

CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Summer 2008

Mid Florida Chapter



50 YEARS OF ACTIVISM

This summer marks the 50th anniversary of the National MS Society Mid Florida Chapter's formation. Over these five decades of activism, the Chapter has grown to serve a 23-county territory, offering programs and services to some 70,000 people with MS and their families.

For a look back on our Chapter's history, we turned to two long-time members. Dr. Peter Dunne, chair and professor emeritus of neurology and medicine at University of South Florida, and Ocala resident Arthur Bourgeois recalled the challenges they encountered some 25 years ago when they first became involved with the Chapter.

Dr. Dunne, who has chaired the National MS Society's Clinical Advisory Committee at both the national and chapter levels, said, "Our biggest challenges were financial and

membership. When I became involved in 1983 with what was then the Tampa Chapter, it was in financial disarray. Through appropriate financial management and consolidation of the Tampa and Orlando Chapters, we were able to overcome that which helped greatly with the second challenge; members weren't getting much from membership. This was in part due to an overall lack of understanding in both the general and medical communities about the disease."

Arthur Bourgeois agreed. Diagnosed in 1983, he recalled that he was told at the time to go home and get his affairs in order because he had five years to live. "There was no money at the national or local levels, and because of that, the MS Society had a very limited ability to get information out," he said.

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PRESIDENT'S IMPRESSIONS

In 1958 a group of Floridians decided to put together a grassroots effort to help people struggling with MS in Florida. This year we mark the 50th anniversary of the formation of our local Chapter of the MS Society. With the support of our incredible volunteers, that grassroots effort continues to grow, allowing us to provide more services and programs each year.



Tami Caesar
Mid Florida Chapter
President

In this tough economic climate, people need the services we provide more than ever. Our Quality of Life Assistance Grant Program has already exceeded last year's total and this year's budget allotment. Regardless, the Board and the staff are committed to continuing to provide support. We are here for you.

In response to the overwhelming need, our Board of Trustees has taken on a new grassroots fundraising initiative. This fall will bring 50 Celebrations in 50 Days, a series of house parties and private fundraising events hosted by individuals and/or companies.

Just as no two people with MS are affected the same way, no two parties will be the same. Whether it's a backyard barbecue, a costume party, a cocktail party, a wine tasting or a scavenger hunt, I know the creativity our volunteer hosts will make this campaign a success as together we celebrate getting closer to finding a cure for MS.

Enjoy the summer and lets all keep working together to keep the momentum going.

Yours,

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

Be Cool Tricks

If you are newly diagnosed, you may be new to the impact heat has on many people with MS. (To learn why, visit nationalMSSociety.org.



Cooling Vest
(Silver Eagle
Outfitters)

Type “heat” in our search feature.) But can you still be cool as a cucumber? You bet.

Body coolers can help you beat the summer heat smackdown. Here are just a few you can find online:

Silver Eagle Outfitters (silvereagleoutfitters.com) offer an item called the “Dew Rag” (\$16), a cooling head wrap that looks good on its own or even fits under a bike helmet. If you’re gardening or just lazing on the porch, check out the cool brimmed summer hat and vest at Polar Products (polarsoftice.com) for \$110. The hat uses the evaporation method; the vest fits gel packs. Polar also

offers a gel-pack-loaded “Cooling Seat Pad” ready to go with you on your scooter or to cool you off at your desk.

Steele Body Cooling Comfort Systems at steelevest.com has a \$10 gel hat cooler you can stick under almost any headgear; they also have gel bra coolers for \$10 and neck scarves that can be filled with cold water.

You can also get wrist, ankle and foot coolers ranging from \$12 to \$25 at coolbandcity.com and polarsoftice.com.

Hold down your costs and keep your cool with a little ingenuity. Freeze plastic bottles of water. Wrap in a towel to make cool packs and drink once the ice has melted. (Leave a few inches of empty space at the top, because ice needs more room than water.) Carry a squirt bottle of water for a cool mist as needed. Before going out, get into a bathtub of cool water. The water should be comfortably lukewarm to start. Then add cooler water as you soak.

Be Cool with No-Cook Meals

Baby, it’s hot outside! Keep it cool inside by **not** cooking. The Internet offers a cornucopia of ideas for no-cook meals.

- Myrecipes.com has a wide selection of no-cook menus. Scroll down to “Easy ways to find recipes” and plug in “no-cook.”
- A search for “no-cook” on Epicurious.com brings lots of mouthwatering results, but check that they don’t require any preparatory cooking. It’s easier to look under Epicurious’ “drinks” section, where you’ll discover unusual options like Cucumber-



Lime Agua (or Blackberry-Thyme Margaritas if you like your drinks with a kick) that at most require a stint in the freezer.

- Foodnetwork.com has an entire section devoted to no-cook menus. Click the “Holidays & Parties” tab, then “All Parties,” where you will see the link.
 - Visit Chow.com/tags/281-no-cook to find off-the-beaten-track no-cook recipes like Kulfi (an Indian dessert) or Double Cheese and Black Bread Terrine.
- Happy no-cooking! ■

Private Disability Insurance Claims: A Guide for People with MS

If you're covered by a disability insurance policy through your employer, or one that you bought on your own, get up to speed on your rights and responsibilities

before you file a disability claim.

The Society's new guide offers a step-by-step explanation of the claims process, with tips to help you get approved.

A companion guide

for professionals, **Supporting MS-Related Disability Claims to Private Insurers: The Physician's Role**, provides doctors with a checklist of things to include in their supporting statement to document their patients' claims for benefits. Call us for a copy of either booklet. Or go to nationalMSsociety.org/insurance and click on "Other Insurance."

