

Spring/2006

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msconnection

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Research Highlights

Martha Montgomery Tribute

artha Montgomery was a great friend, wife, volunteer and Champion for MS. She passed on Wednesday, January 11, several days after sustaining severe injuries in a fall. Martha was loved by many and loved everyone that she came in contact with through her church, her community and her MS. Everyone associated with

the Kentucky-Southeast Indiana Chapter of the National Multiple Sclerosis Society will miss her.

We asked people that she knew to share a few of their thoughts about Martha...

"Like many people, I admired Martha for her kindness, her sense of purpose and her humor. Despite her MS, Martha would often speak of the many blessings in her life, especially her husband, Grover. A while ago Martha gave me a little prayer rock to remind me to take time out of the day and count my own blessings. I carry that little



rock in my lab coat and now feel as though I also have an Angel in my pocket."

> Julie Naville, OTR/L, MSCS Director, Occupational Therapy Baptist Hospital East

"Martha was ALWAYS there with a smile and did what needed to be done."

Earl Shiring Vivid Impact Former Chapter Board Chair

"Martha was the 'glue' that kept our group together. If it weren't for Martha, there probably wouldn't be as many self-help groups in Kentucky. Martha was the first person I met with MS after I was diagnosed in 1978. She was at the first meeting I went to in 1979 at the "old" Baptist Hospital on Baxter Avenue. Martha was always so friendly, upbeat, helpful, thoughtful, generous, shared her advice and her home. She loved everyone, and everyone loved her. She was "one" in a million as far as being the most wonderful person I

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msconnection SPRING2006

502-451-0014 or 1-800 FIGHT MS

Publication of the National Multiple Sclerosis Society (Kentucky-Southeast Indiana Chapter)

Chairman Mark Carter

Vice Chairman Don Gerard, Jr.

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Chapter President Douglas Dressman

Newsletter Editor Kelley Reeves

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. National MS Society medical advisors recommend that people with MS talk with their health care professionals about taking one of these medications and about strategies and effective treatments to manage their symptoms.

If you or someone you know has MS please contact the National Multiple Sclerosis Society today at www.nationalmssociety.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.

The National Multiple Sclerosis Society is dedicated to ending the devastating effects of MS.

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LETTER FROM THE PRESIDENT

s it Spring yet?!?!? What a busy time of the year for us all, including our staff and volunteers as they prepare for the many programs and events that help to define who we are and what we do.

Maybe we met at Louisville WAMS on February 16, or we will meet at the Louisville or Lexington MS Walks on April 15, or in Paducah at the MS Walk on April 22. Are you registered? If not, go to www. kynmss.org and sign up! Make sure you introduce yourself to me at the MS Walks.

We have many programs planned across the Chapter during the coming months. I will be at some; staff will be at them all. Please stop us and say "hello" and share with us how we can be of additional service to you and your loved ones.

As always, I encourage you to feel free to email me at doug.dressman@kyw.nmss.org, call me at 502-451-0014 or 1-800 FIGHT MS, ext.223, or write to me at the Chapter office, 11700 Commonwealth Drive, Suite 500, Louisville, KY 40299, if you have any questions, suggestions or comments regarding the work of the Chapter or the National MS Society.

Thank you for your continued support and involvement.

Sincerely,

Douglas C. Dressman Chapter President

How doctors know it's MS: The McDonald Diagnostic Criteria

he famous trickiness and variation of MS is part of the disease from the very beginning. There is no single examination or test that positively proves a person has MS. Instead physicians rely on a set of diagnostic criteria—a group of results. Taken together, they rule out any other possible explanation for MS-like symptoms and provide facts consistent with MS.

A new need for speed

Many people with MS tell a story of seeing doctor after doctor, and a frustrating period of confusion before their disease is finally named.

Today, the time between initial symptoms and a diagnosis may be a medical as well as a personal crisis. All the treatments available to help control relapsing forms of MS work best the earlier they are started.

A long delay between symptoms and diagnosis may represent lost opportunity as well as painful uncertainty.

The National MS Society has taken the lead in helping physicians arrive at a definitive diagnosis by organizing meetings where experts hammer out standards.

The International Panel on Diagnosis of MS, organized in 2001 by the Society with support from the MS International Federation (MSIF), brought experts together to agree on what combinations of facts can only mean "this is MS." The panel created the "McDonald Criteria," named in honor of Dr. W. Ian McDonald, who chaired the 2001 panel.

New in 2005

The work did not stop then. In 2005, the 14-member panel was reconvened, chaired by Dr. Chris Polman. The group reviewed new research and sought input from leading MS practitioners worldwide. The 2005 Revisions to the McDonald Criteria was published in the December 2005 Annals of Neurology.

Most of the changes reflect recent data about MRI results. The changes mean that some people who will be asked to have two MRIs may know their results in about a month, rather than a much longer time. Most people may forgo a spinal tap, provided other findings clearly point to MS. And, as in the original criteria, some people with crystal clear signs



Dr. Aaron Miller, chairman of the Society's Medical Advisory Board, gives a patient a clinical examination.

