

# Can one person's voice launch a movement?

aura Wieden, the daughter of Dan Wieden, has been living with MS since she was 24. Dan's awardwinning 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 was 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. 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

story continues on page 3

## Planned Gifts Make a Difference

Pequests are one of the simplest and most common types of planned gifts. Regardless of your life circumstances or estate size, your will is perhaps the most important document you will create. A thoughtfully crafted will expresses your wishes and values and provides for the people and charitable causes important to you. Preparing a will is not just for seniors or baby boomers; many individuals write their first will in their 40's.

One of Greater Illinois Chapter's Pillar of Society members says, "I named the Chapter in my will because it is just what I do. The NMSS is making big progress with its research. I wanted to support the Society in any way I could."

Denise Wassenaar, President of Alliance Pharmacy, changed her will after she was diagnosed with MS so she could continue to support MS education and enhance the Society's research efforts. She feels it is important for



individuals to learn about planned giving. "Make sure you pre-plan; if you don't, it won't happen."

A new opportunity for lifetime giving is available thorough making a Qualified Charitable Distribution from an IRA. Under the Pension Protection Act of 2006, you can make a lifetime gift using funds from your IRA with no out-of-pocket tax expense to you. You can make a substantial gift now –and witness the benefits of your generosity. You could take advantage of this opportunity if:

- You are 70-1/2 or older
- The gift is \$100,000 or less
- You make the gift before Dec. 31, 2007 for the 2007 tax year
- You transfer funds directly from an IRA, Rollover IRA or a Roth IRA to the National MS Society

As with any financial decision, consult your own financial advisors. If you are contemplating a gift to the Society, please inform us so we can ensure your gift can be used according to your directions. The Society is pleased to acknowledge individuals and families who remember the Society through bequests, gift annuities and other deferred through our recognition program, Pillars of Society.

For more information about making planned gift or Qualified IRA Distribution, call 1-800 FIGHT-MS or visit our website at <u>www.msillinois.org</u>.

#### Creating Movement continued from cover

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.

We are asking everyone to Join the Movement. To learn how, visit <u>www.msillinois.org</u> or <u>www.jointhemovement.org</u>.

## do u IM?

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

Visit <u>im.live.com</u> for more details and to sign up. *Join the movement!* 

Windows Live Messenger

Aultiple Sclerosis ociety Greater Illinois Chapter

## People Living with MS and Their Supporters are Declaring Victory in Illinois

ctivists from the National Multiple Sclerosis Society – Greater Illinois Chapter scored a major victory late last year when Governor Rod Blagojevich signed SB 2917 into law (now Public Law 94-1076), making Illinois the first state to mandate private insurance coverage for preventive physical therapy for people living with multiple sclerosis.

#### What does this mean to you?

Public Law 94-1076 significantly improves access to health care and dramatically improves the quality of life for people living with MS.

Physical therapy has been clinically proven to help MS patients maintain current mobility and muscular strength, though it does not result in marked improvement in functioning. That had been the reason why many private insurers denied coverage in the past.

Thanks to the new law, people with MS no longer have to battle the bureaucracy of an insurance company in order to continue getting coverage for the physical therapy services that have kept them out of a wheelchair, stopped muscle atrophy, prevented falls and kept them active in the community. If you have a private insurance plan and have been struggling with getting consistent, ongoing coverage for physical therapy, this law requires that you can get access to the preventative physical therapy you need. As defined in the new legislation, "preventative physical therapy" includes physical therapy that is prescribed by a physician (anyone licensed to practice medicine) for the purpose of treating parts of the body affected by multiple sclerosis. The prescription for physical therapy must include reasonably defined goals (including, but not limited to, sustaining the level of function the person has achieved) with periodic evaluation of the efficacy of the physical therapy against those goals.



Coverage required under this Section will be subject to the same deductible, coinsurance, waiting period, and costsharing limitation, treatment limitation, calendar year maximum, or other limitations as provided for other physical or rehabilitative therapy benefits covered by the policy.



## How do you find out if you can access this law?

• Contact your doctor; consult him/her about physical therapy and obtain a prescription. In order for the law to be applicable, your doctor must prescribe physical therapy.

• Call your insurance company to make sure they are aware of the law.

 Individuals with federal or state insurance plans are not covered under this law. If you currently have one of these plans and are experiencing difficulty accessing physical therapy, please contact the Chapter to share your story. We are currently compiling data and stories to advocate for change at the state and federal level. We need your help to do so, so please take the extra step and speak out.