How're We Doing? See our Annual Progress Report

Moving Forward Together is now on the Society website, reporting on milestones for fiscal year 2007. (The 2007 fiscal year began October 1, 2006, and ended September 30, 2007.)

Type "annual report" in the search box on the Society's home page for a colorful look at the year's achievements.

Live links connect to the complete financial spreadsheets and to other resources on our website. If you cannot access the Internet, please call us and we'll print one out for you.



Café con Leche

Buenas noticias para las personas hispanas/latinas con EM. **Café con Leche** ha regresado. Para más información llame al **1-800-344-4867**. ■



living with MS in your 20s and 30s
Wondering how to balance your career and your MS? Is fatigue interfering with your social life? Considering telling the person you are dating you have MS? At **Real Talk. Real Answers. Living with MS in your 20s and 30s** you'll find discussions on these topics and more—and get some answers to the questions that matter. Go to realtalkrealanswers.com for live webcasts, virtual journals, tips from others living with MS and other features.

Real Talk. Real Answers. is made possible through a collaboration of the National MS Society and MS LifeLines.

African American Advisory Council Reaches Out

While Caucasians have a higher incidence of MS, the disease can follow a different and sometimes more severe course in African Americans. The newly formed National African American Advisory Council held its first meeting in February to discuss how to get the message about MS out to the African American community.

Dr. Mary Hughes, a member of the Society's Board of Directors and a neurologist at Medical College of Georgia, whose sister Dora has MS, chaired the meeting. Other attendees included neurologists, people with MS and family members, physical therapists, counselors, a public health expert, a pediatric nurse and a neuro-ophthalmologist. The Society received a grant from the Medtronic Foundation for this meeting.

Dr. Mary Hughes (L) and Dr. Dora Hughes



Milton Morris Photography

Inviting people in

Following the Council's recommendations, the Society will seek to develop relationships with African-American celebrities, historically black colleges and leaders of churches and other faith-based institutions to raise awareness about the disease.

Other recommendations include developing a booklet for African Americans with MS, and encouraging more African Americans with MS to participate in MS clinical trials.

The Council agreed that meeting once a year was not enough, and is planning to talk again.

MS Activists Visit Capitol Hill

In May, more than 400 MS activists from all 50 states visited their U.S. senators and representatives asking for support of:

- **The Ending the Medicare Disability Waiting Period Act of 2007** (S. 2102/H.R. 154). This bill would phase out Medicare's 24-month disability waiting period.
- **The National Multiple Sclerosis Disease Registry Act** (H.R. 5874), which will get an accurate measure of the incidence and prevalence of MS in the United States.

- **Federal investment in MS research** at the Department of Defense through the Congressionally Directed Medical Research Programs. Research on the increased MS incidence among combat veterans could lead to better understanding of potential environmental triggers.

Add your voice! Go to the MS Activist Toolkit (nationalMSSociety.org/ActivistToolkit) on our website to learn how to fit activism into your life. ■

The Skinny on Skin

Most organs like the kidneys, liver and stomach are tucked inside and out of view. But what protects them? Skin, the largest organ of all.

Skin keeps germs, dirt and damaging sun rays out, and important things, such as water, blood and fat, in.

Some MS symptoms, such as bladder and bowel problems, numbness (see sidebar), and lack of mobility can negatively impact the skin's health.

The injectable MS drugs can also affect skin. Skin reactions at injection sites can range from annoying to serious.

Maintaining healthy skin

- Don't smoke. It dries out skin and makes it harder to heal from injection-site reactions.
- Keep hydrated. Here's one more reason to drink the recommended eight 8-ounce glasses of fluid a day. And, as beauty magazines say, moisturize regularly.
- Wear hats, long sleeves and pants in the middle of the day. Use a broad-spectrum sunscreen with an SPF greater than 15, even if your skin is very dark.
- Inspect skin regularly for bruises, cuts, marks or other damage. Don't forget the soles of the feet and in between the toes. "If you notice something is not healing, let your healthcare provider know as soon as possible," Anjali N. Shah, MD, told **MS**

Connection. Dr. Shah is the director of Neurorehabilitation at the University of Texas Southwestern Multiple Sclerosis Center in Dallas.

Incontinence

If you have bladder or bowel issues, make sure to clean and dry your skin regularly and after any incontinence. Tuck dry underwear, moist wipes and soft paper toweling in a baggie and stash in your backpack, briefcase or shoulder bag.

Managing injection-site reactions

Reactions can include redness, itchiness and swelling. Subcutaneous injections tend to cause more skin reactions than intramuscular injections, although the latter may produce mild bruising and be slightly more painful.

More severe reactions include wounds, ulcerations, lumps or atrophy. Occasionally, surgery and antibiotics are needed.

Dr. Shah recommends:

- Learn a good injection technique from your nurse or the patient assistance program your drug company offers.
- Make sure skin is cleansed with soap and water and then disinfected with alcohol before injecting.
- Let medication warm to room temperature to reduce burning or stinging.
- Ask your healthcare provider about an autoinjector, which allows people to choose injection depths.
- Rotate injection sites!

Decreased sensation or numbness



There is no medical treatment for numbness. Because numbness is essentially a decrease in sensation, it's possible to burn or injure skin more easily. Keep an eye on anything hot—the stove, candles, radiators. With coffee or other hot beverages, use a mug with a lid to prevent spills, and wait a while for your drink to cool down before taking a sip. Get a set of unbreakable dishes.

- Topical agents such as lidocaine can be applied to the site to help decrease pain or irritation.
- Talk with your healthcare provider about applying a warm or cold compress beforehand. Some people do better with one or the other.
- For itchiness, try an over-the-counter antihistamine such as topical Benadryl.