How doctors know it's MS (continued)

and symptoms may need no MRI at all. The revisions frame the questions so that doctors can get clearer answers sooner.

One major aspect has not changed: objective, measurable evidence of MS has

The main types of evidence

- Medical history—From medical records and questions the doctor asks about you and your family.
- Clinical exam—Some are simple observations; for example, how easily you move or respond.
 Other parts of a clinical exam involve direct examination and on-the-spot tests.
- Laboratory results—These may include information from MRI scans, spinal taps, blood work, "evoked potential" tests, and possibly more.

to be interpreted. No general practice neurologist should be offended if individuals or insurance providers ask for a second opinion by an MS expert.

Getting the word out nationwide

New criteria won't speed diagnosis unless physicians know about them. The Society is affiliated with 150 MS clinical centers in the United States, and through referral programs is in contact with thousands of other professionals with an interest in MS. As soon as the revisions were available, the Professional Resource Center prepared a professionals' tip sheet, mounted it on our Web site (nationalmssociety.org/dx-tipsheet), and notified all chapters.

A laminated pocket card was published this January and offered to all chapters for distribution.

Finally, the Professional Resource Center provides one-on-one consultation to professionals via e-mail on a range of MS questions, including diagnosis.

NEWS

PROTECTING TEETH FROM MS

MS affects teeth?

Yes, it can, indirectly. Numb hands or fatigue may mean less effective brushing and flossing. Medications may affect tooth health. Some cause dry mouth, for example. Periodic steroids for MS attacks can increase the risk of tooth decay. And MS can absorb so much room on a personal health-care calendar that regular dental visits drop by the wayside.

Protect yourself from future problems. Smile and download a copy of **Dental Health:** The Basic Facts at nationalmssociety .org/dental.

No Internet? No problem. Call us and we'll mail you a copy.



MEDICARE RX ENROLLMENT DEADLINE MAY 15

If you need help making a decision about prescription drug coverage under Medicare, the Society has a list of resources at nationalmssociety.org/medicare. You will find:

- Tips on Choosing a Medicare Rx Plan
- The webcast "Medicare Drug Benefits: Understanding The Facts, Understanding Your Options."
- A link to Medicare's Web site where you can compare plans (click on Compare Medicare Prescription Drug Plans).
- A link to your State Health
 Insurance Assistance Program
 (SHIP), which offers one-on-one counseling and assistance.

Enroll by May 15 to avoid having a lifetime penalty added to your monthly premium. For help with problems, contact us at 1-800-FIGHT-MS (1-800-344-4867).

READY TO VOLUNTEER?

The National MS Society has joined **VolunteerMatch**, a national database that matches people who want to volunteer with volunteer openings at more than 35,000 nonprofit organizations across the country.

The Society is now one of them.
Using the service is easy. Go to
volunteermatch.org on the Web. You can
select organizations by their type, who
they serve, the distance from your home,
the training offered, and the positions cur-

rently open. More than 2 million people have used this service.

Some chapters previously listed volunteer opportunities with Volunteer Match. As of February 1, 2006, the entire national network of Society chapters and divisions is participating. VolunteerMatch will not only help us recruit the volunteers we need, it will help anyone interested in volunteering to match their personal skills and requirements to a range of choices available in our area.

CHAMPIONS BUDDY UP

Every year, hundreds Champions of thousands of event against MS. participants come together to walk, ride and fundraise to work towards ending the devastating effects of multiple sclerosis. A National Multiple Sclerosis Society program, Champions Against MS is a critical part of the fight against MS. Champions Against MS strives to connect people living with MS and MS Walk or Toyota MS 150 bike the bluegrass team participants. Paired Champions are encouraged to connect before, during and after the event. All it takes is a letter, e-mail and/or a phone call to acknowledge the importance of your Champion's involvement. This connection fosters education, awareness, gratitude, and most importantly, hope,



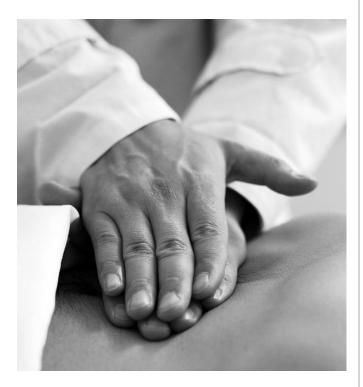
through the symbol of a bright red bandana. By joining Champions Against MS you "put a face on MS."

To learn more about the Champions Against MS program, visit our website at www.kynmss.org or call us at 1 (800) FIGHT MS.

The medium is the massage

assage therapy has been practiced for thousands of years, from ancient Greece and Egypt to India and China.

In the U.S. today, more than 150 kinds of massage therapy are used but most are variations of Swedish massage, which was invented in the 19th century.



What massage can do for you

Most of what we know about massage is anecdotal. In one small scientific study of 24 people with MS, massage appeared to improve self-esteem and body image.

Patricia Kennedy, RN, CNP, MSCN, a nurse practitioner at the Rocky Mountain MS Center in Colorado, told **MSConnection** that many of the people she sees report positive benefits.

"My patients use massage to relieve spasticity and pain," Kennedy said. "Massage can also provide a chance to relax, helping to relieve anxiety and fear. The simple act of touch conveys comfort, caring, and acceptance," she said.