#### Multiple sclerosis is an exemption category with physical therapy caps for Medicare beneficiaries. Many people living with MS who are on Medicare are denied access to maintenance/on-going physical therapy. Many physical therapists are unaware of the Medicare exemption categories and do not know that they can help advocate on behalf of their patients. If you receive Medicare but have not been able to access physical therapy services, contact the Chapter to receive the Medicare exemption document to share with your physical therapist.

We extend our deepest appreciation to the Governor, Speaker Michael Madigan, and SB 2917's sponsors and co-sponsors whose support of this vital legislation ensured that people with MS no longer have to worry about gaining access to the physical therapy services that have kept them mobile, independent and actively contributing to their community.

How can I make a difference for people living with MS in Illinois? Join the Action Alert Network at <u>msillinois.org</u> or call 800-FIGHT-MS.

#### Are you on Medicare?

Medicare covers maintainence physical therapy for people living with MS.

#### Accessing the New *MS Connection:* Don't Miss an Issue!

tarting this summer, *MS Connection* will be published almost exclusively in a digital format, available via e-mail and at msillinois.org. To receive *MS Connection* as a digital download, you must be registered as a member on msillinois.org, which is free. Once you have registered, simply check the box for *MS Connection* on the registration form.

If you have registered previously, log in at msillinois.org and click the link to "Edit Your Profile." Once in the "Edit Your Profile" section, click the link near the top for "Special Interests." By opting in to the e-mail group for *MS Connection*, you will receive notice via your specified e-mail account as soon as the new issue is published. A link to the new issue will also appear in the Publication Archive, which can be found in the "Library of the "Information & Resources" section. If you don't have access to a computer, there are still ways you can get information from *MS Connection*. Most libraries offer free web access; check with your local branch to see what services they offer. If you don't know where the nearest library is, contact the American Library Association at 1-800-545-2433.

There may also be a community center in your town or city which offers access to computers and the Internet; if you are unsure whether one exists in your area, contact the Community Technology Centers' Network (CTCNet) at (202) 462-1200. For a small fee, you can also usually rent time on a PC at a FedEx Kinko's; you can find a location near you by calling 1-800-254-6567.

Print versions of the publication will continue to be made available only to those who specifically request them. If you require a printed version, please call the Chapter at 1-800 FIGHT MS.



CHAPTER CONNECTIONS SPRING 2007

If you don't have access to the internet, many community resources are available for you. In addition to libraries, food chains such as Panera Bread, Culver's, and Hardee's, most coffee/tea

Chicago Alliance Bakery & Cafe 1736 W Division St. (773) 278-0366

Atlas Cafe International Kitchen 3028 W. Armitage (773) 227-0022

Bobtail Soda Fountain 2951 N. Broadway (773) 880-7372

> Cafe Mestizo -*Tianguis Books* 1646 W. 18th St. (312) 421-5940

First Bytes Computer Center 2nd Floor, Berger Park, CPD [building and campus grounds] 6205 N. Sheridan Rd. (773) 761-5792

The Heartland Cafe 7000 North Glenwood (7730 465-8005

Bridgeport Coffee House 3101 S. Morgan

*Bronzeville Coffee House* 528 E. 43rd St. (773) 536-0494

> Peoria TwinTowers 456 Fulton St.

Squeaky Clean Laundry 1008 N. University St. (309) 672-9400

Panache Cafe 4203 N. Sheridan Rd. (309) 589-1844

Kades Coffee and Tea 2535 W. War Memorial Dr. (309) 689-3333

One World Main and University (309) 672-1522

Hanssens Le Bakery & Cafe 4700 N. University St. (309) 693-9190

Digital Courtyard at the Peoria County Courthouse

Mark Twain Hotel - 225 NE Adams St.

Quad Cities Bennigan's 226 17th St., Rock Island (309) 786-8686

The Captain's Table 4801 River Drive

Moline Municipal Airport (309) 797-9222

around Illinois (many more can be found at <u>wififreespot.com/il.html</u>):

shops, as well as some hotels, offer free

wireless Web access. Listed below is a

partial listing of free WiFi hotspots

#### Rockford

Damon's Grill 755 Clarke Drive (815) 484-1000

*Phoenix Traders* 215 7th Street (815) 962-4212

Octane 124 N. Main St.

*Kryptonite* 308 W. State St.

Swilligan's 200 N. Church St.

*noir* 317 Mulberry

Mary's Market Bakery & Cafe 2636 McFarland Rd. (815) 986-1592

The King's Table West State Street

Candlewood Suites 7555 Walton Street (815) 229-9300

Ramada Suites and Convention Center 200 South Bell School Rd.

