberg, Venice
University of North
Florida, Nursing**

When Alicia Mossberg learned that her mother was diagnosed with multiple sclerosis, fear and uncertainty became part of the eight year old's life for the first time.

After a long hospitalization followed by several years of determined rehabilitation, Alicia's mom has achieved her goal of reclaiming her active life.

Alicia has learned valuable lessons from her mom's undefeatable attitude. "...there may be unexpected devastating things that cross your path, but you can conquer them. What she has taught me is when you have a goal you have to work to achieve it. She is an amazing woman, and without her and her experiences through life ...I would not be the person I am today."



**Bernadette Ricard,
Wesley Chapel—Florida
State University, Media
Productions**

Multiple sclerosis has greatly influenced Bernadette Ricard's life since her mother's diagnosis.

The day-to-day uncertainty of how symptoms will manifest themselves or unexpected adverse reactions to new medications have taught Bernadette to take nothing for granted, and to identify with her mom's continual battle against the advance of MS.

"I hadn't learned much about MS in school until my senior year anatomy class, and even then only briefly. I think it would be a great benefit to many to learn about MS through curriculum. I would also like to see more people get involved through volunteering for MS Walks, whether by sponsoring or walking themselves. Maybe middle or high school students can have their own walk- or dance-a-thon."



**Eric Schubert, Palm Coast
Florida State University,
Communications**

One of Eric Schubert's earliest memories is riding on his father's electric scooter.

Diagnosed with MS 15 years ago, Eric's dad has fought to keep its symptoms in check, continue working and be actively involved with his family.

"I thought that my family was special, not different. Even though my Dad can't throw a football or build many things, he still shares his exceptional talents with me. While working on our car, he talks me through changing the oil and repairing a broken horn. Instead of playing catch together, we watch and track our favorite football and baseball teams. Has life been challenging? Yes, but as a family we try to never lose hope."

CONTINUED ON PG 15

Scholarship Winners cont.



Catlin Thompson, Palm Coast Flagler College, Graphic Design

Catlin Thompson's family always loved freedom and adventure. When she was seven years old, her family began a three-year journey traveling the United

States in an RV. Soon after settling down in Summerland Key, however, Catlin's mother was diagnosed with MS.

"Seeing my mother overcome her disease and still get the most out of life empowers me to do well and get the most out of my own life. I know that without the love and support of my mom I would never have graduated with honors, had the courage to choose my future or gotten acceptance to my first choice college. My mother and my family took a disease that would otherwise have been a curse and turned it into a blessing in disguise!"



Jessica Thompson, Belleview—Thiel College

Since being diagnosed with multiple sclerosis six years ago, Jessica Thompson's father has worked to control the symptoms and progress of the disease with medication, and

to stay as active as possible. His refusal to give in has been a constant source of inspiration to Jessica, who cherishes all that they are still able to share.

Jessica's family moved back to Florida from Pennsylvania for the health benefits of the state's warm weather, which lessened her dad's MS-related joint and muscle pain. Since then, she and her sisters consider every day a valuable gift. "Even if one day something happens to him, we'll always be there because no matter what, we're still family."



Richard Wilson, Seminole University of Florida, Engineering

Richard Wilson learned early in life about the impact that MS has on families. Through his mother's philosophy, "I have MS, MS does not have

me," Richard has been able to hit the curve balls that their dealings with the disease have thrown him.

"I entered high school with a driving motivation. I have done my best with the situation and can now say that I've achieved the goals I set for myself. I knew from an early age that life is not fair at times and that it can be difficult. MS has taught me a lot about life: the importance of compassion, hard work, and perseverance."

To learn more about these scholarship winners visit www.nationalMSSociety.org/flc and click on the scholarship icon.

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.



“Expressions of Activism”

ANNUAL MEETING

November 10
Celebration Hotel
Celebration, FL

The National Multiple Sclerosis Society Mid Florida Chapter’s 2007 Annual Meeting, “Expressions of Activism,” will be held November 10 at the **Celebration Hotel, Sabal Ballroom** in Celebration, FL from 11 a.m. to 2 p.m., with keynote speaker; Simon G. Gregory, PhD., of the Duke Center for Human Genetics. In keeping with this year’s theme, **“Expressions of Activism,” celebrates the unique talents of all who give back to the fight against MS in their own special way.** The meeting will highlight local artist William Oliver. Mr. Oliver expresses his activism by providing his art as a resource for MS fundraising activities to honor his late wife, Nancy Wooten Oliver, who battled MS throughout her life.