A few cautions

Massage therapy is generally safe. However, consult a physician if you have:

- Pain. Get a recommendation for the best type of massage therapy for you.
- Pressure sores. While massage may be helpful in preventing pressure sores, it should be avoided if pressure sores or reddened areas of inflammation are present on the skin.
- Edema. Swelling caused by a buildup of fluid can have many causes. Get a diagnosis before beginning massage.
- Osteoporosis. People with MS tend to have lower bone mass and have a greater risk for fractures. When osteoporosis is present, massage therapy should be given only with the advice of a physician.

Write it off

Forget your insurance—few plans cover massage, and never long-term. But you may be able to write it off on your taxes as a medical expense. Kennedy said that many people get prescriptions from their doctors, which they save with their tax records. Consult with a qualified tax specialist.

People who knead people

Ready for a massage, but not sure how to find a masseuse? The American Massage Therapy Association can supply names of approved therapists. Most states also have licensing programs. Call us for massage therapists on our referral lists.

(continued next page, bottom)

Just been diagnosed? Start with the basics.

S isn't well understood yet, so there is plenty of misinformation about it. Here is some of what we do know:

- MS is not fatal. Statistics show that most people with MS have a near normal life span. Most deaths associated with MS are due to complications in advanced, progressive stages of the disease. Early treatment should help to prevent those complications.
- MS cannot be cured, but it can be managed. In addition to "disease-modifying" drugs, there are a number of treatments for MS symptoms. Go to nationalmssociety.org/Brochures-SpecificIssues.asp for free brochures on symptom management, or call us.
- The decision to tell anyone you have MS is yours. Our fact sheet, Disclosure: The Basic Facts, discusses both personal and work situations. Download a copy at nationalmssociety.org/Brochures-Disclosing.asp, or call us.
- Self-help groups and family counseling can help. Self-help groups bring together people who share a common life experience, for support, education, and mutual aid. Contact us for referrals.

Knowledge Is Power

This at-home study program provides a

basic education in MS, including symptom management, treatment options, disclosure, family issues, and employment. Sign up to receive the six weekly mailings (e-mail or snail) online at **nationalms** society.org/Knowledge, or call us.

If you need more

Other free publications are on our Web site at **nationalmssociety.org/ NewlyDiagnosed**. Or call us to request a list.

We also recommend:

The First Year—Multiple Sclerosis: An Essential Guide for the Newly Diagnosed, by Margaret Blackstone. Marlowe & Company, 2003, 232 pp., \$15.95.

Multiple Sclerosis: A Guide for the Newly Diagnosed, 2nd Edition, by Nancy Holland, RN, EdD, T. Jock Murray, MD, and Stephen Reingold, PhD. Demos, 2002, 160 pp., \$21.95.

Multiple Sclerosis: The Questions You Have—The Answers You Need, 3rd Edition, by Rosalind C. Kalb, PhD. Demos, 2004, 640 pp., \$39.95.

Books from Demos are discounted when you order from their Web site: **demosmedpub.com**.

The medium is the massage (continued)

- American Massage Therapy Association, 820 Davis Street, Suite 900, Evanston, IL 60201. Web: www.amtamassage.org. Phone: 877-905-2700.
- Touch Research Institutes, Department of Pediatrics, University of Miami School of Medicine, P.O. Box 016820, Miami, FL 33101. Web: www.miami.edu/touch-research. Phone: 305-243-6781.

What we're learning from the MS Lesion Project

eople with MS have known all along that there are huge variations in MS. Among other things, some people respond very well to certain treatments, while others get little benefit. Are these variations due to basic biological differences in the disease?

Since 2000, the MS Lesion Project has coordinated an international team of

researchers focused on this question. Scientists in the United States, Germany, and Austria are examining tissue from MS lesions—areas of brain where myelin has been stripped from nerve fibers—and comparing what they find with records of the person's actual symptoms and disabilities. The project is



Claudia Lucchinetti, MD, heads the Society's MS Lesion Project.

ties. The project is scheduled to be completed with \$1.2 million to be raised in the next four years by the Society's **Promise: 2010** campaign.

Preliminary findings underscore the promise: "There may indeed be several types of MS and these types may have different immune-related causes," wrote Dr. Claudia Lucchinetti of the Mayo Clinic, Minnesota, who is the lead investigator.

The group has identified four distinct lesion patterns in MS. The tissues studied in the project come from autopsy specimens and from brain biopsies, usually performed when a brain tumor was suspected.

Data from the 280 tissue samples analyzed by the end of 2005 indicate that each falls into one of four patterns—and that no one person had lesions matching more than one pattern. However, the common types of MS (relapsing remitting, primary progressive, relapsing progressive,

and secondary progressive) do not appear to correlate with these lesion patterns early in the disease. Dr. Lucchinetti stresses that longer follow up is needed to determine if the patterns help predict the disease course over time. Here is a sample of other findings of the MS Lesion Project:

- People with one lesion pattern that includes specific antibodies respond better to plasma exchange therapy than those with the other three patterns.
- One lesion pattern is associated with loss or damage to one particular myelin protein while other proteins remain intact.
- People with neuromyelitis optica (also called NMO or Devic's syn-

What we're learning from the MS Lesion Project (continued)

drome) can be clearly distinguished from those with MS by the presence of a specific antibody. NMO is often confused with MS.

