

Getting the support you need

On the Web or face-to-face, find people who'll help you take charge of your MS. Meet three people who've done it.

Reaching out

"Some people don't want to tell their friends," James Sagen, 22, who lives in Washington, told **MS Connection**. "But I told mine, and their laughter and humor helped me get through the months after diagnosis. Then I began a live blog. By chance, one girl replied that she had MS, too. Now she's one of my best friends."



living with ms in your 20s and 30s

Just recently, James' Society chapter started luncheons for young people. "Meeting more young people with MS opened my eyes," James said. "It made me see you can live with MS comfortably."

Tara Lane was diagnosed in 2000 when she was getting married in Vail, Colo.

"I participated in Bike MS, and Walk MS events," said Tara, 37, who teaches figure skating. "That gave me the idea for an MS Skate-a-Thon. When I met another woman in the skating community who had MS, we started our own group, reaching out to more people. The greater my network is, the better educated I become."

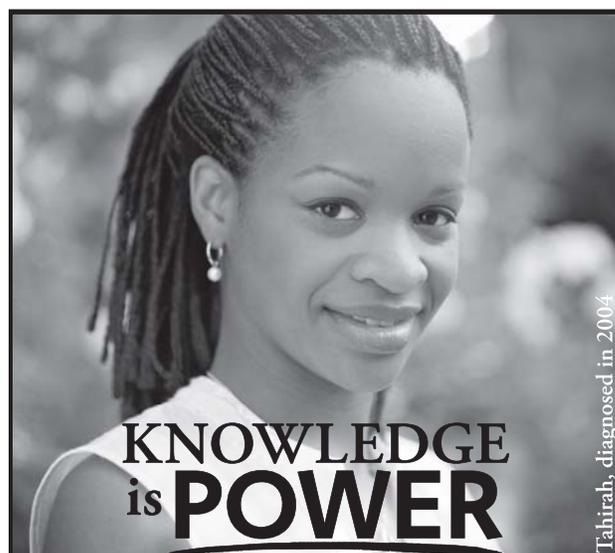
When Tiffany Jones went off to college, she decided not to disclose her MS on campus. "I have my family, the Society and members of

my church for support," the 20-year-old said. Tiffany, a dancer, attends Chicago's Trinity United Church, where she learned "praise dancing" —ballet dancing to gospel songs. Now as an MS Ambassador, she performs praise dancing at Society events to spread the word.

Take a step

If you'd like to increase your support network, **Real Talk. Real Answers. Living with MS in Your 20s and 30s**, sponsored by the Society and MS LifeLines can help. This online program provides young adults with an opportunity for candid and frank discussion and offers answers to some of the questions that they have about living with MS.

Visit **RealTalkRealAnswers.com**.



Knowledge is Power is a six-week, free, at-home educational program for people who are newly diagnosed. Mail or e-mail formats. To register, call **1-800-344-4867**, or visit **nationalmssociety.org/knowledge**.

Join the movement.



move it.

Access life skills online

The right introduction can open all sorts of doors—to new friends, a job, or a new way of thinking about problems.

The Web site livinglifetothefull.com offers a free and easily accessible online course on life skills that can help people change negative patterns of thinking.

When to get professional help

The online course is no substitute for one-on-one time with a professional therapist. But it can help people who have been hesitant about getting help—whether because of time, money, or simply not knowing where to start. It's also a good introduction to cognitive behavior therapy, a form of therapy that focuses on helping people change how they think about their problems.

A spectrum of life skills

"MS is an unpredictable disease, and that unpredictability can cause a world of anxious feelings," said Rosalind Kalb, PhD, vice president of the Society's Professional Resource Center. "Living Life to the Full won't make that go away. However, it helps you identify any self-defeating thought patterns that aren't getting you anywhere," said Kalb.

Module topics range from practical problem solving to building confidence. Kalb particularly likes the one on sleeping. "Sleep problems are very common in MS," she said. "This was a very good introduction to learning how to start helping yourself by using better sleep habits."

Click onto MS Learn Online®

MS Learn Online® celebrates its 10th year of online educational programs with a slew of new features and an all-new player.

Round the clock information

"The programs are available 24/7," said Julie Gibson, a special project consultant with the Society's Programs and Services department. "There's likely something for everyone." The upgrade was funded in part by Teva Neuroscience and EMD Serono/Pfizer, Inc.