Springfield Shudo-Kan Karate Club 1200 N. Bradfordton Rd. (217) 787-9092

Visit our Website at: www.msillinois.org

## Volunteers Keep Bike Tour Rolling Along

olunteers are essential to the fight against MS, and nowhere is that more true than the MS Bike Tour. This June, when 2,000 cyclists kick-off a weekend of "touring the farms," few will realize that the ride they are enjoying came about because of the hard work started 10 months earlier by a dedicated group of volunteers.

The members of the MS Bike Tour Steering Committee help plan and support nearly every aspect of this signature event, from planning every mile of the route, setting up new cyclist training programs, recruiting volunteers, planning the entertainment and creating and staffing the route support and safety plan. Because of the expertise needed to plan and run a three-day bike tour, many members of the steering committee donate their professional skills and experiences.



Some Steering Committee members, such as Allison Scholss, started their involvement with the Bike Tour because of a personal connection to MS. "My mother had MS and I began riding to help try to find a cure for the horrible disease that caused her so much pain and changed her life forever."

A cyclist and top fundraiser on the MS Bike Tour for many years, Allison was asked to join the Steering Committee in 2006 to bring her experience as an officer with the Chicago Police Department to the Ride Marshal program. "I think it is the advantage of what I do for a living that I can bring my expertise to such an important event and to something that means so much to me."

Oliver Gross found out about the MS Bike Tour at a cycling expo. "I was riding a lot, but I wanted to ride for someone else, not just myself." After one year on the tour, he was hooked. When asked to join the Steering Committee and run the Medical Team, Oliver decided it was a "great fit, with my nursing background and friends and family members with MS."

Now in his third year as the Lead for the Medical Team, Oliver coordinates the pre-event and weekend of volunteer efforts of paramedics, sports medicine doctors from Resurrection Health Care, nurses and local EMS crews. So does working with the medical community 24-

SPRING

7 get old? "Sometimes," says Oliver, "but in the end all the hours are well worth the effort. Seeing everyone out the weekend of the ride takes care of any feelings of having too much going on. It is worth every minute."

John Nugent came to the MS Bike Tour with a long resume of event experience, volunteering on motorcycle crews for multiple-day events throughout Illinois. So why did John decide to give so much of his time to the MS Bike Tour? "I've met many people living with MS, many on the weekend of the event and some on the committee...I am constantly reminded why I donate my time to the event."

In his fourth year helping plan the event, John has stepped up as a Steering Committee Chair. "My enthusiasm and commitment to the MS Bike Tour grew each year. I saw the opportunity to be involved with the growth of the event significantly...the Bike Tour has provided me with the opportunity to donate my time and skills, and have an impact on the future success of the event."

Allison sums up the sentiment most feel about why Steering Committee members come back year after year: "Most importantly, I stay involved because this ride is run by a committee of volunteers and so much of the money raised goes to help those with the disease and to research to help find a cure." If you are interested in finding out how you can join Allison, Oliver and John in helping us get ready for the MS Bike Tour, please contact us at volunteers@ild.nmss.org or 1-800-FIGHT-MS, press 2. To find out more about riding or volunteering at this year's MS Bike Tour on June 22-24 go to the <u>RideforMS.org</u> website.

Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with multiple sclerosis. Talk to your health care professional and contact the National MS Society at msillinois.org or 1-800-FIGHT MS to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

Visit our Website at: www.msillinois.org

## Someone You Should Know: Molly Heiler

olly Heiler is a born fighter. It's something she probably learned from her mother, who was diagnosed with MS when Molly was young. Even at a young age, Molly realized that her mom faced challenges that other mothers did not. And if her mom could care for two children, work, and fight multiple sclerosis simultaneously, then Molly could certainly do more to raise the quality of life for those living with MS, including the woman who raised her.

It was just a year ago, however, that Molly began to fully realize her potential as an advocate for people living with multiple sclerosis. When the Greater Illinois Chapter organized the first annual MS Lobby Day in March of 2006, it opened up a world of possibilities to her. As an MS Lobby Day volunteer, Molly saw that she had a unique opportunity to help mold public policy – and recruit other activists to join the cause.

That day in Springfield, Molly met a few people who would become dear friends, but she also met Illinois legislators and policy makers and talked with them about what it means to live with MS. Emboldened by the positive experience there, Molly was ready for more. That following May, she traveled to Washington D.C. to storm Capitol Hill, advocating for greater support of stem research, improvements cell in Medicare, and implementation of the

respite care act. This was only the beginning.

