

The fourth annual MS Cure Classic was held recently at River Hills Country Club in Valrico. This year's event, organized by Steve Backhaus and Paul Tynan of Express Press in Tampa, raised \$20,000. In fact, since 2004, its inaugural year, the MS Cure Classic has raised close to \$65,000 toward finding a cure for MS. Thanks, Steve and Paul, for all your hard work!

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

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

Ready...Set...Walk!

Walkers all over Central Florida laced up their shoes for the 2007 MS Walk. This tremendous event took place in four locations throughout the Chapter's territory. Thanks to everyone involved - from walkers and volunteers to family members and sponsors. Look for details and a recap in the next issue of MS Connection.



National Multiple Sclerosis Society
Mid Florida Chapter

From your President.....	2	Ways to Give.....	9
Research.....	3	Local News.....	10
Living with MS.....	5	Local Research.....	11
Advocacy.....	7	Local Programs.....	12
Newly Diagnosed.....	8	Local Development.....	14
		Local Fundraising.....	Back Cover



Creating a Movement

Can one person's voice launch a movement?

Laura Wieden, the daughter of Dan Wieden, has been living with MS since she was 24. Dan's award-winning ad agency, Wieden+Kennedy, is world famous for creating brands for organizations like Nike and ESPN, just for starters. So when the Society approached Wieden+Kennedy about working together on a new brand for the organization, Dan Wieden saw it as an opportunity to do something important and long-lasting for his daughter. He asked Buz Sawyer, managing director of the New York Office, if he was willing to work pro bono on the project—he said yes. Sawyer's sister also lives with MS and their mother died from complications of the disease.

A full team of strategic planners and creative staff were engaged to develop the new brand for the Society, resulting in more than \$1 million worth of time and creative talent for the video, print ads, billboards, and TV spots, which debuted in March during MS Awareness Week. The new brand is authentic. Every person featured lives with MS.

Thanks to everyone at Wieden+Kennedy, you'll notice a shift in how the Society looks and talks about itself and the disease. The brand is built around the core concept of movement: "MS stops people from moving. The National MS Society exists to make sure it doesn't. Join the Movement." Because moving is so much of who we all are, we believe that everyone will be able to identify with this universal message and call to action.

A new identity

Our new logo clearly identifies the Society and celebrates movement and personal expression. The color is a warm orange, which creates urgency, and stands out in a world where so many other colors represent so many other things. Through research, we know orange is optimistic, contemporary, and cutting edge. It's also a color that people with MS find highly readable and can become a symbol for MS around the world.

The transformation is part of a long-term process. For a while you'll be seeing both of our looks - old and new - together. But the movement has started.

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2 Toll-Free Number: 1 800 FIGHT MS

FROM YOUR PRESIDENT

Give us your two cents' worth

Spring of 2007 has found the Mid Florida Chapter staff and volunteers busier than ever. We are currently in the process of launching a needs assessment initiative. Conducted by an outside firm, this assessment will help determine the programs and services our community needs and will help us better serve you in the years to come. This is your chance to have a voice in determining and prioritizing the programs and services offered by the Mid Florida Chapter. See page 12 for about how to participate in this very important survey.

During MS Awareness Week, March 5-11, a number of special events and educational programs took place across our 23-county area. Like me, you're probably aware of the devastating effects of MS. It's surprising how many people aren't. Events such as MS Awareness Week remind each of us to spread the word about the disease, whether explaining to someone how MS can affect an individual's life or advocating legislative issues that either assist people with MS or fund MS research. I encourage you to make every week MS Awareness Week and keep talking about MS until we find a cure.

To that end, a number of public policy issues are coming to the forefront in our federal and state legislatures. Our Action Alert Network took part on two Capitol Hill advances - one in Washington, DC, and the other in Tallahassee, FL. Pending legislation ranges from Medicare funding for wheelchairs to extending the line of stem cells used for research, and are detailed in this issue. Take a few minutes to write or call your representatives and let them know these bills are vitally important to you.

This spring also marks a new way of disseminating information to those we serve. As of February 28, all inquiries are being handled by trained personnel at our Information Resource Center. This contract will allow the Chapter's program specialists and managers to concentrate on local programs and

FROM YOUR PRESIDENT

services delivery, while ensuring that the MS community we serve receives continued customer service and accurate information.