The player features three channels of programming:

- **The Feature Presentation**, a 10-to-12-minute webcast on a range of topics. New presentations go live the first and third Thursday of each month.
- **The Daily Minute**, a one-minute factoid about MS every day of the week.



MS Awareness Week March 2-8, 2009

nationalMSsociety.org

- A once-a-week **Q&A** where an MS Learn Online expert answers viewers' questions. Email mslearnonline@nmss.org.

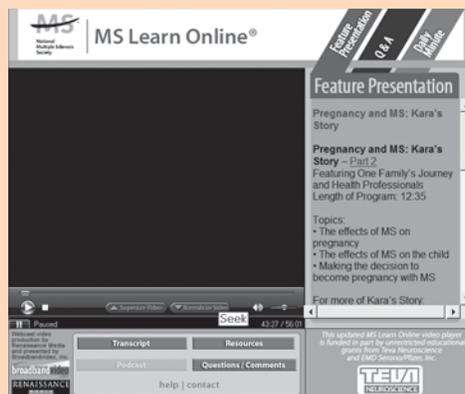
Extra, extra

Some upcoming topics include MS and the workplace, pediatric MS, medical self-advocacy, progressive MS, parenting with MS, and more. Each program features a guest expert interviewed by correspondents Rick Sommers or Kate Milliken, who themselves have MS. "They understand what our audience is living with," Gibson said. "They have their own personal angle on each topic."

How to use the new player

The player launches when you click any topic at nationalMSsociety.org/mslearnonline. It works best with Microsoft Windows; Apple users may need to buy the program WMV Player Pro at flip4mac.com/wmv.htm in order to use the player.

Visitors can download a PDF or an mp3 podcast, if they prefer to read or listen to the program. E-mail mslearnonline@nmss.org for notifications of upcoming programs.



The CHOICE option

More choices for people who prefer to listen because they find reading for fun fatiguing, difficult, or impossible: CHOICE Magazine Listening enables people with disabilities to keep up with the best

in current magazine writing. Produced on two four-track cassette tapes six times a year, CHOICE provides unabridged articles, read by professionals, from such quality publications as **National Geographic**, **Smithsonian**, **Sports Illustrated**, and **The New Yorker**. The articles, short stories, poetry and interviews are selected from more than 100 magazines and other periodicals.

CHOICE Magazine Listening is available free of charge not only to people who are blind, but to anyone who is experiencing vision loss or has other disabilities that limit or prevent reading standard print.

A four-track tape player is needed for listening to these tapes, but it too is free. For information on subscribing and obtaining the free tape player visit choicemagazinelistening.org or call 1-888-724-6423.

Amendment restoring ADA protections passed

MS activists and others in the disability rights movement changed the course of history when they helped to push the ADA Amendments Act through Congress. President Bush signed the legislation in September 2008.

The Act became effective January 1, 2009, bringing millions of people back under the protection of the Americans with Disabilities Act of 1990 (ADA).

How the ADA was eroded

As originally written, the ADA was designed to ensure that all people with disabilities

could receive reasonable accommodations in the workplace.

But over time, court rulings narrowed the definition of “disability” to exclude those who could “control their symptoms.” This

included people with MS responding well to their disease-modifying drug.

Sen. Tom Harkin, D-Iowa, the chief sponsor of the ADA Amendments Act, described the situation: “The more successful a person is at coping with a disability, the more likely the court will find that they are no longer disabled and therefore no longer covered under the ADA.”



The new Act reverses four Supreme Court decisions that had eroded ADA coverage for people with MS and other conditions, including diabetes and epilepsy, that are controlled by medication, are episodic and/or do not always severely restrict major life activities.

New protections

Starting this January, courts may not consider “mitigating measures” such as prescription drugs, hearing aids or artificial limbs. The new law says “an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active.”

To learn more about this historic bill, and the protections it provides, visit adabill.com.

Coalition moves to end the Medicare wait

In November 2008, more than 75 organizations, including the National MS Society, launched a national campaign to end the two-year waiting period for health-care coverage through Medicare that follows a person’s initial approval for Social Security Disability Insurance.