After returning home from the Capitol, Molly was a more enthusiastic activist than ever before, and she found several other avenues to pursue her advocacy. She joined Multiple Solutions (the junior board and auxiliary group of the Chapter), which is a collection of young professionals committed to fostering awareness of MS among young adults and to raising funds through various events. Molly also joined the Advocacy and Governmental Relations Committee (AGRC), taking a volunteer leadership position in the advocacy program and dramatically helping the Chapter expand its grassroots network. Through her tireless work as an MS activist, Molly has managed to accomplish some remarkable things, but if you asked her, she might say that her greatest achievement has been making her mom proud.



Toll-Free Number: 1-800-FIGHT MS

10

SPRING 2007

### Managing Symptoms with MS Learn Online

et facts about options for managing MS symptoms from the privacy of your home computer with MS Learn Online. This series of more than 50 webcasts features experts who delve into such topics as treatment, life planning, alternative medicine, and much more.

Managing Your Symptoms is a four-part program tackling the touchy subjects of bladder dysfunction, pain, vision problems, and sexual dysfunction. Nancy Holland, RN, EdD, and vice president of Clinical Programs at the Society, shares more than 30 years of MS experience and knowledge about physiology, diagnosis, treatments, compensatory strategies, and the social and emotional factors that can make these symptoms so difficult to live with.

Each program runs from 11 to 15 minutes. To view them, go to nationalmssociety.org/ mslearnonline. The programs can also be downloaded as podcasts. If your computer can't access the webcast, program transcripts are available that can be read online or printed. To be notified of future programs, send your e-mail address to MSLearnOnline @nmss.org. You'll get advance information about the presenters and a direct link to the program. For more information, call us at 1-800-FIGHT-MS.

## New Chat Room for Teens with MS

n an effort to provide needed and specialized support for teens diagnosed with multiple sclerosis, the National MS Society has formed a collaborative partnership to introduce Talkin'Teens, a chat room for teens ages 13-18. The chat room can be accessed at <u>MSWorld.org</u> and is offered by MSWorld. MSWorld hosts the official chat and message board. Only preapproved participants can access the chat room, which is available every Thursday evening and is monitored by a parent and a teen with MS.

MS historically has been viewed as an adult-onset disease, but an estimated 8,000-10,000 children may be living with MS. The new MS chat room for teens is one way for young people to

build relationships and mutual support with others in the same situation.

For more information on programming for children and teens with MS, or programming for youth



who have family members living with MS, call 1-800-FIGHT MS and press '2' to speak to a member of our Chapter Programs staff.

## Central Region Spotlight

#### Peoria Facility Receives MS Center Designation

or people living with MS, access to comprehensive medical care in the Peoria area expanded dramatically when the Illinois Neurological Institute was designated as an MS Center by the National Multiple Sclerosis Society. The facility received the credential in January following a comprehensive review of its patient care and treatment programs conducted by a team of MS experts from the National MS Society, Greater Illinois Chapter.

The National MS Society, Greater Illinois Chapter fights multiple sclerosis by working to enhance the quality of MS care and increase access to quality MS care throughout the state.

"We are pleased that this enhanced relationship with the Illinois Neurological Institute will help us further our efforts to end the devastating effects of MS," said Lynda M. Chott, President of the Greater Illinois Chapter. "The research and care offered at the facility will help ensure that MS doesn't stop people from moving forward with their lives."

Facilities designated as an "MS Center" must meet the National Multiple Sclerosis Society requirements for affiliation and must conduct MS specific research. Facilities which meet all the requirements with the exception of research may obtain the designation of an "MS Clinic."

Patient care at the Peoria MS Center location is provided by Dennis J. Garwacki, MD, and Jorge C. Kattah, MD. Mary Ann Cooper is the MS Nurse at the facility.

All facilities affiliated with the National MS Society offer MS related services, such as diagnostic and treatment services, ongoing medical and symptomatic management, nursing services, patient and family education rehabilitation, case management, counseling and supplemental services. The following are also MS Centers or Clinics affiliated with the Greater Illinois Chapter:

 Rush University Medical Center, 1725 West Harrison St., Chicago 312-942-8011

 University of Chicago MS Center, 5758 Maryland Ave., Chicago 773-702-6222

- Consultants in Neurology MS Center, 1535 Lake Cook Road, Northbrook, 847-509-0270
- Central Illinois MS Center Koke Mill Medical Center,

3132 Old Jacksonville Rd., Springfield 217-862-0422

- Northwestern University MS Center
  675 N. St. Clair, Chicago,
  312-695-7950
- Loyola University Medical Center MS Center, 2160 S. First Ave., Maywood, 708-216-8408
- Neurologic Associates MS Clinic, 11824 Southwest Hwy., Palos Heights 708-361-0222