We look forward to your input on our Chapter's needs assessment. Lend your voice and make a difference in our fight to end the devastating effects of MS.

Warmest Regards,

Tami Caesar
President Mid Florida Chapter

Join the movement and make a difference by volunteering

Volunteers are integral partners in the fight against MS, both nationwide and locally. There is a wide range of opportunities available at the Mid Florida Chapter. Whatever your interests, skills, background and availability, we have something for you. Volunteers are a vital component to the success of the Mid Florida Chapter, and we hope you will lend your time, talent and passion. Whether you volunteer once a year, once a week or every day, you make a difference, and we thank you. Come join the movement in the fight against MS!

The Mid Florida Chapter currently needs volunteers in the following areas:

- Peer support
- Program support
- Information and referral
- Community outreach
- Government Relations/Advocacy
- Research advocacy
- Office assistant
- Resource database assistant
- MS 150 Bike Tour, April 21-22, 2007

For more information and to get started, contact: Doris Lill at 1-800-Fight-MS (800-344-4867) Doris.Freire@flc.nmss.org.

RESEARCH

Moving forward on nerve repair



Dr. Calabresi of Johns Hopkins University School of Medicine, heads a multidisciplinary team focused on the repair of nerves damaged by MS. The goal is restoring function - returning abilities that MS has stolen from legs, arms and hands.

Dr. Calabresi's nerve repair research is funded by the Society's Promise: 2010 program. The following is from an interview with Dr. Calabresi.

Old drugs, new purposes

The concept of nerve loss is not a new one to neurologists. We also know from lab studies that nerve loss is reversible. In fact, there are repair or protective medications out there that were tested for Parkinson's, Lou Gehrig's (ALS), and others. They had limited success, but those diseases are diagnosed in older people who have significant damage. We diagnose MS much earlier, when people are younger and healthier. These drugs may work better for them. There are other drugs approved for other conditions that also merit testing in MS.

If your target drug is already approved for something else, you can go directly to what's called a Phase II-B clinical trial. That saves years and years of safety testing.

Which old drug?

At Johns Hopkins, we have a library of some 10,000 drugs and a three-part system for looking at them. First we identify those with the most promising properties. Then we ask about safety and which ones can be given as pills. Parallel with that we have to figure out how we're going to

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know if a drug really makes someone better. It would be great if we could just give something and people would get up and dance again. But nerves aren't like that. They take quite a while to grow out and do their thing. At the very least it would take 6–12 months for nerves to start functioning better or become more normal.

We need to know what's happening sooner. If a drug doesn't work, we want to try another on our top 10 list. We're going to test some of these drugs in people in the next five years. We may even do it in three.

International group finds extensive myelin repair even in elderly

When myelin - the fatty coating that insulates and protects nerve fibers - is damaged by MS, messages from the brain can misfire or be lost. This, in turn, can affect anything from vision to physical movement.

Scientists believe that when damaged myelin is repaired, function may return and that myelin repair (called "remyelination") also protects the nerve fibers themselves from damage. A recent study by an international team suggests that a substantial amount of natural remyelination can occur in most types and stages of MS. It is not confined to younger, healthier people, or to people who do not have progressive disease.

About the study

The researchers examined autopsied brain tissue from 51 people who had lived with MS, including people with relapsing-remitting, secondary-progressive, and primary-progressive disease as well as some whose MS type was unknown. The tissue samples were analyzed for signs of myelin damage and repair using a variety of high-tech microscopic, staining and labeling techniques.

New myelin in progressive MS

The researchers were surprised to note that, in about 20% of the samples studied, remyelination was extensive, including in those with progressive forms of MS. The amount of remyelination ranged from sparse to nearly complete repair—and, another surprise, they found more extensive remyelination in people who had died later in life and/or those who had had MS for the longest period of time. No link was found between the extent of repair and the age at onset, gender, or type of MS.

John Richert, MD, executive vice president of Research and Clinical Programs for the Society, told MSConnection that more research is needed to find out why some people experienced highly efficient myelin repair while others did not. "The findings of variable rates of remyelination will be taken into consideration as we design future clinical trials of ways to stimulate myelin repair," Dr. Richert said.