- A novel mechanism called "tissue preconditioning" appears to be responsible for a pattern of tissue damage in Baló's concentric sclerosis, another rare, severe disease similar to MS.*
- Tissue damage found in areas of the brain where lesions are not seen on conventional MRI may play a critical role in the development of disabilities.
- People with MS who were diagnosed by brain biopsy have clinical courses

- similar to people diagnosed through conventional means. This is important because it suggests that whatever is learned about MS from brain biopsies can be applied to more typical MS.
- And, one of the four lesion patterns has distinguishing aspects that show up on MRI.

This last finding has fueled the hope that it will be possible to identify all four patterns through non-invasive scanning. The project investigators are pushing hard for methods that will make it feasible to type a person's lesions before selecting therapy. Dr. Lucchinetti puts it simply: "This project may get us to the very core of finding better ways to treat MS."

COMING FACE-TO-FACE WITH MS: FOUNDING THE SOCIETY



Sylvia Lawry wanted to help her brother, who was diagnosed with MS. Looking for information, she placed a classified ad in the **New York Times** and found many other people desperate for answers. Sixty years ago this March, she organized what would become the National MS Society and later the international MS movement. Here she is with the first Medical Advisory Board in 1946.

^{*} The National MS Society's programs and services are open to anyone affected by these rarer conditions, as well as by "possible MS" or "clinically isolated syndrome" called CIS.

GIFTS WITH A PURPOSE

Most people have a specific intention in mind when they include a charitable bequest to the National MS Society in their will. A bequest reflects a vote of confidence in the work the Society is doing and serves as a powerful illustration of an individual's life purpose.

Over a lifetime, this purpose can take many forms. Volunteering, participating in fund-raising events, serving on committees, encouraging others to give are all expressions of purpose-driven giving. When writing a will with a charitable bequest, an individual makes a long-term commitment to support that purpose into the future. Put simply, what you put in your will is what people will remember you by. It is your legacy.

An estate gift or bequest is shaped by your interests or by your vision of an outcome in the future. Bequests can be restricted to specific services, such as emergency loans, college scholarships, educational programs, or to research in specific areas. Or bequests can be unrestricted in support of our mission to end MS.

Bequests can come in all sizes—and they may be a specific amount or represent a percentage of the total estate.

Residual bequests are set up to help the National MS Society after family and friends are provided for.

Estate planning experts like to use the "80/20 Rule": 20 percent of what we do now affects 80 percent of what happens in the future. They suggest:

- Consider possibilities. Plan for life's uncertainties.
- Organize. Identify all your assets and liabilities.
- Inform your potential beneficiaries. They will be able to thank you.

• **Use caution.** Consult a qualified estate planning attorney.

National MS Society staff can give you all the information and materials you and your advisor need to develop a purpose-driven charitable bequest that reflects your values and fits your estate plan. Investing your assets to reflect what you consider most important can be deeply satisfying. In addition, careful planning may save your loved ones from complex probate procedures and taxes.

Ask for our brochure, "Creating a Legacy for Tomorrow." Call the Gift Planning office at 1-800-923-7727, or visit our Web site at nationalmssociety.org, click on "Donate to the Society," and explore the "Guide to Giving" section.



Martha Montgomery Tribute (continued)

ever met in my life. I hope that I am a better person myself for having known Martha."

Kathy Ulmer

"I met Martha in September 1965 when I went to work with her at Citizen's Fidelity Bank (now PNC). We became instant friends as she took me under her wing and taught me the job I was to do. Then we became friends outside of work with families visiting back and forth. We recently stayed close by phone, not visiting as much, but always close at heart."

"Martha was the same in 1965 as she was in 2006 when she passed away. In spite of her MS, she was always smiling and happy just to be with friends, family and especially her husband, Grover. Martha and Grover were married 54 years this April and were as much in love or more from the day they met. Grover took such wonderful care of Martha and supported her in anything she wanted to do."

"After being diagnosed with MS in 1970 and having a few bad years, she started MS self-help groups all over Louisville and tried to help each person with MS that she came in contact with."

Pat Thompson

Excerpts from "My Bouts of MS and Present Victory" by Martha Montgomery, September 9, 1982.

"A definite rule to follow: Never retreat into a shell if possible. If you feel or are reminded of this, try to do anything you can to get over it. It is not always possible to bring yourself



out, but really work on it at every opportunity. Get help quick from some other source if necessary. Nobody wants to be around a person who is feeling sorry for herself."

"Remember, you are definitely not alone with MS. Most of all think positive and never give up. No matter how bad you get, you can and do, at times, come back."

The Kentucky-Southeast Indiana Chapter of the National Multiple Sclerosis Society will pay lasting tribute to Martha Montgomery by:

- In 2006, awarding the first college scholarships in the history of the Chapter from the Martha Montgomery NMSS College Scholarship Program.
- Renaming the Chapter's Core Value Award for Integrity after her. Martha received this award in 2004. It will be awarded in her name later this year at our 2006 Annual Meeting & Volunteer Awards Luncheon.