Ask your healthcare provider for other recommendations. ■

Beat the Heat—Get Active in the Water

“In water, people can move in ways that they can’t on land,” Sue Kushner, MS, PT, told **MS Connection**. Kushner is an associate professor of Physical Therapy at Slippery Rock University in Pennsylvania, and a long-time MS Society volunteer. “In the water, people have an opportunity to improve their flexibility, balance and coordination, strength and cardiovascular endurance—and take all that back to land,” she said. “Some may even find some relief from pain or a decrease in spasticity.”

Now, as the temperature soars, it’s a good time to think about starting an aqua exercise program.

Something for everyone

You don’t have to be a swimmer: Aqua exercise can be anything from gentle moving in the water to a full program of vigorous exercises. Routines should suit your mobility and fitness level; your healthcare provider can give you a prescription for a physical therapist.

Tips for success:

- **Check the temperature:** Experts suggest

a water temperature of 82 to 84 degrees, but try anything below body temperature to find what’s right for you.

- **Improve balance:** Walk along the pool wall forward, backward and sideways. “Hold on to the wall,” Kushner said. “And make sure you are moving in all directions.” Also try braiding, where you put one foot in front of or behind the other to further challenge your balance.
- **Get flexible:** Stand facing the pool wall. Stretch one leg straight behind you and bend the other knee as you lean forward. Then reverse legs (a typical runner’s stretch). Or, stand at a corner of the pool where the water is waist or chest deep, place your hands flat against each wall and bend your arms as you lean into the corner. This stretches the chest muscles.
- **Stay afloat:** Strap on a flotation vest to help you remain upright, kick one leg in a circle clockwise and the other counterclockwise (an “egg-beater” kick). You’ll increase flexibility in legs and hips.
- **Get help:** Call us at **1.800.344.4867** for a list of physical therapists or aqua exercise programs. Your parks department will also know about accessible pools. And visit the American Physical Therapy Association’s website at **apta.org**. ■



Researchers Need You

Is a clinical trial right for you?

Scientists are testing new medications for MS in clinical trials across the country and around the world. These trials depend on people who are willing to participate. Volunteering means you could help find a groundbreaking new treatment for you and other people with MS. But there are issues to consider.



What are the risks?

If the treatment works, you have first access. But there can be side effects of the test drug, and adverse events, either mild or serious. Talk with your

healthcare provider about the risks and benefits of any clinical trial.

What are the costs?

An “informed consent” form shows which costs will be billed to you. Contact your insurer to find out what they will cover. Travel and hotels may or may not be reimbursed. You may lose work time for appointments. Ask, “Can I afford it?”

How is the study controlled?

In many trials, some participants receive the drug being tested; others receive a placebo, or inactive “dummy” look-a-like of the medicine. You won’t know what you’re getting, but you can ask what the odds are that you’ll be on active therapy. That’s

important because you may be giving up the safety net of your normal medication.

Are you eligible?

Scientists study how medications work with people at different stages of the disease, at different ages and sometimes of a specific gender, ethnicity or physical makeup. Most calls for clinical trial volunteers include eligibility requirements.

Without volunteers, we could not look forward to new and better therapies. For more information on volunteering and for details on clinical trials taking place in your area, visit nationalMSSociety.org/Need.

Intriguing Leads

- Can robots help train the brain to restore functions that are necessary for walking?
- Will there be more accurate ways to predict how an individual’s MS will change over time?
- Can an adult’s own store of stem cells be tapped to repair MS damage?
- Could the \$28 billion that MS costs the U.S. economy every year be trimmed? Would reducing employment discrimination pay off? Or better healthcare delivery? Or reforms in health insurance systems?
- Will there be disease-modifying drugs in pill form any time soon?

Read all about current research on these questions in **Intriguing Leads on the Horizon**. Just click “Research” in the top bar on the Society’s website (nationalMSSociety.org). And keep abreast of breaking news on MS research by logging on regularly. ■

Society Offers Free Financial Planning

Staying up late at night worrying about the bills, covering the mortgage, changing your job? We can help.

“We’ve enlisted over 600 financial advisors across the country to give free advice to Society members,” said Michael Elder, director of the Society’s Financial Education Partners Program (FEP), a collaboration between the National MS Society and the Society of Financial Service Professionals. “We offer financial education, literacy training and one-on-one consultations, much of it offered on the phone. People with MS are often presented with situations that seem overwhelming—financial matters may be one of them.”

The financial advisors working with the Society cover over 15 specialties—from retirement planning to health insurance to legal services. “These experts can help with employment issues, budgeting and even healthcare,” Elder said. “Often more than one will work together to help a client.”

A common concern among people with MS is career transition. “Our clients want to know, ‘Can I leave my job? And can I afford to be retrained?’ You can find an advisor to help with the financial planning involved in that decision,” Elder said.

The program also addresses financial areas specific to women. “There is a high rate of



divorce among people with MS,” he said. “Men are still more often the breadwinners. We wanted to address the money issues that arise for women out of that situation.” The FEP set up a free “Women with MS” financial workshop in Society chapters with the highest demand.

Elder stressed that the program always looks at the whole picture. “Sometimes people need the services of more than one expert,” he said. “Recently, to address the problems of a family facing foreclosure, the FEP put together a team including a planner, a real estate professional and a lawyer.”

In 2007, the National MS Society awarded the Society of Financial Service Professionals with the National Organization of the Year Award for their many hours of free service.

Call us to speak with a financial consultant and visit nationalMSsociety.org/Insurance for more information. ■

Ways to sell

Whether it's a lovingly hand-knitted scarf or an outgrown pair of jeans, now there's a way you can sell your wares **and** help fund the movement at the same time.