The study, published in the December 2006 issue of *Brain*, was conducted by Drs. Peter Patrikios, Hans Lassmann, and others of the Medical University of Vienna and financed by the National Institutes of Health and the European Union, with additional support from the National MS Society's MS Lesion Project (led by Dr. Claudia Lucchinetti of the Mayo Clinic).

Study refutes MS blood test prediction

Scientists world-wide have been searching for ways to predict if a person will get MS. In 2003, Austrian researchers at the University of Innsbruck thought they had found a way.



The Austrian team claimed to have found levels of two antibodies - anti-MOG and anti-MBP - in blood samples taken from people with CIS that predicted who would later be diagnosed with MS. CIS stands for "clinically isolated syndrome," meaning a single neurological attack. Not everyone who has such an attack goes on to develop MS.

But a new, much larger study by Swiss and German researchers, using methods similar to the earlier study, found no correlation between anti-MOG and anti-MBP levels in blood samples and a later diagnosis of MS.

The new study was published in the January 25, 2007, *New England Journal of Medicine*.

"While the news this time is not what we wanted to hear," said Dr. John Richert, vice president for the Society's Research and Clinical Programs, "we're still hoping to find 'biomarkers' that one day will accurately predict the onset or future course of MS."

LIVING WITH MS

Wheelchair independence

Stanley Fierston has been living with MS for more than 25 years, and has used a wheelchair for 20 of them. He offers these insights:

See an expert first

The purpose of a wheelchair is to keep you active and involved. It's not about giving in. Walking, balance, and fatigue problems may all factor into a decision. It's important to get fitted by a physical or occupational therapist familiar with MS who specializes in mobility devices.

For me, balance issues meant I could not easily sit upright in a standard manual wheelchair.

The arm rests were too far apart and my arms kept slipping off as I tried to sit up. I also wanted to keep using a regular car and to continue to travel by plane for my job.

With the help of an expert, I got a narrow-seat, manual wheelchair that is also lightweight and collapsible. It:

- Fits through most doorways
- Is easy for my caregiver to handle
- Comes apart quickly and stores in the trunk of a car
- Fits in the overhead compartment of an airplane

Choosing a chair - add to your expert's advice:

- Consider your home and community environment, the transportation you use, and the types of activities you want to do. This may narrow your choices.

- Do some consumer research. Abledata.com has the most information about wheelchairs, scooters, and other products.

Tips to roll by

Safety. Keep your arms and hands on your lap when your wheelchair is being pushed. Otherwise, you take the chance of jamming them on something.

Glove your hands. Protect your hands and keep them clean. You don't know where that sidewalk has been.

Keep up appearances. Don't look shabby. Clean your wheelchair regularly, especially before important events. Disposable wipes can do the job.

Easy eating. If you are at a function where food is served, get near a table or an empty chair. You'll need a place to put things down quickly, if you have coughing spells as I do, or just want a graceful way to enjoy the food.



Using the restroom. Get your paper towels before washing your hands. It isn't easy moving a wheelchair when your hands are wet.

Pocket resource. Reaching inside your pants pockets is difficult while sitting in a wheelchair. My solution: a pouch with a waist strap, sometimes called a "fanny pack." I can easily carry wallet, handkerchief, keys to the house and car, and my trusty digital recorder.

"I am the Face..."

Health-care worker Kerrie Fields of Georgia writes: "I was in an unhappy marriage, I had just had major surgery, and we were barely getting by financially.



... The stress, emotionally and physically, were getting to me." Suddenly she was laid low by an attack of neurological symptoms. After a long series of exams she learned the problem was MS. Her marriage ended. But then, she writes, she found "a great new position in my organization." She has gone on to become politically connected and involved: "Aside from the occasional pity party, my spirits remain high. I strive to keep my stress at a reasonable level, take my medications, and live my life."



As Ian Moskowitz, a Nevadan writes: "I have never given up. ... I am not a disease. I just have one."

Fields and Moskowitz are just two of more than 800 people who have told their story on **FaceofMS.org**, an online community created by people living with MS, launched by the National MS Society. It is a place where people can share their experiences and read the stories of others. It is also a space where those who may know little about MS can gain understanding from those closest to the disease.