#### **Carnivale Hits New Heights**

et the good times roll!" Brie Peoria got a taste of New Orleans this past February when Carnivale came to town. And once again, this annual fundraising event exceeded all expectations by raising a recordbreaking \$121,000 to benefit the National Multiple Sclerosis Society, Greater Illinois Chapter. Mik

Carnivale took place at the Hotel Pere Marquette in Peoria and featured a festival of entertainers, games, prizes, a silent auction and raffle. In addition, musical performances by the Prohibition Orchestra and JammSammich kept the crowd entertained and energized.

"Each year this event gets bigger and better and we couldn't be more thrilled to be able to provide such meaningful support for research and programs for people living with MS," said Mike O' Brien, co-chair of the event. "The gen-

> erosity of the Peoria community was clearly evident that night and we made a difference for tens of thousands of people."

## A huge 'Thank You' goes to the 2007 MS Carnivale Committee:

Mike O'Brien & Wendy Kolbus, CO-CHAIRS Pam Shaheen, Amy Paul, Jeff Ward, Jim Scherer, Kim Mitchell, Tracy Sutter, William Mayo, Mark Voudrie, Sue Atherton, Noreen Dillon, Craig Olmstead, Brian Jockisch, Susan Newton, Tracy Sutherland, Mary O'Donnell, Danielle Pflederer, Mike Lechwar, Craig Olmstead, Allison MorseJoy Klintworth, JoEll Allen, Larry Wallden, Gail Mayo, Lisa Emerson

Volunteers Needed for Physical Activity Study Researchers in the Department of Kinesiology and Community Health at the University of Illinois Urbana Champaign are currently recruiting individuals with MS for a voluntary study that examines the relationship between physical activity and quality of life. Anyone interested in more information about this study should contact Rob Motl by email eplii@kines.uiuc.edu or phone (217) 244-1191.

## **MS** Clusters

he University of Illinois College of Medicine at Rockford recently released findings from its fiveyear study of perceived MS clusters in Illinois. Responding to expressed con-

cerns about higher prevalence rates of MS and potential environmental triggers, the study, funded by the Agency for Toxic Substances and Disease Registry, looked at five towns: Paw Paw, Lewistown, Morrison, Savanna and De Pue.

The Chapter is supporting efforts to secure additional grant funding to study 13 counties.

high at 340 diagnoses per 100,000 for the five cities combined, which translates to one out every 300 women in the study area.

> Even though environmental causes were suspected as being associated with MS by residents, the research could not find definitive evidence of an association or causal relationship. Additionally, genetics is thought to play a part in MS and 11 of the study participants with MS had a blood relative with the disease.

#### Both De Pue and Savanna

are EPA Superfund clean-up sites and Lewistown residents were concerned about sprays of sludge. Morrison and Paw Paw were targeted because of concerns about potential increased rates of disease in the community.

The National Health Interview Survey, the National MS Society and the Mayo Clinic provide standards for identifying typical prevalence rates for MS in communities. These range from 85 diagnoses per 100,000 people to 100 diagnoses per 100,000 people to 177 diagnoses per 100,000 people respectively.

#### **Findings**

The study found that, although the overall prevalence rate for the five communities fell within normal ranges, Paw Paw, Lewistown and Morrison did have elevated rates. Additionally, the MS prevalence rate for women was especially The idea that small towns such as the ones studied may be home to numerous related persons may also be a contributing factor to the increased prevalence rates.

Overall, the exact reason for the prevalence was not determined. Cluster studies have not yet produced clear evidence pointing to a definite trigger for MS.

## What is the Greater Illinois Chapter Doing?

The Chapter supported efforts to secure the original grant for the study and promoted information about it in publications and mailings to select cities. Additionally, several of the Chapter's Support Groups, including Lewistown and Morrison served as sounding boards for discussion and informational resources. The Regional Manager of the Central Region attended several hosted community meetings with the Coordinator of the study and provided educational materials and resources to MS Support Groups in the five community areas.

Additionally, the Chapter is supporting efforts to secure additional grant funding to study 13 counties: Boone, Bureau, Carroll, DeKalb, Henry, Jo Daviess, La Salle, Lee, Ogle, Rock Island, Stephenson, Winnebago and Whiteside. If you are interested in enhancing awareness through existing support groups or starting new groups as the study progresses, please contact Carol Choutka, Manager Regional Programs at 309-282-2466 or Linda Powless VP of Programs at 312-423-1127.