MS Awareness Week March 13-17, 2006



Come face to face with MS.

As part of the MS community, we all have a story to tell about what it means to live with multiple sclerosis. This is why we need you to share your experience to help build the Face of MS.

To launch MS Awareness Week, March 13 – 17, the National MS Society unveiled The Face of MS. This online, interactive and collaborative art project representing the face of MS is a platform for everyone allied in the fight against MS to tell their story, to hear from others, and to give both the general public and those within the MS community a deeper understanding of a disease that impacts each and every person in a different way.

> It is only by putting a face on MS will we begin to understand what it means to live with the disease.

It is only by putting a face on MS will we begin to understand what it means to live with the disease. The face will continue to grow as more people contribute their stories through video and written testimonial, and will evolve into a kaleidoscopic collaborative work of art filled with hundreds of thousands of faces all morphing into the "face" of MS. Tell your story, hear others and to encourage your friends and family, visit www.faceofms.org.

MS Awareness Activities across the country and here in Kentucky and Southern Indiana

The Society hosted a week of web casts with six great minds in MS research. Participants learned about cutting-edge research and what's next on the horizon. Tuesday, March 14 was the Society's "Day of Hope." Participants were encouraged to wear their MS Band of Hope or other society items to raise awareness about MS in their communities.

The Kentucky Southeast Indiana Chapter also organized MS Awareness Days at the Kentucky State Capitol. Volunteers worked the booth and educated legislators about multiple sclerosis and the issues that people with MS face. The Chapter also worked with Kentucky Tennessee Kiwanis to organize readings of "Grampy Can't Walk", a children's book on living with MS, at primary schools across the state. MS Walk and Toyota MS 150 participants were encouraged to promote MS Awareness in their offices and communities to help fundraise and teach others about MS.



Advocacy Moment

Victory! P&T Committee Approves All Disease Modifying Therapies!

s noted in the Winter MS Connection, in November, Chapter staff attended a meeting of the Pharmacy and Therapeutics Advisory Committee. This committee reviews and makes recommendations on what drugs should be covered under Medicaid.

The committee was asked to review the four disease-modifying therapies available for treating MS and approve language stating that patients should be prescribed the most cost effective disease-modifying therapy available. If not, the patient would be required to have prior authorization through Medicaid in order for the therapy to be covered.

The MS Society requested time on the January agenda to make a statement against basing a patient's MS therapy on economic evaluation. Representatives also asked that the P&T committee consider removing language that would place undue hardship on both the Medicaid recipient and neurologist by asking for monthly preauthorization.

Dr. Thomas Badgett, Chair of the P&T Committee, kindly agreed to meet with staff from the Chapter office on January 13, and received a crash course on multiple sclerosis. He graciously passed on the information he received from the National MS Society to the rest of the P&T Committee members.

Chapter staff recruited members of the MS Society to speak before the committee, to

let them know how limiting access to much needed therapies would affect them and their families. Dot Patterson and Michele Games each told committee members about their personal struggles with MS and their experiences with disease-modifying therapies. Also testifying were: Yvette Rojas, Executive Director the Louisville Comprehensive MS Care Center, neurologist Dr. James Winkley of Lexington, and representatives from Serono.

As a result of these combined efforts, the P&T committee recommendations were changed to reflect coverage of all four disease-modifying therapies without consideration of economic evaluation. In addition, there will be no preauthorization requirement for any of the currently available medications. The recommendations passed unanimously.

A special thanks to the committee and to all who testified on behalf of those with multiple sclerosis. Your efforts truly made a difference in the lives of people living with MS in Kentucky. Keeping access to all the disease-modifying therapies means that Medicaid recipients will continue to have all doors open when it comes to their treatment.

For more information on getting involved with advocacy in your area, contact the chapter at 1-800 FIGHT MS.

My Favorite Resource

Keep Up-to-Date on Your State's Legislative Session

ave you ever wondered what's going on at your state capital? Who is your representative? How did he vote on a certain piece of legislation? Were you ever just mad and wanted to write a letter or call your state senator? Your state's legislative website is a great place to find information on bills, representatives or senators, and loads of other information.

In Kentucky, the Kentucky Legislature website, http://www.lrc.state.ky.us, posts all bills and resolutions up for review, including who proposed them and who is supporting them as well as the members of the state house and senate, schedules for committee meetings, and how to contact your representatives.

Under Public Services, you can watch live coverage of committee meetings from the comfort of your living room. Also find out how to contact the Legislative Research Commission, a branch of the Kentucky Legislature dedicated to increase

citizen awareness of legislative activities and to assist members of the General Assembly to communicate more effectively with their constituents. The LRC exists to help you learn more about bills that are up for review and how you can impact the way your representatives vote.

If you live in Indiana, visit www.legislative.IN.gov. The Indiana General Assembly website has all the information you need to learn more about the democratic process and participate in state government. You can watch or listen to general assembly sessions, obtain legislative contact information, search for state legislators, and search for bills and resolutions.