"I'm here to say my life with MS sucks," Michael Magalotti writes. Magalotti, 32, lives in New Jersey, and offers a no-holds-barred glimpse of MS: "I'm not going to sugar-coat it for you. ... Every new exacerbation will bring new feelings of despair, frustration, and all the rest. If you keep it bottled up inside, you'll explode. ... We should be allowed to scream from the highest mountain 'MS sucks!'"

Visitors to **FaceofMS.org** add their stories, post their thoughts, and connect with others through their stories. Visitors can browse alphabetically by first or last name, by location, or by theme: Facing MS with Attitude; Facing MS with Purpose; Facing MS with Knowledge; and Facing MS Together.



"I had an epiphany today," writes North Carolina real estate broker and model Charisse Workman. "What does the face of MS look like?" Workman's poem, "I Am the Face," excerpted below, captures some of the contradictions and complexities:

"I am the pretty face

I am the hated face

I am the desired face

I am the designated face

I am the lucky face

I am the cursed face

I am the face that I have to face

I am just a face

I am one of many faces ..."

Please visit **FaceofMS.org** and support this ongoing movement by and for those who know MS best.

ADVOCACY

Getting the benefits of insurance

Health, disability, and life insurance ensure our long-term economic security. How do people with MS fare in the insurance world? To find out, the Society funded a telephone survey that asked 983 working-age people with MS (ages 21 to 64) about their insurance coverage.

Mixed picture

The good news is that most have health insurance. People who work or have a working spouse have the most benefits. The not-surprising news is that a majority struggle to meet expenses, even when they have health insurance. In addition, services such as rehab, home care, mobility aids, and complementary and alternative therapies are limited or not covered.

Survey details:

- Almost all (96.3%) had some health insurance, a much higher rate than the general population. About 40% have Medicare or other public health insurance.
- Almost 75% had private health insurance. This includes people who have Medicare plus private supplemental insurance. Over 40% had this insurance through a partner.
- Despite having health insurance, 70% reported financial difficulties paying for health care. About 30% of this group spent less on food, heat, and other necessities in order to meet their health-care needs.
- In the previous year, 20% did not fill a prescription, skipped medication, or split doses because of cost concerns; 30% postponed health care.
- One-third of the group received Social Security Disability Insurance (SSDI) benefits and almost 9% received Supplemental Security Income (SSI). About 30% in each of these two groups had their initial applications denied.
- Up to 15% paid for home care services out of their own pocket. Of this group, 20% said paying for these services was very difficult.

Working for improvements

In December, MS activists pushed Medicare to revise a restrictive evaluation and reimbursement policy for wheelchairs and power scooters. A major push to address the high rate of SSDI/SSI denials is in progress. Society staff and volunteers are working with Social Security offices nationwide to improve understanding of MS problems. And a new video for employers shows that accommodating employees with disabilities can be good for business. More initiatives are in the works.

Go to nationalmssociety.org/Planning for information on getting and keeping health insurance. Click on **Health Insurance and Medicare** for FAQs on health insurance, help with SSDI applications, to order the book **Health Insurance Resources—Options for People with Chronic Disease or Disability** and more. A link to **Medicare Interactive** provides an online tool for Medicare information. To join the MS activists, go to nationalmssociety.org/ActionNetwork or call us at **1-800-344-4867**.

NEWLY DIAGNOSED

Newly diagnosed? Get a team on your side

Society president and CEO Joyce Nelson likes to tell people that the toughest part of multiple sclerosis isn't the "sclerosis," it's the "multiple." Living well with MS requires multiple game plans and a team of people.

The medical stuff

First there's the multiple medical aspect. Most people are diagnosed by a neurologist ... and thus begin their MS journey with two doctors, a family practitioner (their "regular" doctor) and neurologist. What is their relationship? What is covered by insurance? Is it feasible or important to have an MS specialist? A team of specialists?

We can help. People with MS successfully manage their medical care in a number of different ways. We have referral lists of clinical centers and professionals in this area who have patients with MS. Give us a call. Also ask for the booklet *Choosing the Right Health Care Provider*, or check it out online at nationalmssociety.org/HCPProvider.