An unjustifiable delay

The newly formed Coalition to End the Two-Year Wait released a letter to members of Congress, urging them to end the “unjustifiable delay” for Medicare. The coalition declared its support for the **Ending the Medicare Disability Waiting Period Act**, sponsored by Sen. Jeff Bingaman (NM) and Rep. Gene Green (Tex.). Green attended the kickoff event on November 12, 2008. When the 111th Congress convened this

Activists secure \$5 million for MS research

MS activists made history last fall when they moved Congress to approve \$5 million for MS research through the Congressionally Directed Medical Research Programs (CDMRP). This is the first time that MS has received a line item allocation under CDMRP, which is funded through the Department of Defense (DOD).

Activism victory

The movement to obtain MS research funds from the DOD began in late 2006 when activists collected more than 100,000 signatures.

Activists participated in hundreds of congressional meetings, took the case to the media and town hall forums, and collaborated with members of the American Academy of Neurology, the Paralyzed Veterans of America, United Spinal, AMVETS, the Vietnam Veterans of America, and the Disabled American Veterans to petition Congress.



January, the bill was reintroduced in both the House and Senate. The bill had wide support during the 110th Congress with 103 co-sponsors in the House and 23 in the Senate.

“Sick and uninsured”

In a statement for the coalition, Yvonne Brown described her long and awful journey to get health-care coverage after her diagnosis with MS in 2000.

“I had nearly 40 unfilled prescriptions that would have helped treat my MS and associated symptoms,” she said. “I would take one pill every other day rather than two pills twice a day to stretch my supply. With my disease-modifying drug, I would administer that injection every other week instead of once a week as prescribed. Because of this constant worry, I developed severe hives,

all due to the stress of unpaid medical bills, being homeless, being sick and uninsured.”

Too high a cost

According to the coalition, 1.5 million people are waiting for Medicare coverage.

Brown is now insured through Medicare. But, she said, “I struggle daily with the devastating financial effects and health consequences of living through the Medicare two-year wait period.”

Get moving

To learn more about the coalition and get involved in MS advocacy, visit nationalMSsociety.org/advocacy, where you can sign up to receive news and updates on health policies, help find solutions to MS issues, and take action on legislation that matters.

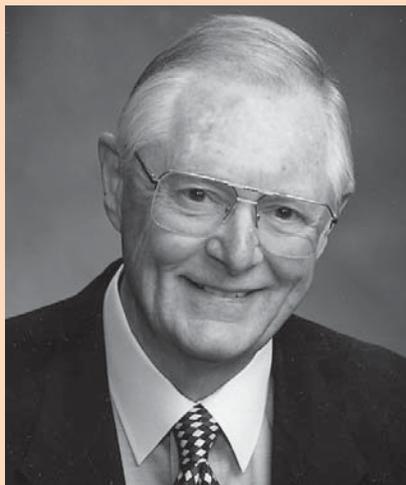
Historic conference motivates new MS researchers

Last fall, nearly 100 Society-sponsored young research fellows met in Chicago to share information, generate new ideas, and strengthen their commitment to MS research.

The Tykeson Fellows Conference featured talks by 21 fellows, in addition to presentations from more seasoned investigators, including a keynote address by Stanford University's Lawrence Steinman, MD.

Presenters analyzed what is known about the development of MS—and the roles played by genes and the immune system. Fellows discussed their work on strategies to stop MS immune attacks, including:

- Yueting Zhang, PhD (Mount Sinai School of Medicine), who presented findings from a team led by her mentor Gareth John, VetMB, PhD, on an immune messenger protein called interleukin-11 that promotes the survival and maturation of myelin-making cells.
- Philip L. De Jager, MD, PhD (Brigham & Women's Hospital), who reported on his team's finding that CD58, a possible MS susceptibility gene, appears to contain genetic variations that affect inflammation and nerve degeneration separately, suggesting that they might be two different genetic processes.



The conference was sponsored by a generous contribution from Donald Tykeson, Honorary Life Director of the Society's National Board of Directors, with additional support from Avanir Pharmaceuticals, Biogen Idec, Genentech, and the Society's Wisconsin Chapter.

Moving to the next level

Held in conjunction with the Society's National Conference, the Tykeson Conference offered young scientists a chance to meet people who live with MS every day.

"You can read about MS in medical papers," said fellow Jennifer Kanter, PhD (Harvard University, Boston), "but what you learn from talking to someone with the disease is so much more real." She knows this personally because her father had MS.

Dr. Kanter does the 50-mile Challenge Walk MS with her mother and sister. At the National Conference she

encouraged her colleagues to participate in the Society's WalkMS and BikeMS events. "If you want to feel the happiness that you get when an experiment goes well, go to a Society event—you'll feel it every time!"