When you offer items through the "Community Marketplace" on the Society's website, you can designate the percentage of proceeds that you'd like to donate to the Society and you can specify what chapter you would like the proceeds to benefit. The Community Marketplace is powered by **missionfish.org**, the administrator of eBay's Giving Works program. It allows sellers to give proceeds from their sales to a nonprofit organization of their choice.

From bracelets to binoculars

A sampling of the items recently on sale at the Marketplace includes multiple sclerosis "hope" necklaces and awareness bracelets, a Chicago Bulls "Ultimate" card collection, Roy Orbison's all-time greatest hits (on vinyl!), spaghetti paintings, original photographs, purses, sandals, vintage comic books, knitting patterns, binoculars—and loads more.

Become a seller—and a supporter

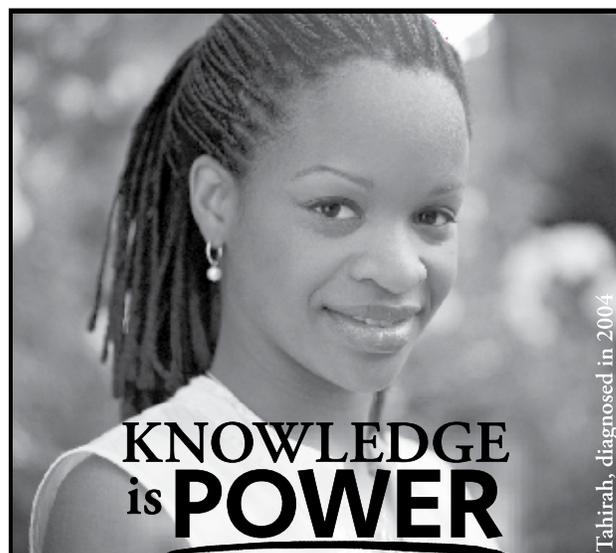
If you're already an eBay seller, click the "Sell" tab at the top of the listings. If you're not a seller, but would like to become one, the site will lead you step by step on how to register after you've chosen where you'd like your donation to go. Anything that can be sold on eBay can be sold on Community Marketplace, whether it's a first edition of *To Kill a Mockingbird*, or a dog-eared paperback of John Grisham's latest. While all sellers pay fees, which usually range

between 3–7% of the final sale price, eBay gives a fee credit to sellers who donate through eBay Giving Works. The credit will be reflected in their account approximately six weeks later.

Getting there

Click "Get Involved" at the top of the Society's homepage at **nationalMSSociety.org**. This will lead you to a link to the Community Marketplace—as well as to the Society Store and the Movement Marketplace.

The Society Store offers top-quality wearables and collectibles—with our logo and in our brand colors—at a fair price, providing an opportunity to show support and increase awareness of the MS movement. The Movement Marketplace features special offers from the Society's corporate supporters. ■



Knowledge is Power is a six-week, free, at-home educational program for people who are newly diagnosed. Mail or email formats. To register, call **1.800.344.4867**, or visit **nationalmssociety.org/knowledge**.

Join the movement.



50 Years of Activism (cont. from cover)

According to Dr. Dunne, that lack of information extended to the medical community as well. “When I first became involved with the Society in the 1960s, there was so much misinformation and misunderstanding of the disease. People weren’t aware that it’s a disease affecting young people and they often confused it with muscular dystrophy. Among many physicians, it was sort of an orphan disease due to failure to diagnose and failure to appreciate the severity and frequency of the disease and its symptoms,” he recalled.

“Until the introduction of Betaseron in 1992, we had only symptom treatment. The tendency was for doctors to tell patients it was all in their minds, there’s nothing that can be done, go home and learn to live with it, or even worse, that they were going to die,” Dunne said.

“There’s still a mindset among older people that there’s nothing you can do,” he continued, “but there’s been a revolution in the way good neurologists think about MS. It’s now a subspecialty. There are new articles every week in medical journals. In the old days, there was maybe one a year.”

Educating the public and physicians about MS is just one part of the Chapter’s mission. In addition to raising funds for MS research, the Chapter provides programs and services to people living with MS. “We as a chapter, give 40 percent of our income to the National MS Society to fund research. That’s hard, but they’re doing a very good job at closing in on a cure. Some may feel that we’re constantly hitting them up for money, and in the past, that seemed to be a bigger focus. Now, the Chapter’s

services are better than ever and members can see funds going for grassroots needs, such as wheelchairs, cooling devices, transportation and more,” Dunne noted.

Arthur Bourgeois stated that the Chapter now helps out groups and individuals more than ever. “Communication and training are key and the Chapter is doing a great job in both these areas. It’s particularly important for people newly diagnosed with MS,” he said. For 10 years, Bourgeois ran the Ocala self-help group and he remains an active group member. “You can attend any self-help group you want, but without training, you’ll never come to understand the disease.”

“We used to have to go to Orlando for meetings and training, but now it’s all done over the phone,” he continued. “And the Chapter’s willingness to respond doesn’t end with the newly diagnosed. If I need something, all I do is call and they’re there. Years ago, they didn’t have the funds to help. Now they do, because of walkMS and other fundraising events.”