The Mid Florida Chapter is seeking nominations for the following award categories. To nominate an individual, business, corporate entity or foundation for any or all awards, please visit our website, www.nationalmssociety.org/flc, and click on the Mid Florida Chapter Mission Awards. Nominations are due by October 19.

Perpetual Idealist

Individual who embodies the mission of the National MS Society Mid Florida Chapter through activities such as fundraising and programs that raise awareness of MS within the local community.

Relentless Champion

Individual who advocates to meet the needs of the MS community for rights, assistance, research and other quality-of-life issues – can be on the federal, state or local level.

Proponent to the Cause

Individual who goes above and beyond proscribed volunteer duties to make an even greater positive impact in the MS community.

Breaking Down Barriers

Individual with MS who has achieved extraordinary accomplishments in personal and/or professional life.

Visionary

Individual or organization that organizes successful community awareness and fundraising events to benefit the Mid Florida Chapter.

Valiant Supporter

Recognizes companies and corporations that do one or more of the following: encourage volunteerism, lend their name to fundraising events, contribute in-kind and cash sponsorship, support the establishment of corporate teams, provide expertise and leadership for the Mid Florida Chapter, advocate for increased accessibility for people with MS, as well as fund programs and research for a cure.

Unparalleled Unity

Recognizes entities that work together for the mission of the Mid Florida Chapter – for example, businesses that collaborate for an event in which one business donates the venue, another donates refreshments and yet another donates a live remote broadcast.

Mid Florida Chapter Community Events

Numberous dedicated volunteers are hosting fundraising events throughout the year to benefit programs and services for the Mid Florida Chapter as well as fund research to find a cure for MS. 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 407-478-8880, option 2, ext. 22.

MID FLORIDA CHAPTER COMMUNITY EVENTS

September 21 & 22

West Pasco MS Silent Auction Extravaganza, hosted by The Crab Shack, 5430 Baylea Ave. Port Richey, FL, Friday starting at 7 p.m., Saturday starting at 2 p.m. Lots of games, live music, prizes and silent auction: (727) 843-8043.

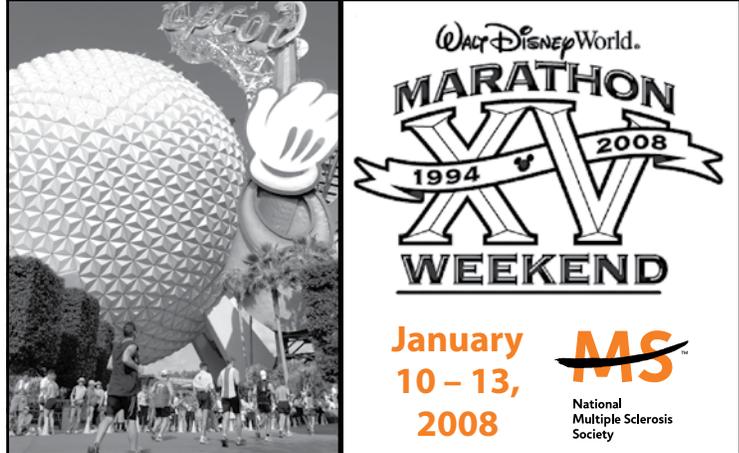
September 28 - 30

MS Crop for Hope, scrapbooking fundraiser, silent auction and raffle, The Courtyard Marriott, 4014 Tampa Rd., Oldsmar, FL 34677. Starts Friday at 3 p.m. and lasts until 3 p.m. Sunday, Jackie Durning, coordinator. (813) 265-4849, scrapnfla@hotmail.com.

October 6

Olympics at the University of Central Florida, field day activities are open to students, faculty, employees and alumni of UCF. Event is from noon to 5 p.m. Check out the Mid Florida Chapter's website for more details www.nationalmssociety.org/flc.

Marathon Strides Against MS



Join us for the Walt Disney World Marathon Weekend. Run or walk the half-marathon or full marathon.

Make the dream to end MS a reality by being a part of the fun!

Register online at www.nationalmssociety.org/flc or for more information, contact Phil Deal at phil.deal@flc.nmss.org or call 1-800-344-4867, option 2.



The National Multiple Sclerosis Society, Mid Florida Chapter Proudly Presents the

**16TH ANNUAL
MS PRO AM INVITATIONAL
Friday, October 19**

Location: Falcon's Fire Golf Club in Kissimmee, Florida

Time: 12:00 p.m. Shotgun Start

For foursome and sponsorship information call Phil Deal 1-800-344-4867, option 2 or email phil.deal@flc.nmss.org

Community Partner Spotlight

Ride-Away

In Florida, much of our ability to live independently relies on our ability to drive. People with limited mobility face special challenges. Fortunately, Ride-Away has made a tremendous difference through its dedication to providing transportation solutions for those who need vehicle modifications.