Moving forward

"This first-ever Tykeson Fellows Conference was a resounding success," said Patricia O'Looney, PhD, vice president of Biomedical Research at the Society, who is already planning the next meeting.

The second Tykeson Fellows Conference will be held in 2010 in conjunction with the joint annual meeting of the Consortium of MS Centers and ACTRIMS (Americas Committee for Treatment and Research in MS).

Smart tax prep for people with MS

by Martha King

Deductions, exclusions and credits that may apply to YOU

Taxes pay for many things we all need. But that doesn't mean any of us should pay a penny more than the law requires.

IRS Publication 907, Tax Highlights for Persons with Disabilities has important details for you or your tax preparer. It's downloadable at www.irs.gov or telephone **1-800-829-3676**.

- **Gross Income:** Supplemental Security Income (SSI) and certain veterans (VA) disability benefits are excluded from your gross income. However, Social Security Administration payments may be taxed, and income from disability insurance that was **paid for by your employer** (or former employer) is taxable. See IRS publication 525.
- **Impairment-Related Work Expenses:** If a physical or mental disability limits your ability to function as an employee, you may be able to deduct **work** expenses related to that impairment. Examples: wages for an on-the-job personal care attendant, or the cost of a text-to-speech computer program. See IRS publication 907 for details.
- **Medical Deductibles:** You may deduct your medical and dental expenses for the year to the extent that they exceed 7½% of your adjusted gross income, with a few exceptions. You may count the cost of home improvements or equipment to alleviate your physical or mental condition as medical expenses. Examples include
 - installation of ramps or air conditioning,
 - the amounts paid to purchase, train and maintain a service animal, and more. See IRS publication 502.
- **Dependent Care Credit:** If you pay someone to care for a dependent person so that you can work or look for work, you may claim a credit for those expenses. The dependent can be your spouse or another adult who lives with you, even if that person has some income, as long as he/she is physically or mentally unable to be left alone. See IRS publication 503.
- **The Earned Income Credit (EIC):** You may be due a cash payment if you worked in 2008 for a low annual wage — up to \$12,590 for a single person with no dependents and up to \$39,783 for a married couple, filing jointly, who have more than one dependent child. To get the check, you have to apply. See Publication 596.
- **Credit for the Elderly and Disabled:** Low-income individuals with taxable disability income may qualify for a tax credit. See Publication 524.

Start planning now. Get free help from the IRS at 1-800-829-1040. Call early, not on April 14th!



Bike or walk your way to ending MS

Clayton Giraudin still has the bicycle that he rode at his very first Bike MS event 10 years ago.

“I rode on a mountain bike given to me on the Donnie and Marie Show,” Clayton, the recipient of a 2008 Society scholarship, remembered. He and his mom, who has MS, appeared on the show to talk about the disease. “It was a little blue bike.”

He had decided to participate in the event with his older brother, Scott. “We both felt it was something we wanted to do for our mom.” Unfortunately, Scott left little Clayton, at the time 10 years old, behind—way behind. “I was, I believe, one of the last 13 people to come in,” he said.

But that didn’t deter Clayton, who has ridden every year since then—although not on the same bicycle. “In the future, I hope to do Bike MS events on a BMX bike,” he joked. “But seriously,” he added, “I enjoy doing something for a good cause while doing something I’m passionate about, like biking.”

How to get moving

Hundreds of Walk MS and Bike MS events take place across the nation. Call 1-800-344-4867 or visit walkms.org or bikems.org, where you can search by ZIP code or month, or click on a region to bring up a scroll-down menu with a list of local events.

Online maps display event locations; click on them for additional information. Events are rated “easy,” “moderate,” or “difficult.” Choose what’s comfortable for you.

Once you’ve picked your event, click “Join the Ride” or “Join the Walk,” which will help you find and contact the chapter organizing the event.

Join the team

All you need to form a team is four participants. Once registered, choose your team’s name and set a team goal. You can design team T-shirts and hats and receive a team picture. Forming a team will guarantee that you’ll be walking or biking in great company.

Other ways to participate

Click on “Sponsor a Walker” or “Sponsor a Rider” at the walkms.org and bikems.org sites if you want to sponsor a particular person. Or follow the links to a local event to make a general donation.