Dr. Dunne added that the consolidation of the Tampa and Orlando Chapters in 1998 helped the organization better provide services and education. “With the tremendous population growth throughout Central Florida, joining as one chapter has given us more clout with the National MS Society and given us a greater source for funding. That’s what has helped us most. We’ve been able to bring MS out in the open, raising awareness among patients, families and the general public and the importance of finding a cure and about dealing with the disease.” ■

Volunteer Spotlight: Dave Johnson



Ask Lake County self-help group leader Dave Johnson about his MS activism, and he immediately turns the attention to others. This year, Pity-Us-Not, Johnson's group, formed a 32-member walkMS team. Of this team, two live in assisted living facilities. "Normally, you might say their physical abilities are limited, but not when it comes to fundraising," Dave exclaimed. "One team member, Pamela, sat outside the facility in her wheelchair and sold pens and pencils to people coming in. With the help of another resident, she raised \$350 this way."

"Then there's JoAnne," he continued. "She can only move her neck, but she used her

voice-activated phone to call her friends and ask for donations. The checks rolled in regularly and she kept this up all the way until the deadline when she reached her goal of breaking \$1,000."

"When I took over this self-help group last July, I'd been wanting to do some fundraising for a while. When Jamie Elasick called from the chapter and asked to visit the group to talk about the upcoming Walk, it put a smile on my face because I had missed the previous year's Walk," Dave said.

As Team Captain, Dave helped set up team member's websites, picked up donations, and kept track of member's fundraising totals. Because a number of other group members were having difficulties with mobility, he ordered pens, keychains and other items for them to sell. In its first year, the Pity-Us-Not team raised \$6,900 and Dave hopes to top that total next year.

As enthusiastic as he is about the team's fundraising success, Dave admits that raising money is not his only motivation. "I loved every bit of this volunteer work both in heading up the group and helping out with fundraising, but I have a selfish reason for being involved. I go to visit Pam and Joanne and now a third team member who lives in a Pam's facility and they cheer me up every time," he said. "Here are the ones who are in the worst of shape physically and yet they have the best outlook. They set quite an example and I'm constantly inspired by them." ■

"Here are the ones who are in the worst of shape physically and yet they have the best outlook. They set quite an example and I'm constantly inspired by them." —Dave Johnson

Ten Students Awarded MS Society Scholarships

Multiple sclerosis affects those diagnosed with the disease as well as their families. Each year, the Mid Florida Chapter awards scholarships to graduating high school seniors who either have MS or whose parents are challenged by the disease.



This year, the Mid Florida Chapter awarded \$22,000 in scholarships. In addition, **Anna Marie Crum** of Lakeland was selected nationally to receive the \$10,000 National MS Society Presidential Top Scholar Award. Anna Marie was diagnosed with MS at age 16. A graduate of the Harrison School of the Arts with a straight A average, Anna will attend Florida State University in the fall where she will major in English.

Throughout high school, Anna was a member of the National Honor Society and the Arts Council. She was twice the recipient of the Community Service Award and ranked in the top 10 percent of the Talented 20 program. Published in the Polk County Teacher’s Poetry Anthology, Anna was named in *Who’s Who Among High School Students* in 2007. Activities included Teen Trendsetter, Missionary Youth Choir, volleyball team manager and the Lakeland High School dive team.

Anna Whitman, itinerant teacher of the visually impaired for Polk County Schools, said, “Anna is one of the most motivated young ladies I know. She is a perfectionist and works very hard. She is a joy to work with.”

The National MS Society is delighted to reward Anna’s hard work and perseverance with the Top Scholar honors. We know she’ll do us proud! ■

[READ ANNA’S ESSAY ON PG 15.](#)

“Anna is one of the most motivated young ladies I know. She is a perfectionist and works very hard. She is a joy to work with.”

—Anna Whitman

Check out the other winners on the next page ►

Other Scholarship Winners

LOCAL NEWS

\$3,000



Adriana Espinosa
Tampa



Kristine Gonzalez
Kissimmee



Robert Winston of *Sarasota* is the recipient 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. The scholarship is awarded to a volunteer annually who exemplifies volunteer leadership throughout their high school career.

\$2,000



Kelsey Harshman
Clearwater

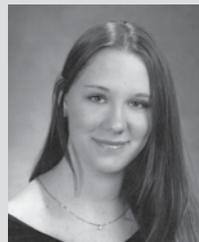


Aleksandra Jaquith
Crystal River

\$1,000



Rhianna Donnelly
North Port



Devon Holder
Seminole



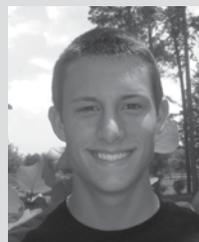
Shelby Kirkman
Lakeland



Samantha Lilly
DeLand



Michael Myregaard
Safety Harbor



Kyle Sullivan
Sorrento



Krystal Tucker
North Port

To learn more about these dedicated scholars, visit nationalMSsociety.org/flc.

Anna Marie Crum's Essay

We are all faced with a negative experience sometime in our lives, but I have learned that how it affects your life is your choice. For years, I struggled with being labeled a hypochondriac. Symptoms would randomly appear and it felt like my body was constantly under attack and no one understood why. For years the doctors failed to come up with a diagnosis, dismissing it as a mental problem or a symptom caused from stress.

Teachers and classmates distanced themselves and more than anything I wanted to learn what was wrong with me so I could maybe stand a chance at regaining my reputation or keeping a friend or two. My wish came true a few years down the road but the aberrant diagnosis was the farthest thing from what we all wanted or expected. On August 24, 2006, at the mere age of 16, I was diagnosed with multiple sclerosis, a lifelong debilitating disease.

All my life, I have been known for being a very independent individual. At first I struggled immensely for I believed that multiple sclerosis was a disease that would force dependency, but I began to realize that it can only take away my independence if I allowed it to do so.

Seventy-five days after my initial diagnosis, I lost all of my sight—I was legally blind. As an honor student and a vocal major in a performing arts school, my schedule of performances and academic classes suffered greatly as my ability to learn music was obviously hindered and homework became nearly impossible to complete, even with using several magnifiers or trying to complete it orally.