The home team

We hope you are interested in our 6-week home study series, Knowledge Is Power. But individuals also need to create a home team based on individual needs. The partner or family members who are closest are often struggling with their own overwhelming feelings about the diagnosis. They need time and knowledge to be your best home team. (Consider sharing Knowledge is Power, especially the introductory DVD.) If you're a parent, ask about our materials for your kids. A good home team usually goes farther: Would you benefit from contact with an MS friend? An old hand or someone who is also new to MS? Mental health counselors offer a safe place to unleash emotions and hash out tough issues. Remember, too, your spiritual or religious advisors.

We can help you locate many resources. Ask us about our newly diagnosed programs—and explore the online chat groups hosted by our partners at MSWorld. Visit www.msworld.org.

At work or school

As much as people may want the relief of having their employer, teachers, or peers know what's going on, it's wise to plan disclosure at work or school very carefully. Here's why: a person's first few months with MS may provide little indication of how the disease will behave later on. Waiting will provide perspective.

Ask us about our employment advisors, financial planners, even referrals to legal help. And go to nationalmssociety.org/Employment for more information online.

KNOWLEDGE

Is Power

Knowledge is Power is a 6-week free, at-home educational program for people who are newly diagnosed. Printed or electronic formats are available. To register, call 1 800 FIGHT MS (1-800-344-4867), or visit www.nationalMSSociety.org.

This is why we're here.

WAYS TO GIVE

Retire - without losing momentum



Because financial markets are unpredictable, many people of retirement age are turning to the Society's gift annuity program for guaranteed income and potential tax benefits.

What it is

A gift annuity is a contract between a donor and the Society wherein the donor transfers money or property to the Society in exchange for fixed payments for life. In addition, a transfer of appreciated securities may avoid capital gains taxes, provide tax-free income for a period of years and provide an immediate tax deduction. Gift annuities provide an ideal way for people to support the movement while making certain they have first provided for themselves.

How it works

Mr. and Mrs. Thompson are both 75 years old. They donate \$50,000 to the Society in exchange for a charitable gift annuity that pays them 6.3% percent (based on their combined ages) or \$3,150 every year for the rest of their lives. Upon the death of either partner, the surviving spouse will continue to receive the same fixed payments for the rest of their life. Because the payments are backed by the full assets of the National MS Society, their annuity checks will always be there for them. They also have confidence that their charitable donation supports the movement to end MS.

Annuity rates are determined by your age, your choice of an annuity for a single life or two lives, and your preference of immediate or deferred payments. Older donors and single life annuitants receive higher payment rates.

To find out more about the gift annuity benefits and rates, contact our Special Gift Office at (800) 923-7727.

Do U IM?



Thanks to a new Society relationship with Microsoft, every single time you have an IM conversation using Windows Live™ Messenger, Microsoft will donate a portion of the program's advertising revenue to the National Multiple Sclerosis Society. There is no fee for using Messenger, and it only takes a minute to download and select the Society as your organization when you join.

Visit im.live.com for more details and to sign up. Join the movement.



MS Awareness Week puts movement in the spotlight

The week of March 5-11, 2007, proved busy for all involved with the Mid Florida Chapter. Participants ranged from the students of Myakka River Elementary School in Charlotte County, who conducted an MS Awareness Week Penny Drive, to Dr. Jack Llewellyn, the Atlanta Braves' sports psychologist whose *Winning Sure Beats Losing—Living With a Winning Attitude* address motivated those who attended the St. Petersburg event.

The Mid Florida Chapter kicked the week off on March 5 by asking everyone in Central Florida to stop moving for one full minute at 12:05 p.m. in order to understand what it's like to live with the immobilizing effects of MS.

The cities of St. Cloud and Kissimmee both issued proclamations declaring MS Awareness Week.

In addition to having weeklong access to an MS Awareness information booth at Fawcett Memorial Hospital, those in the Port Charlotte area were invited to participate in *Living Well with MS*, a self-defense class designed specifically for people with MS.

An MS Awareness luncheon took place in Port Orange, and an MS Awareness breakfast in Tampa featured guest speaker Patricia O'Looney, Ph.D., Vice President of Biomedical Research for the National MS Society.

10 Toll-Free Number: 1 800 FIGHT MS

In Orlando, *The Clues to Epidemiology* was presented through the National MS Society's North American Education Program. In Brevard County, *Moving Forward* - a program for those newly diagnosed with MS - took place.