Keeping up with what's going on in your state can take a lot of effort. The tools on these websites will allow you to access all the information you need to stay informed and active in your state's political process.

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 contents of any product or service mentioned.

FREE Employment Training Opportunities

he Kentucky-Southeast Indiana Chapter of the NMSS is excited to announce a new opportunity for people with MS wishing to reenter the workforce. On October 1, 2005, Skill Enhancement & Employment Center (SEEC), located in Lexington, KY, received notice that they had been approved for a Projects with Industry grant from the U.S. Department of Education's Rehabilitation Services Administration to provide job placement assistance to individuals who have been diagnosed with chronic neurological disabilities such as multiple sclerosis.

The Projects with Industry grant awarded to SEEC has been named Effective Placement in the Community (EPIC). EPIC will serve participants in 17 Kentucky counties including: Franklin, Scott, Harrison, Nicholas, Bourbon, Anderson, Woodford, Fayette, Clark, Powell, Estill, Madison, Garrard, Lincoln, Boyle, Mercer, and Jessamine. Over the course of the three-year grant cycle, SEEC must place 112 individuals with chronic neurological disabilities into competitive employment within their communities. To accomplish this goal, SEEC will provide all necessary training and preparation to qualifying participants. Possible training opportunities include:

- Benefits Counseling-Lets you know how much income you can have without affecting your SSI or SSDI benefits. In doing this you will be ensured that you will not lose any SSI or SSDI benefits.
- Evaluation-Vocational testing will determine your individual strengths, weaknesses, interests, and abilities.

- Learning Strategy Classes- These classes will teach organizational and time management skills, memorization skills, how to disclose your disability to an employer, etc.
- Job Readiness Classes-These will include resume writing, interviewing skills, mock interviews, etc.
- Site-Based Assessment-These assessments will allow you to experience different job settings to see which best matches your interests, needs and abilities.
- Job Placement Services-SEEC will assist you in obtaining actual permanent employment.
- Job Coaching-SEEC provides you onthe-job assistance to help learn job tasks in a way that is best suited to your individual strengths. SEEC will also stay on the job with you until you are able to perform it on your own.
- 90-Day Job Placement-Upon completion of 90-days on-the-job, SEEC will provide you with a \$100 bonus.
- Continued Follow-Up-SEEC will continue to contact you for the first year after successful employment to offer assistance in the form of supportive services once you have completed the EPIC program.

Please take advantage of this unique opportunity to reenter the workforce by learning a new skill. SEEC will provide all necessary training, your SSI and SSDI benefits will not be affected, and best of all, the EPIC program is completely FREE of charge to you!

For more information, or to register, please contact Kara Baber at 859-233-1900 or by email at kbaberseec@alltel.net.

FDA Advisory Panel Recommends Tysabri's Return To Market For Relapsing MS

he FDA advisory committee has recommended that Tysabri (natalizumab) be approved for return to market for the treatment of relapsing multiple sclerosis. While the FDA is not required to follow the recommendations of its advisory committees, it usually does. The FDA is expected to make a final decision about whether to approve the drug for market by the end of March 2006.

The advisory committee met in early March to evaluate whether Tysabri could safely return to market following its withdrawal due to safety concerns in February 2005. The committee reviewed data about the drug's effectiveness and its side effects; the proposed risk management

plan developed by the drug's sponsors and the FDA's assessment of the safety and efficacy of the drug and risk management issues. The committee also heard extensive public testimony from concerned citizens and patient groups. The National MS Society is relentless in our pursuit to give people with MS more choices for safe and effective treatments. We applaud the FDA advisory committee's efforts and findings. We will continue to provide the best available information regarding any developments through our Web site (www.NationalMSSociety. org/Tysabri). Once a determination is reached, we will do everything possible to ensure that people with MS fully understand the decision.

Save the Date for the 2006 Best of Louisville Bash!

Mark your calendars!

The Kentucky – Southeast Indiana Chapter and *Louisville Magazine* will host the 2006 Best of Louisville Bash on September 22, 2006 at Bowman Field in the Louisville Executive Aviation Hangar. This annual community celebration salutes Louisville's finest, as selected by the Louisville Magazine readers' and critics' poll. All proceeds from this event will benefit the Kentucky –Southeast Indiana Chapter of the National Multiple Sclerosis Society and support the programs and services delivered annually to the 4,000 people living with MS in Kentucky and Floyd and Clark counties in Indiana.



We need your help!

Do you want to be an integral part of one of Louisville's favorite celebrations? We are looking for dedicated volunteers to join the 2006 Best of Louisville Bash Committee and help us plan this year's event. Contact Michelle Forsting at 1-800 FIGHT MS, ext. 226 to find out how you can be an important part of this exciting event!

If you are new to MS...

hat do you do now? The National MS Society has many resources for you and your family to explore. Here are some suggestions on where to begin.

Knowledge Is Power is a free educa-



tion program of 8 weekly mailings sent to your e-mail or postal address on such issues as treatment options and the impact of MS on the family. Sign up online at **na**-

tionalmssociety.org/Knowledge, or call us.