During that time, mobility too became an increasingly prominent issue as it was incredibly difficult to maneuver around school or even around my home. I was forced to depend on someone to escort me and couldn't obtain a driver's license as most 16-year-olds do. Five months later, with my vision partially back, I learned to be proficient in mobility by using a cane and became fluent in the basics of Braille. That particular instance of losing my vision, coupled with other more recent symptoms, have taught me that it is okay to need help; to need people in my life. However, more importantly, it has taught me to think with originality—to find new ways around a problem.

Although this disease has enfeebled me physically, it was made me a stronger person by increasing my drive and determination to overcome anything I encounter. I finished the year still with an A average, which showed me the value of hard work—hard work that has placed me sixth in my graduating class of 96 seniors. Now even with all of my vision returned, I still miss out on performances here and there because my body is constantly fatigued. My limit is not that of a normal 18-year-old and it will take time to learn how far I can push my body until it tells me it can't take any more.

Through the ordeals I have already gone through and those that are to come, I will hopefully be able to raise awareness to others so they too can begin to learn that things are not always what they seem. "Never judge a book by its cover." In a high school with a disease that attacks

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Anna Marie Crum's Essay (cont.)

you almost relentlessly causing physical disabilities, you are placed in a spotlight—everyone notices, everyone talks. I lost a lot of friends and gained quite a misled reputation.

Because people most often judge what they cannot understand, I am still occasionally on the receiving end of peoples' premature judgments. Also in an attempt to raise awareness, I have taken on a project of writing and brailing books for children who suffer from being visually impaired.

I have also gained something valuable through this ordeal that helps me overcome any obstacle: to rely solely on faith. My certainty in my beliefs has increased dramatically as I have learned to relish each moment as it passes, not worrying about tomorrow, or what may or may not happen. It took almost a year to begin successfully coping with emotional effects that this disease had on my life

and in that year the fear, pain, confusion, and stress of it all ate away at me for five months, not only mentally, but physically until I was a mere 106 pounds.

MS is completely unpredictable in its symptoms and their severity and is certainly scary to live with, but this disease has also drastically altered my perspective, teaching me not to worry about things over which I have no control. Instead all we need to do is make the best of what we are given.

Although multiple sclerosis may be a part of who I am, it will never define me. I am a stronger person from it and can still achieve anything I desire. I believe and live by the words of Helen Keller: "Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved." ■

Advocacy in Action

Five MS volunteers and three chapter staff ascended on our state Capitol in Tallahassee for our first Advocacy Day during the legislative session in March. In years past it has been called Tally Watch, however we are beginning a new era with advocacy as our primary focus. Adorned with MS orange neck scarves and ties to help brand the new MS logo, we took the Capitol complex by storm. During a tight budget year we did not have financial requests, but wanted to educate our legislators about MS.

Working with legislative staff is only half of coalition building; the executive branch and our state agencies offer limitless opportunities for

CONTINUED ON PG 17



partnerships and education all across the state for various programs. In a unique opportunity, the Florida Department of Health Deputy Secretary Kim Berfield and Lucy Mohs, Legislative Affairs Director from the Agency for Persons with Disabilities, attended our first day of training for our Advocacy Day. They participated in an informal chat with participants discussing the role our state agencies can play in MS advocacy. Berfield and Mohs further explained the programs and services already available to those in the MS community.

On the second day, we had appointments in various House and Senate offices where we educated staff and members about MS, its challenges and how to improve our laws and budget for all disabilities. Before leaving, we took in a thorough tour of the chambers from an experienced tour guide. Lastly but more importantly, we were recognized in the House gallery before drawing the trip to a close. Attendees learned the real meaning behind the policy discussions they heard and the procedures they witnessed.

Continuing the momentum, advocates attended the National MS Society Public Policy Conference in Washington, D.C. this year. In a record number of visits, they met with 14 Florida House member offices and one Senate office. Several of these meetings took place with the legislators as well as their staffs. The public policy agenda this year was to push for renewal of the Congressionally Directed Medical Research Program (research funding for MS as well as the prevalence of veterans diagnosed with MS), to end the 24-month waiting period for Medicare and to establish a national MS registry. Along with the three bills, we educated federal staff about Society programs and services. Chapter staff looks

forward to serving as an information and referral catalyst for their constituents back in the district.



Those of us in Florida can be proud because we were the first state to establish a partnership with the AARP for their “Divided We Fail” (DWF) Campaign (www.dividedwefail.org). DWF is a national campaign designed to engage the American people, elected officials and the business community to find broad-based, bi-partisan solutions to the most compelling domestic issues facing the nation—healthcare and the long-term financial security of Americans. Recognizing that the National MS Society should be at the table during these candidate debates and discussions, we established the partnership and immediately held trainings in July and August to educate MS volunteers about DWF and recruit them for MS advocacy events in the future. If you missed the trainings and are interested in participating please contact Jenna Labadie at 813.889.8363 or via email at Jenna.Labadie@nmss.org.

Advocacy is fun, so we hope you will join us! See you soon. ■

Community Partner Spotlight ResponseLINK

A new partnership offers added peace of mind to people with MS who either live alone or spend time alone in their homes. ResponseLINK and the National MS Society Mid Florida Chapter have partnered to help bring people with MS a sense of security and independence in their homes. ResponseLINK is now a preferred provider of the National MS Society Mid Florida Chapter and offers their service at a reduced rate through the Chapter's Quality of Life Grant.