For more information on the results of the first study, contact:

Joel Cowen, Principal Investigator Barbara Sjostrom, Project Coordinator Health System Research University of Illinois College of Medicine Rockford 1601 Parkview Avenue., Rockford IL 61107 (815) 395-5639 or toll free 1-800-854-4461 Email: joelc@uic.edu or barbsjos@uic.edu

SOURCE: HEALTH SYSTEM RESEARCH: PREVALANCE OF MS IN FIVE SMALL ILLINOIS COMMUNITIES FINDINGS

#### msconnection MAY 2007

Publication of the National Multiple Sclerosis Society, Greater Illinois Chapter

910 West Van Buren, 4th Floor Chicago, Illinois 60607-3523 рноме: 312-421-4500 800-FIGHT-MS FAX: 312-421-4544 E-MAIL: cgic@ild.nmss.org

> Lynda M. Chott PRESIDENT

**CONTRIBUTORS** Danielle Estler Coleen Friedman Jackie Guthrie Chaunda Roseborough-Smith Jason Sommer Jeremiah Worth

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

Information provided by the Society is based upon professional advice, published experience and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National Multiple Sclerosis Society recommends that all questions and information be discussed with a personal physician. The National Multiple Sclerosis Society is dedicated to ending the devastating effects of MS.

© 2007 NATIONAL MULTIPLE SCLEROSIS SOCIETY, GREATER ILLINOIS CHAPTER

## 2007 Legislative Issue Priorities

he Greater Illinois Chapter joins chapters across the United States to fight for Federal Issues that impact individuals living with MS. Here are the top priorities in 2007:

#### Medicare Wheelchair Coverage

The National Multiple Sclerosis Society is lobbying Congress to lift current Medicare "in the home" restrictions that, to date, have meant that beneficiaries can only access mobility devices for use in the home. By lifting the restriction, more beneficiaries will be eligible to receive wheelchairs or scooters that will help them get around their homes and outside in their communities.

The MS population provides a clear example of the problem with Medicare's "in the home" coverage limitation: People with MS face a chronic disabling condition that is variable and unpredictable. They can have significant functional loss and complex, clinical issues that require specialized medical care. For people with MS who need mobility



equipment outside their homes—due to nervous system damage or other adverse effects of the disease — the current policy poses a major access barrier.



#### Embryonic Stem Cell Lines Available for Federally Funded Research

As expected, the new stem cell research bill was one of the first things considered by the 110th Congress. On January 11, the House of Representatives passed H.R. 3, the Stem Cell Research Enhancement Act, by an impressive vote of 253-174. The Senate is expected to address the legislation in February. If passed, President Bush has again vowed to veto the legislation.

To find new ways to prevent, slow the progression, or repair the devastating effects of multiple sclerosis, the National MS Society supports the conduct of scientifically meritorious medial research, including research using human cells, in accordance with federal, state, and local laws and with adherence to the strictest ethical and procedural guidelines. The Society believes that 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.

Similar to the previous version, this legislation allows federally funded research on new stem cell lines generated from excess embryos that would otherwise be discarded from in vitro fertilization clinics. But

it also establishes strict ethical guidelines. Donors would be required to provide written consent to donate the embryos for research and could not be paid for the donation.

For more information on symptoms the Society's stem cell research position, read our white paper at: <u>www.nationalmssociety.org/pdf/researc</u> <u>h/nmss\_stemcell\_statement.pdf</u>

#### **Generic Biologics**

Currently there is no generic competition for one of the fastest growing and most expensive category of drugs known as biological drugs or biopharmaceuticals. The pending "Access to Life-Saving Medicine Act" would allow FDA to approve abbreviated

The Society believes that 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.



applications for generic versions of biotech drugs licensed under the Public Health Services Act.

Generic drugs (first made possible under the 1984 H a t c h - W a x m a n Amendments) have been extremely successful in bringing down the high cost of prescription drugs. Generic drugs save patients and payers \$10 billion a year. But there is currently no statutory pathway for approving lower

cost versions of biotech drugs licensed under the Public Health Services Act, even after all patents have expired. Introducing fair competition for biotech drugs could be essential to keep the lifealtering treatments affordable as well.

For more detailed information and to get involved, please join the Action Alert Network. Visit <u>msillinois.org</u> to learn more.

## 3T Imaging, MS Society Team Up to Provide MRIs

hanks to a new partnership between the National MS Society, Greater Illinois Chapter and Morton Grove-based 3T Imaging, people living with MS who can demonstrate financial need will have access to the MRI services that have proved to be

the most effective tool in diagnosing and tracking the progress of MS.