We want to be your mainline to services. Our offerings include **physician referrals** and **self-help groups**.

Our Web site houses more than 3,000 pages of up-to-date information on MS. For easy access, click on the words "Site Map", located in the upper-right corner of every page, just beneath the search icon.

To network with others, there are **chat rooms** and **message boards**. Sign up at **nationalmssociety.org/chat.asp**.

Brochures and other publications are all available on the Web site. The Newly Diagnosed page at nationalmssociety. org/NewlyDiagnosed links to brochures on topics ranging from MS drug treatments to choosing a health-care provider. If you don't have Web access, call us.

Publications for families are also on this page. Click on the icon for **Teen**

InsideMS, our quarterly Webzine by and for



teens affected by MS. For younger kids, **Keep S'myelin** is available in print and as an interactive Web site. The icon will take you there.

And if you'd like someone to talk to or to be added to the chapter's mailing list, call us at 1-800 FIGHT MS (1-800-344-4867). This is why we're here.

Buy Your MS Band of Hope Today! - \$1

he MS
Band of
Hope is an
opportunity for
you to share the
MS cause with others. One side of the
band is embossed
with the word



co-workers. Join together to give hope that soon we will find the cause and cure for multiple sclerosis.

"HOPE" and the other side with the National MS Society's web address.

Give them to family, friends and

All proceeds from the sale of the MS

Band of Hope benefit the National Multiple Sclerosis Society and our mission to end the devastating effects of MS.



with MS for 20 years.
It seems as though
everything you
do has to do with
people who have
been newly diagnosed. I get the MS

Connection newsletter and the Inside MS magazine, but what else is there that the MS Society has to offer to me?

Signed, Old Timer

Dear Old Timer:

While it is true that the MS Society puts a lot of effort into educating people who have been recently diagnosed, it is also our goal to try to provide useful information to people who have been living with MS for a long time. Not all of our educational programs are just for those who are newly diagnosed.

For example, we also have programs on symptom management. It is possible that you may develop some new symptom. In that case, a program or piece of information that may not have pertained to you last year is suddenly of use. Another area of interest may be the ever-changing face of MS research. We host annual research symposiums that provide the most upto-date info on upcoming and existing research. In addition, we hold programs on various aspects of living well with MS that focus on general health, nutrition and exercise including yoga, aquatics and general fitness.

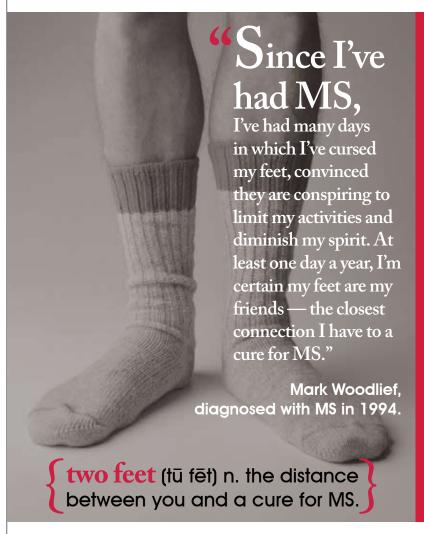
Perhaps the way you can get the most out of the MS Society is by giving of yourself. We are always interested in having people share their experiences with others through leading a support group, making follow-up calls to people who are newly diagnosed, visiting people with MS living in long-term care facilities, participating in our grassroots advocacy network, starting a walk team, or sharing your story by becoming an MS Ambassador.

Each one of us has something to contribute. It is simply a matter of matching your particular interest with activities at the Chapter. Please contact us at 1-800-FIGHT MS (1-800-344-4867) option 2 for information about volunteer opportunities. Together we can make a difference.

Send your questions to MS Know It All National Multiple Sclerosis Society Kentucky – Southeast Indiana Chapter 11700 Commonwealth Drive Suite 500 Louisville, KY 40299 Fax: 502-451-9747

Are you on our mailing list?

If you are not receiving regular mailings for client programs, volunteer opportunities and special events, please contact the Chapter office (1-800 FIGHT MS) so that we may add your name to our master list!



mswak

saturday,

april 15, 2006

Louisville, Waterfront Park Lexington, KY Horse Park

saturday,

april 22, 2006

Paducah, Noble Park



We cordially invite you to attend the First Annual Paducah Picnic in the Park

April 22, 2006 Noble Park in Paducah, KY 11:00 am to 1:00 pm

(immediately following the 2006 MS Walk Paducah)

Join us for food, fun and a chance to meet others in your community affected by this devastating disease.

Whether you participate in the walk, or just want to come out and enjoy the beautiful spring weather, we want you to come!

Climb for Hope '06 Update

Summit of Kilimanjaro Reached, Fundraising Goal...Almost

By Craig Coleman

oyce and I were a part of the first group to follow the tragic rockslide incident that killed three Americans and a couple of porters while they traversed around a difficult section along the Western Breach route. Due to this incident, the Park Service closed the route, forcing us to deviate and change to a longer, more difficult route called the Machame Route.

Our climb started from 6,000 feet through the mountain's rain forest. The trip would eventually lead us through five different ecological zones. Each day's camps usually netted an additional 3,000 feet in altitude but that often didn't account for the descents we had to make. The downhill slopes really took a toll!