ResponseLINK has been serving customers since 1997, providing state-of-the-art medical alarm systems for the physically challenged, disabled, visually impaired and those with limited mobility. The one-touch emergency medical alarm and medical

response system enables people to live safely and independently at home. In case of a medical emergency, all one needs to do is press the button on the medical alarm device. Immediately, you are put in touch with trained staff at the central monitoring station who respond and summon emergency medical help. With ResponseLINK, people can lead a life of safety and independence in their own home with 24/7 emergency care.

For more information on ResponseLINK, visit their website at www.respondelink.com or call 1.866.802-3676. To request a Quality of Life Grant application from the Mid Florida Chapter, or for questions related to the Quality of Life Grant program, please contact the National MS Society at 1.800.344.4867. ■

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.

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MSTM

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Ask an Attorney:

Be your own disability insurance activist

By: John V. Tucker, Esq.

This article is a glimpse into the legal complexity surrounding disability insurance policies. Please contact a lawyer to discuss the specifics of your case.

QUESTION: My disability insurance company denied my disability benefits, saying that they would not consider my job duties, but instead were looking at how my job “was performed in the national economy.” The job they have come up with is very different from my job. Can they do that?

ANSWER: The answer to that question depends on what your Long Term Disability insurance policy or group benefit plan says. It is very common today for insurance companies to insert language in policies that allows them to evaluate a person’s disability based upon their occupation, not their job. That means that they consider how your job is performed by most people in the economy, not the specific duties of your job.

This makes it very difficult for many people because our jobs are often very peculiar to our particular company. You may have accumulated different duties from your employer over years of working at a company that makes your job much more complex than the way the job is performed in the general economy. Similarly, your job may require different hours or travel that is not required by most people doing the same type of occupation in the economy. An insurance company will use this against you by evaluating the job with Department of Labor statistics that are published in a book called the Dictionary of Occupational Titles (“DOT”). A big problem with the DOT

is that it has not been updated since 1991, but insurance companies continue to use it. Often, a bigger problem can arise when a person suffers from a condition like multiple sclerosis that slowly takes away their ability to do certain tasks over time. Employers will often work with someone and modify their job or put them in what is often called “light duty” when this happens.

Unfortunately, modifying your job can actually lead to it being changed altogether for disability insurance purposes. If it is modified so much that it no longer resembles the type of work you are doing, the insurer will find the closest approximation for the job that is being done at the time a person becomes disabled. This is particularly true for individuals who have agreed to a temporary change to another position to see if their abilities can be accommodated. When an employer accommodates a disability and modifies or changes a job, that can literally place the worker in an entirely new category as far as the disability insurance plan administrator is concerned.

Making the decision whether to ask your employer to change your job duties is part of the difficult process that individuals are often confronted with when they are trying to avoid becoming disabled. You can actually hurt your disability case without realizing it by trying to have your job modified. Being aware that job modifications can have this impact is a crucial point in having all of the information necessary to make decisions about whether you can continue working or should seek disability benefits. Read

CONTINUED ON PG 20

Ask an Attorney (cont.)

your disability insurance policy or group plan to find out whether it is your specific job duties or the job as its performed in the national economy that will be evaluated if you become disabled and make a claim for benefits. ■

John V. Tucker is a disability attorney with the Clearwater, Florida law firm of

Tucker & Ludin, P.A. (a preferred provider 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 727.572.5000 or via email at tucker@thedisabilitylawfirm.com.

Activism, One Step at a Time

This past spring, walkMS was held in six locations in Central Florida. Each community came out in strong support and together raised over \$566,000! Dollars raised through walkMS are used to support local programs and services including Kid's Camp, SeaWorld Day of Discovery, the Quality of Life Grant, Homecare Assistance and Enhance the Romance Getaway Couples retreat...just to name a few. In addition to local support, a portion of the funds raised is also allocated to support research to find a cure for this devastating disease.

It is with the help of all our walkers, sponsors, planning committees and volunteers that we are able to create such successful events to offer these services to the 70,000 people affected by MS in Central Florida. Thank you to everyone who came out this spring to Join the Movement. You are a true reflection of community activists! ■



As of June 25, 2008

Orlando	\$137,943
Tampa	\$124,846
Sarasota	\$107,935
Cocoa	\$105,896
St. Petersburg	\$46,139
Lady Lake	\$44,128
"We Will" Virtual walkMS	\$2,216



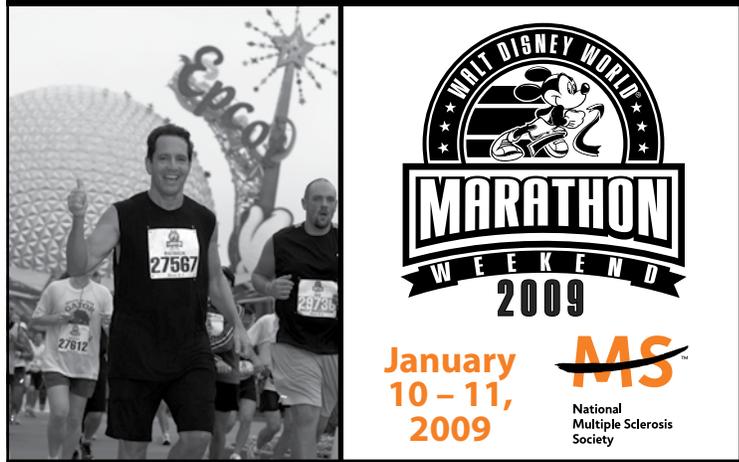
Top walkMS Fundraising Individuals

Jenna Felder	\$11,475
Debbie Sirkin	\$7,945
Betty G	\$6,923
Roxan Kelley	\$6,885
Stacey Jacovina	\$6,776
Erin Crumbley	\$6,300
Gail Farb	\$5,370
Diana Paver	\$4,680
Jeff Provinse	\$4,070

Top walkMS Fundraising Teams

Friends of Hope	\$30,848
Villages MS Support Group	\$17,412
MaSquerade	\$11,750
Jody's Pit Crew	\$10,890
Living Well with MS	\$10,280
Planet Fitness	\$10,050
Team Durning	\$9,554
Farb/Ogletree Deakins	\$9,193
Mitzvah Makers	\$8,930
Kevin Kelley's Walkers	\$8,802
Betty's Team	\$7,418

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 Ryan.Bumgardner@nmss.org or call 1.800.344.4867, option 2.