Neurology Associates in Maitland and MS Comprehensive Care Center in Orlando both featured MS Awareness Week Mission tables in their facilities.

On the heels of a very successful MS Awareness Week, we'd like to encourage you to make MS awareness part of your everyday life. Spread the word about the effects of MS and the need to fund research. Here are just a few ways you can join the movement and join our Chapter as we work to end MS while helping people move forward again.

- Visit jointhemovement.org
- Call the Mid Florida Chapter to learn about volunteer opportunities.
- Make a donation, online, by mail, or by phone.
- Cycle in the MS 150 Bike Tour on April 21-22 (or sponsor a cyclist or team).
- Distribute MS 150 Bike Tour Brochures.
- Write a letter to your newspaper editor about the need for insurance coverage for all MS drugs, or about other MS-related issues.
- Call or email your legislative representatives about issues important to people who have MS.
- Tell business and restaurant owners when their building is not accessible.
- Send an email stating several facts about MS to five people and ask them to pass it on.
- Spend one hour with someone living with MS to better understand their daily challenges.
- Commit to building a movement to cure MS while improving the quality of life of those affected.

Join the local research movement

MS research takes place across the country as thousands of physicians and clinicians strive to find answers to the mystery that is MS. Within the Mid Florida region, we are fortunate to have several MS experts participating in MS research. Participants are needed for the following clinical trials, to be undertaken soon.

Axiom Clinical Research of Florida

is enrolling for many MS trials including, two oral and two injectable medicines, neutralizing antibody testing and a mild cognitive impairment study. Interested patients between the ages of 18-55 who have a diagnosis of MS should contact Axiom at (813) 353-9613.

Axiom Clinical Research of Florida
(A division of the South Tampa MS Center)
2919 Swan Avenue, Suite 105 A
Tampa, FL 33609

Neurology Associates, P.A. in Maitland Florida

(East of Orlando) is currently enrolling for many multiple sclerosis trials including Oral, Combination, and Monotherapy trials. Studies conducted are:
CombiRx Trial-NIH
Oral MS Trial-Novartis
Teva GA 0012-Forte Study
Teva Nabs Study
MS Cognition Trial
FTY 2302 Novartis Trial
UCB Pharma – Oral MS

Interested participants should contact Karen at (407) 647-5996 x 241
Neurology Associates, P.A.
331 N. Maitland Avenue
Suite A-1
Maitland, FL 32751

Neurological Services of Orlando

is conducting a research study for anyone who has been on a high-dose interferon (Betaseron and/or Rebif) for no less than 12 months and no longer than four years. Participants must be 18 years of age and willing to complete all study procedures.

Please contact Sharon Parrish, ARNP, and Research Coordinator at (407) 540-1774 x 25
Neurological Services of Orlando
1111 S. Orange Avenue
Orlando, FL 32806

University of South Florida, Department of Neurology, Multiple Sclerosis Division

is currently enrolling for several multiple sclerosis clinical trials. For information concerning the details of these trials, please contact Lise Casady, ARNP at (813) 974-8859.

The Comprehensive Multiple Sclerosis Center at the University of Florida and Shands Jacksonville

is seeking participants for a new research study for patients with Relapsing/Remitting Multiple Sclerosis (RRMS). This study is looking at the safety and effectiveness of an investigational oral medication for patients with RRMS. This study is primarily for patients who are unable to tolerate the current injectable therapies, or who are unwilling to use them. As in most clinical trials studying new medications, if you chose to participate in this study, you will have a 2/3rd chance of being on the oral medication and a 1/3rd chance of being on a placebo (an inactive pill that is used for comparison to the active medication). Which group you participate in is based on a random selection, much like a coin toss. Neither you nor your study doctor will know which medicine you are assigned to.

If you would like more information about participating in the above mentioned trials, or information on other trials, please contact

Visit our website at: nationalMSSociety.org **11**

Jay Pietrzakowski at (904) 244-9686 or Raam Sambandam at (904) 244-9468.

Help us meet your needs

The main goal of the Mid Florida Chapter is to best meet the needs of those living with MS across our 23-county area. To this end, we have hired an outside firm to conduct an objective and thorough needs assessment of people diagnosed with MS. This process will determine our Chapter's program needs and will help guide our strategic planning for the next two-to-five years.