Founded in 1986, Ride-Away is the largest supplier of handicap-modified vehicles in the United States. The company specializes in modifying a wide variety of vehicle makes and models with adaptive equipment that allows optimum ease of vehicle entry and exit, operation, comfort and safety.

Modifications range from hand controls and lifts to raised-door and lowered-floor vehicle modifications.

Because each customer has very individual requirements for vehicle modifications, Ride-Away takes care to hire staff members who are adept at assisting in all aspects of the modification—for example, finding the right lift that fits both the wheelchair and the vehicle. Working within the budget of each customer is another company commitment.

Recognizing that the quality of life in its community directly affects the success of its business, Ride-Away has created a company culture that emphasizes giving back to the community. Its philanthropic commitment occurs on several fronts, most notably through corporate giving and employee involvement.

Ride-Away is a preferred provider of the Mid Florida Chapter and supporter of local programs and services. For more information on services, contact Forrest Bateman at (813) 628-4255.

FLORIDA AUTHOR JOINS THE MOVEMENT

Author Richard Goulding of Melbourne, FL, is donating proceeds from the sale of his new book, "Dead Man's Hand" to the National MS Society. Donations will begin immediately and continue through the remainder of 2007. Find full details on the author's fundraising efforts and purchasing the book on his website: www.deadmanshandbook.com

"Multiple Sclerosis has impacted millions of people around the globe. I commend the MS Society for taking action to gain victory over this illness and for sharing this victory with people around the world.

Thank you for offering me the opportunity to Join the Movement in helping to create this victory!"

– Richard Goulding

Volunteer Spotlight: Foresters

Members of Foresters (formerly known as the Independent Order of Foresters) have participated in the National MS Society Mid Florida Chapter's Bike Tour for numerous years. Some have even volunteered since the very first ride in our area – 21 years ago!

The Foresters look for opportunities to share their prosperity with their community and with their member's families. In doing so, members from several area Branches and Chapters have chosen to assist at MS events, particularly the MS Bike Tour. Participation included volunteering at numerous rest stops along the route and providing financial support to the event. Members who volunteer encourage and motivate the cyclists, as well as hand out snacks and refreshing drinks.

"As the Rest Stop Coordinator for the MS Bike Tour for the last five years, I was 'overwhelmed' by my first ride in 2003, and have been back every year since. I'm amazed at how large our Tour has grown, and continue to be blown away by the enthusiasm of all the cyclists, the countless volunteers (from families affected by MS, the medical staff, bike shops, the MS staff and others)," boasts Tony Wangryzht. "I'm glad to be part of this event as well as the MS family, and plan on continuing my family's involvement."

Mid Florida Chapter Mission Volunteers

Office Volunteers:

- Sofia Alvarez
- Nayda Cuevas
- Laurie Geving
- Shane Jackson
- Heather Nail
- Judy Ortiz
- George Rector
- Connie Sirignano
- Grace Vallier

Peer Counselors:

- Karen Henry
- Lisa Little
- Zulma Merced
- George Rector
- Connie Sirignano
- Bob Theisen
- Ingrid Von Thaden

Self-Help Group Volunteers:

- Mary Kay Bixby
- Art Bourgeois
- Judy Brown
- Nayda Cuevas
- Myra Cusella
- Diane Davis
- Vicki Dimaria
- Diane Howe
- Florence Foster
- Lisa & Gus Garcia
- Renda Gardner-Agnew
- Joanne Green
- Jeff Hamilton
- Judy Heath
- Joan Jaeger
- Dave Johnson
- Milcah Jones
- Kevin Kelley
- Deanna Khashan
- Kelley Klein
- Cheryl Lambert
- Bud Llewelyn

- Julie Manning
- Barbara Marchant
- Dolores Matthews
- Jean McGrail
- Rodney McIntosh
- Peggy Morisi
- Eileen Murray
- Michelle Pitch
- Judi Quinn
- Veronica Reddell
- Linda Reeves
- Joe Renshaw
- Michelle Romano
- Beth Satkowski
- Rita Schallenberger
- Kathy Schure
- Eileen Smith
- Marylin Tait
- Janet & Jim Turvey
- Michele & Ray Wages
- Gabrielle Walsh
- Elwood Ward
- Peggy Wilson
- Beth Ann Young

Chapter Mission Committee:

- Forrest Bateman
- Patricia Bobyrk, MHS, PT, MSCS
- Jackie Durning
- Deb Hamlin, RN
- Cathy Kerns
- Robert Lacey
- Joanne Nelson, Ph.D
- Patricia Pagnotta, ARNP
- Derrick Powell
- Lea Richmond
- John Tucker

William Oliver: Evolution Of Movement



Pictured are Michelle Turman, Executive Director of the Gulf Coast Museum of Art, William Oliver, Artist, and Tami Caesar, President of the Mid Florida Chapter of the National MS Society.