Experts agree that magnetic resonance imaging (MRI) scans are the most sensitive non-invasive way of imaging the brain, spinal cord, or other areas of the body. Demyelination, or the

destruction of myelin—the fatty sheath that surrounds and protects nerve fibers—causes nerve impulses to be slowed or halted and produces the symptoms of MS. MRI is particularly useful in detecting central nervous system demyelination, which makes it especially beneficial in establishing a diagnosis of MS.

Subsequent scans following a positive MS diagnosis may prove useful in track-

ing the progress of the disease, or possibly helping to establish a prognosis a prediction of the course of a disease. However, MRIs are expensive and, particularly for the uninsured or underinsured, the technology is not easily accessible.

The company

donated \$5,000 to

the 2007 MS Walk and has generously donated

\$15,000 in services to offset

the cost of MRI

at its facility.

accessing MRI is critical to helping people living with MS most effectively manage their disease," said Lynda Chott, President of the National MS Society, Greater Illinois Chapter. "We are committed to making sure that this technolo-

"There's no doubt that

gy is available to all who need it."

3T Imaging, a physician-owned and operated medical diagnostic outpatient facility, provides Ultra High Field 3 Tesla MRI, the only such magnet available in an outpatient setting in the Chicago area. Ten times more powerful than the typical Open MRI and twice the strength of the 1.5 Tesla MRI available in most hospitals, their product offers faster scan times and more detailed imaging.

# OF MORTON GROVE

Toll-Free Number: 1-800-FIGHT MS

SPRING 200

"In the spirit of fighting MS by directly affecting the lives of people with the disease, the physicians at 3T are proud to partner with the Greater Illinois Chapter," said Dr. Steven Goldin, Director of 3T Imaging. "We offer a unique combination of patient care and commitment to technology and we are proud to make this available to clients of the National MS Society."

The company donated \$5,000 to the 2007 MS Walk and has generously donated \$15,000 in services to offset the cost of MRI at its facility. The free MRI services will be a part of the Chapter's Direct Assistance Program and will only be available for those clients who meet the criteria for Direct Assistance and who have also received a referral from their physician. Clients who do not qualify for the Direct





Assistance may still call or visit the center with a standard prescription for imaging from their physician.

If you believe that you could benefit from MRI services, to either confirm a diagnosis or monitor the progression of your MS, be sure to tell your physician about this exciting new program.

For more information, call 1-800-FIGHT MS or visit <u>msillinois.org</u>.

Visit our Website at: www.msillinois.org

## Young Fundraiser Makes a Big Difference

eremy Handley was up for a challenge. The 12 year old was already an avid cyclist, having earned his cycling merit badge in Boy Scouts. And his family had long instilled in him the importance of giving back to the community.



So when he learned about the National Multiple Sclerosis Society's MS Bike Tour last year, he saw an opportunity to help raise money to find a cure for MS, learn more about the disease and spend some time biking with his family. Signing up for the ride was a no-brainer.

But what started as a simple premise has turned into a major accomplishment for one special young man who is bringing a lot of hope to more than 20,000 people who are living with MS in Illinois. Increasingly interested in the cause, Handley registered with his mom for the two-day MS Bike Tour during which participants can cycle a total of 35, 70, 150 or 175 miles.

The late wife of Handley's basketball coach, Maria Walsch, served as his Mission Star – the inspiration for training, fundraising and completing the ride.

Handley knew a little bit about MS. Multiple sclerosis is typically not a fatal disease, but Walsch had been among the rare cases when a patient dies of complications from MS.

Handley committed to learning as much as he could about MS and set about educating others about the disease – and soliciting donations. That's where he got creative.

He collected money at his school, St. Barbara in Brookfield and helped orchestrate an out-of-uniform day where students who donated 50 cents or more could wear something besides their required uniform to school.

Jeremy raised donations from friends and family and his parents, Michelle and Jeff, tapped into co-workers. The result was an outpouring of donations – and a realization that so many of the people they knew had also been touched by MS.

"We started finding all these connections where everyone seemed to know someone with MS," Michelle Handley says. "That's how [Jeremy] realized he needed to stay with this."

By raising more than \$2,000, Jeremy Handley became the youngest person named to the MS Bike Tour's Gold Spokes group – the event's top 150 fundraisers.

This year, Jeremy is back on board for the MS Bike Tour, which will take place on June 22-24 in DeKalb, and he has identified a new set of Mission Stars, a brother and sister who are living with MS.