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

17TH ANNUAL MS PRO AM INVITATIONAL
Friday, October 17

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

Time: 12:30 p.m. Shotgun Start

For foursome and sponsorship information call Phil Deal 1.800.344.4867, option 2 or email phil.deal@nmss.org.

Million Dollar Miles



It's been an amazing two years for the Mid Florida Chapter's bikeMS: Bright House Networks MS Ride! 2007 was our first million-dollar ride ever in Central Florida and now you've done it

again. The 2008 ride topped one million dollars again thanks to the 1,500 cyclists and 300 volunteers from across the nation who came together for one common goal—to create a world free of MS.

In the past few years, bikeMS has seen tremendous growth, not just in funds raised, but in participants and volunteers as well. This growth has allowed the Mid Florida Chapter to provide more programs and services to the 70,000 people affected by MS in Central Florida, and to fund more cutting edge research than ever before.

Mark Your Calendar for these Upcoming Community Events

Thank you to the volunteers and MS clients who continue to host a variety of fundraising events. These efforts benefit the programs offered by the Mid Florida Chapter of the National MS Society and fund research to find a cure for MS. The Chapter invites you to attend these upcoming events near you and support the MS Society! Contact Phil Deal at the Mid Florida Chapter at 1.888.950.9080, ext. 22 or via email at phil.deal@nmss.org if you wish to organize an event to create a world free of MS.

The miles each cyclist ride and the dollars each of them raises really makes a difference! Many thanks goes to everyone associated with this year's ride including our cyclists, volunteers and generous sponsors —Bright House Networks, Central Florida News 13, Bay News 9, CuraScript, Lockheed Martin, RD Michaels, Giunta Ventures, The Foresters, Greenway Ford, Sonny's Real Pit BBQ, American Medical Response, SeaWorld Orlando and Cypress Gardens.



As we wrap up the 2008 ride, preparations are already being made to make sure the 2009 bikeMS: Bright House Networks MS Ride is bigger

and better than ever. Until a cure is found, we will ride! ■

September 13, 2008

MaSquerade

USF Gibbons Alumni Center, Tampa, 7 p.m.
A casino night featuring a silent auction and raffle, incredible food and much more. Contact Ande Felder at [727.215.0906](tel:727.215.0906) or via email at MaSqueradeEvent@aol.com. www.masqueradeoftampabay.org/home.html.

October 3 – 5, 2008

Pasco County MS Silent Auction Extravaganza
The Crab Shack, 5430 Baylea Ave., Port Richey,
Starting at 7 p.m. on Friday; 2 p.m. on Saturday & Sunday.
Games, live music, prizes and a silent auction. Contact Beth Cohen at [727.843.8043](tel:727.843.8043) or via email at btcp@production@tampabay.rr.com.

November 7 – 9, 2008

MS Crop for Hope

The Historic Kenilworth Lodge, Sebring
Starts Friday at 3 p.m. and lasts until Sunday at 3 p.m.
 Scrapbooking fundraiser, silent auction and raffle. Contact Jackie Durning at **813.265.4849** or via email at scrapnfla@hotmail.com. ■

Special Thank You

Special thanks goes to all our friends at Kangaroo Express Stores across Florida. In April, more than 400 stores sold over \$82,000 in \$1 bikeMS pinups to create a world free of MS. This is an amazing first-time effort so next time you visit a Kangaroo Express store near you, please make sure you thank their staff for helping people living with MS!



50 Celebrations in 50 Days

Join us in celebrating the 50th Anniversary of the Mid Florida Chapter of the National MS Society. The Chapter hopes to recruit 50 volunteers to host individual “celebrations” to increase awareness of multiple sclerosis and raise funds to help create a world free of MS! Could your celebration raise \$50, \$500 or even \$5,000?!

Be creative! You can do anything: host a cocktail party, have a local restaurant donate a percentage of sales, organize a pot luck dinner or cook dinner and pull out your china.

It’s really very simple to do. Think about a date for your celebration. The Mid Florida Chapter is targeting September 1 through October 20, 2008 to conduct all 50 celebrations across Central Florida. And think about how much you want to raise. Ask for a minimum donation from each

guest by dividing the number of people attending by your goal amount, i.e., 10 guests at \$10 each or 10 couples at \$50 each.

To help you, the Mid Florida Chapter will provide a template for a sample invitation that you can send to coworkers, family, friends, etc. In addition, the Mid Florida Chapter will send you a professional one-pager that you can distribute to your guests explaining multiple sclerosis, the services the Mid Florida Chapter provides, and the progress in finding treatments and a cure for MS during the past 50 years.

Please host a celebration and let the Mid Florida Chapter know by calling our office at 1.888.950.9080 or email Phil Deal at phil.deal@nmss.org. We will provide you all the details you need to guarantee a successful celebration! Thank you for helping us create a world free of MS! ■



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Mid Florida Chapter**

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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 Michelle Pearson at 800.344.4867, option 2, or michelle.pearson@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 michelle.pearson@nmss.org.