The Gulf Coast Museum of Art and the National MS Society Mid Florida Chapter partnered together to present the exhibit, **William Oliver: Evolution of Movement, July 28 through October 14, 2007.**

This first-time partnership between the Gulf Coast Museum of Art and National MS Society Mid Florida Chapter represents the effort of both to showcase the work of an influential American artist while raising awareness of multiple sclerosis. Oliver's late wife, Nancy Wooten Oliver, died of complications of MS. Two thirds of the approximately 200 people who are diagnosed with MS each week are women.

Born in Georgia, Oliver graduated from the Georgia Institute of Technology with degrees in science and architecture. His experience as an architect has greatly influenced and informed Oliver's career as a painter. Corporate and government architectural commissions include the acclaimed aesthetic enhancement of the Atchafalaya Basin Floodway wall at Morgan City and Berwick, LA.

William Oliver: Evolution of Movement, attests to his passion for contemporary art. His large abstract acrylic works are both colorful and spontaneous, representing a common theme: the evolution of movement. This exhibition honors Nancy – and Oliver's devotion to her – while calling attention to the cause of finding a cure of MS.

The museum and the National MS Society Mid Florida Chapter held an opening reception on July 27. Giclees of Oliver's acrylic works are on sale throughout the exhibit, which ends Oct. 14, with all proceeds going to both organizations.

The Gulf Coast Museum of Art is located at 12211 Walsingham Rd., Largo. Hours are 10 a.m. to 4 p.m. Tuesday through Saturday, and noon to 4 p.m. Sunday. Closed Monday. Phone: (727)518-6833.

Ask an Attorney:

What Types of Disability Benefits Are Available?

By: John V. Tucker, Esq.

QUESTION: My MS has gotten to the point that I do not think I can work any longer. What types of disability benefits are available to me?

ANSWER: Disability is not something that individuals choose. It chooses them. Evaluating the different types of disability benefits that might be available to you before you become disabled is important to do. The following are the most common types of benefits that might be available to someone working in Florida:

1. **Social Security Disability and SSI:** This is the most commonly known type of disability benefits. If you meet Social Security's requirements, you can receive a monthly benefit before your retirement age. Under the Social Security Disability program, the amount of assets that you have does not matter, and as long as you have worked enough and paid taxes into the system to be covered. The SSI is an indigent program with stringent asset tests. To qualify for benefits under either program, you have to prove that you have been unable to work for 12 months, or that you expect to be unable to work for 12 months. You will also have to demonstrate that your condition keeps you from working in the types of jobs you have done in the last 15 years, as well as other types of work depending on your age, your education, and your past work experience. There was an excellent article on applying for Social Security Disability in the April/May 2007 edition of Inside MS, called "Loosening the SSDI Knots."
2. **Short Term Disability:** Typically, Short Term Disability ("STD") is something that

workers have through their employer. Benefits typically run for 6 months or less, and often the amount of benefits is a percentage of your salary. STD is usually paid if a person is not able to do their own occupation. However, one has to look at the specific language in the policy to confirm the actual definition of what entitles a person to disability benefits.

3. **Long Term Disability:** There are usually two different types of Long Term Disability ("LTD") benefits. One is insurance that you purchase on your own, often referred to as individual disability insurance. The other is through an employer plan. Individual disability insurance is covered by State law, and employer sponsored insurance is covered by ERISA, the Federal Law regulating employee benefits. Hopefully, you have purchased individual disability insurance in addition to the group benefits you may have at work. The reason for this is that State law has more protections for the insured person than the Federal ERISA law.

Under either type of LTD coverage, the actual definition of disability in the plan or policy describes what you have to prove to get benefits. LTD benefits are often paid based on your inability to do your own occupation, but more and more plans and policies are limiting that to the first two years of benefits. After that, they convert to what is called "any occupation" coverage. To get benefits under an "any occupation" policy, you have to prove that there is no job that you are able to do. This includes simple jobs like taking tickets at a movie theater.