Your participation in this needs assessment is VITAL. We're asking that you log on to www.zplink.com/msfl between April 2 and April 20, 2007 and complete the online survey. If you don't have Internet access, call 1-800-550-8312 to complete the interview over the phone.

We encourage you to give us a few minutes of your time so we can give you the programs and services that best meet your needs.

LOCAL PROGRAMS



Registration for kids camp 2007 has begun

In its 10th year, MS Kids Camp is a program designed for children who have a parent or caregiver who has been diagnosed with MS. Kids Camp 2007 will be held May 18-20 at Camp Immokalee. Here, children will spend a weekend with other kids from

across Florida who share their daily challenges. Together, they'll be empowered to learn positive coping skills. Kids Camp is about making friends, creating memories and more importantly, building hope for the future. Children will also be offered the opportunity to participate in an educational session with children their own age to learn more about MS, and discuss concerns they might have about the disease.

MS Kids Camp is open to kids between the ages of 7-12 who have a parent or caregiver who is living with MS. There is no cost to participate. Camp activities include swimming, water park play, field games, arts and crafts, bonfire, rock climbing and more.

To register your child for this fun-filled pirate-themed weekend, call or email Gabriela Casado, Family Programs Manager at 1-800-FIGHT-MS (1-800-344-4867) or gabriela.casado@flc.nmss.org.

Café con Leche features monthly talk in Spanish

The National MS Society offers a new monthly telephone group, completely in Spanish. Café con Leche, Conversation and Support for People Living with MS, is an opportunity to talk about your concerns and meet others who understand your situation. Topics will focus on areas of interest to people with MS. The group will be facilitated by Moyra Rondon, LCSW, Director of Public Education and Hispanic Outreach for the NYC Chapter of the National MS Society. Additionally, three times a year, experts from different areas of specialization in MS will join us to speak about important topics in MS care.

We invite our Hispanic members to join those from all the Society's chapters across the country and participate from the comfort of your home or office phone. The monthly calls will be free and will take place from 2 to 3 p.m. (EST) on the following

- Tuesdays:
- April 24
- May 22
- June 26
- July 31
- August 28
- September 25
- October 23
- November 20
- December 11

For more information or to register, call 1-800-344-4867, option 3. Then grab your coffee cup, sit back, and listen to the experiences of other people with MS.



Advocating for MS issues on the national stage

On March 11-15, MS Society Chapters from across the nation gathered in Washington, DC, to advocate for issues important to people living with MS. The Mid Florida Chapter sent two staff members and one volunteer advocate to this important event, which saw members of our Action Alert Network visiting their representatives in Congress to discuss issues of importance to those living with MS. During this week, our advocates discussed with their representatives the Society's 2007 legislative issue priorities, which include:

Medicare Wheelchair Coverage lifts the current "in the home" restriction on mobility devices and allows beneficiaries to obtain wheelchairs or scooters for use inside and outside the home.

The expansion of **Embryonic Stem Cell Lines Available for Federally Funded Research** may find new ways to prevent, slow the progression, or repair the devastating effects of multiple sclerosis. The Society believes all promising avenues that could lead to the cure or prevention of MS or relieve its most devastating symptoms by repairing MS damage must be explored – including expanding the stem cell lines that are currently available for federally funded research.

Access to Life-Saving Medicine Act would allow the FDA to approve abbreviated applications for generic versions of biological drugs or biopharmaceuticals licensed under the Public Health Services Act. We favor this legislation because disease-modifying therapies can be cost-prohibitive for people with MS.

Medical Research Funding via the Department of Defense offers a potential avenue for increased federal funding for MS research as medical research programs through the DOD have become integral components in efforts to fight many difficult diseases.