You can join Jeremy and more than 2,000 other cyclists at the 2007 MS

Bike Tour. Register today at <u>www.RideForMS.org</u> and get ready for an unforgettable cycling adventure.



#### MULTIPLE SCLEROSIS STOPS PEOPLE FROM MOVING WE EXIST TO MAKE SURE IT DOESN'T

Multiple sclerosis interrupts the flow of information between the brain and the body and stops people from moving. With the help of people like you, the National MS Society addresses the challenges of each person whose life is affected by MS and helps them stay connected to the great big moving world.

Join the movement at nationalMSsociety.org



National Multiple Sclerosis Society Greater Illinois Chapter

Carole, diagnosed in 2005 Geoffrey, diagnosed in 1987

Visit our Website at: www.msillinois.org

## Advocating for You

id you know it costs an estimated \$50,000 each year, with a lifetime cost of more than \$3.2 million, to pay for the medications, medical equipment, therapy and other costs associated with treating multiple sclerosis?

For many, the out-of-pocket costs associated with treating MS can pose a significant, sometimes insurmountable, financial hardship – one that often means patients can't afford all the care they need.

Assistance is available – if you're willing to advocate for yourself. Take it from Jenny.

Diagnosed at age 25, Jenny has lived with MS for 15 years. Today, her symptoms have progressed and, with limited mobility, she has determined that she needs a scooter to get around.

Determining how to pay for the scooter, however, was another story. After contacting several providers, Jenny was shocked at how expensive scooters were to purchase. With her limited income and the cost of her disease, she couldn't afford to buy one.

Jenny was faced with a decision: give up on accessing a scooter, stay at home, rely on others to get to appointments and quit her part-time job. OR, keep fighting to protect her independence.

Jenny chose to fight. She learned about

the Direct Assistance program offered by the National MS Society, Greater Illinois Chapter. By accessing support from the program's coordinator, she learned about additional resources available through insurance and other sources.

She continued to work with her doctor and physical therapist to secure the prescription and evaluation needed to secure durable medical equipment from a vendor.

Thanks to the Direct Assistance Program, she could access the funds to cover the co-pay for her new scooter. It didn't happen overnight and the process wasn't without its share of frustrations, but because she stuck with it, today Jenny has her scooter – and the ability to stay active in her community.

You can be an advocate for yourself as well. If you have financial needs related to your MS, contact the Chapter's Direct Assistance program for help. No one should go without the services they need to stay healthy and active.

You can also be an advocate for others by supporting the Direct Assistance program. The program is funded through the State Income Tax Check Off program. You can donate to the Multiple Sclerosis Fund when you file your Illinois Income taxes or you can donate by calling the Chapter at 1-800-FIGHT MS.

H

VENTS

## Skydiving for MS 10 - MSX

ooking for a unique way to raise money for multiple sclerosis? Ever wonder what it feels like to soar two miles above the ground at more than 120 mph? Here's your chance to check it out.

The 10th Annual Skydiving for MS – MSX is June 9. Join organizers for a day of volleyball, horseshoes, airplane rides, live music, a raffle with great prizes and, of course, SKYDIVING!

Tandem jump times are available throughout the day. The event is fully accessible and open to all participants. Your tandem jump will be done with a certified instructor. The jump fee is \$209.99 and includes a short lesson, equipment, and the jump. Raise \$500.00 for the NMSS and receive a free tandem skydive. Raise \$750.00 for the NMSS and receive a free tandem skydive and DVD! A percentage of the jump fees will be donated to the Greater Illinois Chapter of the National MS Society to support advocacy and other programs for people living with MS.

Even if you'd rather keep your feet on the ground, you can still enjoy the day's excitement. For a \$25 registration fee, you'll get dinner, live music, and an event T-shirt. After a full day of activities, stick around for an evening of food, great music, and a huge bonfire party. Feel free to bring a tent and stay the night. There are showers available and accessible bathrooms on-site.

For more information or to book your jump call 1-800-404-JUMP(5867) or visit www.perfectlygoodairplane.com. Make pledge checks payable to NMSS with "Skydiving for MS" in the memo. For any additional info, contact event chairman Dave Perez at icyou88@sbcglobal.net.



Visit our Website at: www.msillinois.org

## **ARE YOU** 2007 MS BIKE FOUR JUNE 22-24, 200 WWW.RIDEFORVE.ORG



910 W. Van Buren St., 4th Floor Chicago, Illinois 60607

NONPROFIT ORG U.S. POSTAGE PAID CRYSTAL LAKE, IL 60014 PERMIT NO. 174

National Multiple Sclerosis Society Greater Illinois Chapter