That does not mean that you should avoid group coverage through your employer.

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If that is all that is available to you, you should certainly sign up for it. In fact, individuals with multiple sclerosis who have the chance to increase their coverage at work without any underwriting (i.e., answering questions about their health), should maximize the amount of coverage they have. Typically, once an individual is diagnosed with MS, it is too late to buy individual disability insurance coverage.

4. **Pension Disability:** If you participate in an employer provided Pension plan, you may be eligible to apply for an early disability pension. Instead of having to wait until age 55 or later under the terms of your plan, you may be able to draw an early pension at a reduced rate because of your disability. If you work for the state government, many county governments, or the local Sheriff's office, you may participate in the State of Florida Retirement system which has a similar benefit.

Keep in mind that many disability insurance policies and employee benefit/pension plans require you to apply while you are still an employee. This means that you must obtain application paperwork and apply before you quit or get fired. It may take many months to get approved for some of these benefits. If you can, try to have a cash reserve to meet your living expenses while you are waiting to be approved.

Applying for disability benefits is a difficult choice. It is a good idea to arm yourself with as much information as possible before you have to make that decision. Maximize the amount of coverage that will be available to you, and learn what it will take to qualify for the different types of benefits that you may have available. Consulting with an experienced disability attorney before you file your application may save you thousands of dollars in lost benefits. Although it is a difficult choice, you do not have to make this type of

decision alone, and you can be prepared for the day you are faced with not being able to work any longer.

John Tucker is a disability attorney with the Clearwater, Florida law firm of Tucker & Ludin, P.A., a preferred provider and member of the Chapter's Mission Committee for the MS Society Mid Florida Chapter. Mr. Tucker's practice includes Short Term and Long Term Disability, Pension Disability, Social Security Disability, and Veterans Administration Disability claims and litigation. He can be reached at tucker@thedisabilitylawfirm.com

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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Congratulations Friends of Hope MS Walk Team!

The Sarasota-based Friends of Hope MS Walk Team raised more than \$19,000 for the 2007 MS Walk season, making them this year's top MS Walk Team. Led by Team Captain Deanna Khashan, this 54-member Walk Team originally set its fundraising goal at \$5,000, then increased it to \$9,000. Before Deanna knew it, they were well on their way to over \$10,000!

Part of Deanna's competitive advantage is the fact that she's been participating in the Walk for the past seven years. Friends of Hope has been a team for five years, thriving even more with each succeeding season.

Mid Florida Chapter staff traveled to Sarasota to congratulate Friends of Hope. "It was truly a pleasure to be a part of their well-deserved celebration and listen to their thoughts and comments on fundraising efforts and plans for next year. Their successful fundraising style and enthusiasm serve as a tremendous inspiration for us all," boasted Walk Manager Jamie Elasick.

Honored to be the Captain of the top fundraising MS Walk Team of 2007, Deanna is very proud of Friends of Hope. Her competitive edge will keep Deanna and her team members motivated as we move into the 2008 Walk season.

"I do like the enjoyment of being Number One, but that is only because it is for such a great cause," Deanna said. "It means so much to get us closer to a cure."

Thank you Friends of Hope and all of our Teams who came out to Join the Movement in the 2007 MS Walks!

Just Around The Bend

For many, the MS Bright House Networks Bike Tour is an opportunity to get on the bike and put in some miles. For the 73,000 people affected by MS in Central Florida alone, it's so much more. The efforts put forth by cyclists, sponsors and volunteers change lives, and because of those efforts we are on the verge of a huge breakthrough.

After three decades of work, scientists have identified two human genes that can cause MS. By finding these two genes, researchers can now develop new drugs that could block the disease before it starts. It's a very exciting time for MS research. Just think, in the early 1990s MS was a disease that had little, or no treatment available. In just these few years, scientist, and researchers have made great strides in learning about and treating this disease. Imagine what they will be capable of during the years to come.

We are on the precipice of finding new treatments, new ways of thinking about the disease, and finally a cure. We are so close to doing what others have yet to do; so close to ending this fight, but we need your help to take the next step. Be a part of the 2008 MS Bright House Networks Bike Tour, whether you ride or volunteer: Join the Movement against MS.

In the coming years, we may not need to walk to raise funds and awareness, or ride our bikes 150 miles to raise funds. We will be walking and riding in celebration: the celebration of knowing that we made a difference, the celebration of a cure.

Until then, we will ride, and we will walk. We will do whatever it takes to make this dream a reality. Until then, there is the National MS Society. Join the Movement!

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.**

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.



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