The Action Alert Network – affecting Florida legislation

In addition to taking part in the Society's weeklong legislative canvass on Capitol Hill, the Action Alert Network brought the fight to Tallahassee. At the state level, volunteer advocates and four staff members spent March 20 and 21 making over 32 visits to legislators in order to advocate for bills that have an impact on individuals living with MS. The bills we advocate in favor of are as follows:

Biomedical Research Trust Fund provides that Institutional Review Board within the Department of Health shall not review certain research within jurisdiction of Stem Cell Research Advisory Council; creates Florida Better Quality of Life and Biomedical Research Act; creates Stem Cell Research Advisory Council & Biomedical Ethics Advisory Council to regulate research procedures and enforce ethical guidelines; provides for grants-in-aid program for purpose of conducting stem cell research; prohibits certain acts relating to purchase or sale of embryonic fetal tissue for research purposes and human reproductive cloning; provides penalties; and provides continuing appropriation.

Florida Association of Centers for Independent Living administers a personal care attendant program for persons with specified disabilities and revises provisions governing eligibility requirements for participation in the program; also provides for review and revision of policies and procedures by an oversight group.

Statewide, the National MS Society will begin to make an impact on meeting the needs of those in long term care. More than 600 people with MS across the state live in assisted living facilities. It has become a priority of all three Florida State Chapters to focus on how to address public policy support of long term care housing, planning and support. Over the next year, the NMSS coalition will focus on ways to advocate and support bills in favor of

improving long term care. If you are interested in helping with this movement, contact Melissa Mulcahy at 1-800-FIGHT-MS or email melissa.mulcahy@flc.nmss.org.

We continue to watch and support these bills. Our heartfelt thanks go out to those legislators who have supported these important legislative issues. An additional thank you to all the MS Advocates who voiced their support and shared their story on Capitol Hill! For more information on any of these issues or to join our Action Alert network, visit our website at www.nationalmssociety.org/flc.



LOCAL DEVELOPMENT

Keeping the promise alive

Promise: 2010 is a nationwide initiative established to raise over \$32 million by 2010. These funds will support MS research in the four most promising areas that may hold the key to finding better treatments and someday a cure. These areas are:

Nervous System Repair and Protection

This bold new initiative for tissue repair and protection in MS involves the largest grants ever

offered by the Society and sets the stage for translating basic lab research into clinical efforts to restore nerve function in people with MS. Interdisciplinary teams will develop non-invasive tools and models, and design clinical trials to pave the way for clinical testing to restore function in people with MS.

The Sonya Slifka Longitudinal MS Study

The first study of its kind in the U.S., the Sonya Slifka Longitudinal MS Study is a repository of in-depth information about the lives of people with MS. Investigators are collecting detailed data from a national sampling of 2,000 individuals. This study integrates clinical information, healthcare practices, and socio-economic data to learn what happens to people with MS over time and what factors influence the long-term course of MS.

Pediatric MS Treatment Centers

There are about 8,000–10,000 children or adolescents who have MS nationwide, and another 10,000-15,000 who have experienced what may be symptoms of MS. This disease is more difficult to diagnose in children and many pediatricians are not familiar with MS. For these reasons, the National MS Society is establishing regional pediatric MS centers to set the standard for pediatric MS management and care and to offer optimal medical and psychosocial support to children and their families. The centers will also create the framework to conduct critical research to understand how best to treat pediatric MS. This research is thought by many to hold great promise for unlocking the mysteries of MS in adults.

The MS Lesion Project

This international collaboration seeks patterns in the MS damage seen in brain tissue and attempts to correlate those findings with actual clinical signs, symptoms, and response to therapy. This effort provides vital information on the underlying pathology of MS and the impact of specific

treatments. With this knowledge, we can map out better ways of treating people who exhibit specific patterns of disease.

As our part of the Promise: 2010 campaign, the Mid Florida Chapter has committed to raising \$250,000. If you would like more information or to make a contribution to support Promise: 2010, please contact Tami Caesar, President NMSS Mid Florida Chapter, 2701 Maitland Center Parkway, Suite 100, Maitland, FL 32751, 1-800-FIGHT-MS, option 2, ext. 25 or tami.caesar@flc.nmss.org.

Wanted: telephone research participants

The National MS Society has funded a project to gain input from individuals who have a strong interest in MS research. The National Research Call program enlists individuals who are willing to participate in monthly hour-long telephone calls. Participants will have advance notice of topics, which will include areas such as gender differences, new horizons in MS research, epidemiology research and genetics. If you're interested in participating, call or e-mail Tami Caesar at 1-800-FIGHT-MS or tami.caesar@flc.nmss.org. Upon confirmation of interest, details for participating will be provided.