Along the way, our team encountered other climbers. Many were Americans and that offered a unique opportunity to swap stories or share where we were from, which felt good, like we were more connected, despite being thousands of miles from home.

On the summit day we had 4,000 feet left to climb. Twice the distance if we had been able to follow our original route. We started early in the day and had reached 18,000 to rest and have lunch. Unfortunately for me, this is where I ran out of water. Joyce and I were laboring to make it farther. I worried about the effects of dehydration but took consolation in moving one step at a time and knowing that we were almost there. By the time we crested the mountain, at 19,000



Craig and Joyce reached the summit on January 16.

feet, we could see the summit marker—some 340 feet away, but the distance between seemed like an impossible point to reach. We were exhausted!

Peer pressure willed me to the summit. I was in my weakest condition and felt the remainder of the climb was the most difficult thing I had done. That night we had medium to severe headaches and the longing to do nothing but sleep. Our oxygen intake levels were the lowest they had been. Mine were 72-percent. Joyce's were 68-percent.

We started out the next morning to descend, but before we could climb out of the crater, Joyce began to waiver. Several porters quickly came to her aid, as she appeared likely to faint at any moment. Later she would admit to hallucinating at that point. She was showing signs of

severe altitude sickness. Porters rushed her immediately down the mountain to a safer elevation. The remainder of the 10,000-foot descent day for me was grueling.

But it helped realizing we had additional incentive to reach the summit.

Our final descent day amounted to 4,000 feet. There was a celebration with the team, a public viewing of the porters receiving their tips and a direct drive to the hotel for our first shower in nine days. What a remarkable feeling that was to have a full shower, second only to a glass of cold bottled beer. We were close to going home, at this point, but it would have to wait for another day.

Joyce and I labored hard during our climb, but it helped realizing we had additional incentive to reach the summit. The fundraising piece of this project was a real blessing, probably more satisfying than reaching the summit itself. We appreciate everyone's support of our efforts to raise awareness of the devastating effects of MS and to raise money to support the work of our Chapter. Our fundraising goal is \$10,000. We have not yet reached that summit, but we are only a few final steps away. Any contribution you can make to help us reach this goal is most appreciated. You may make your contribution online at www.kynmss.org; scroll down on the homepage to the icon for Climb for Hope '06.



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Biogen

Berlex

Fischer's Meats

GE

Kindred Healthcare

Mac Construction and Excavating, Inc.

Power Creative

The following *Corporate Stars* have demonstrated a significant commitment of financial support, expertise, public awareness and volunteer support to the Kentucky-Southeast Indiana Chapter in our efforts to *end the devastating effects of MS*.

Publisher's Printing

Scheller's Fitness and Cycling

Serono/Pfizer

Teva Neuroscience

Toyota Motor Manufacuring, Kentucky, Inc.

UPS

Kindred Healthcare Joins Chapter as Presenting Sponsor for 2006 MS Walks

■he Kentucky – Southeast Indiana Chapter of the National MS Society is pleased to announce that Kindred Healthcare will partner with the Chapter as the presenting sponsor of the 2006 MS Walks. In addition to providing generous cash underwriting, Kindred has also agreed to send a team of employees to walk in the annual event. Last year, under the leadership of team captain Teri Hartlage, Team Kindred raised almost \$8,000 for the MS Walk in Louisville, securing their spot as the number one fundraising team statewide.

Based in Louisville, KY, Kindred Health-care is a national leader in their field, operating hospitals, nursing centers, institutional pharmacies, and contract rehabilitation services through its subsidiaries across 28 states. Kindred Healthcare is dedicated to providing the highest quality long-term hospital and skilled nursing services to people who cannot take care of themselves.

The Spring 2006 MS Walks will take place on April 15 in Louisville at Waterfront Park, and in Lexington at the Kentucky Horse Park. The 2006 MS Walk Paducah will take place on April 22 at Noble Park. Registration for all Walks begins at 9:00 a.m. and the Walks begin at 10:00 a.m. – rain or shine! You can register for the Spring MS Walks today at kynmss.org, or by calling the Chapter office at 1-800 FIGHT MS.





We need volunteers, too! We are looking for enthusiastic and energetic volunteers for the 2006 MS Walks. Like our Walkers, volunteers are essential to the continued success of the MS Walks. You can register to volunteer at www.kynmss.org, or by calling the Chapter office at 1-800 FIGHT MS.

Kindred Healthcare is proud to be a sponsor of this worthy event. We are pleased that we can help support the fight against MS - Susan Moss.



Kentucky – Southeast Indiana Chapter Celebrates 20 Years of the MS 150

Chapter Celebrates with New Sponsor, New Overnight Features and New Sunday Route

n June 3 & 4, 2006, cyclists from across Kentucky will gather once again at the Toyota Motor Manufacturing, Kentucky, Inc. Visitor's Center in Georgetown, KY for the 20th annual Toyota MS 150 – bike the bluegrass. The Chapter is proud to welcome back Toyota as the title sponsor for this important event. "Toyota is proud to renew our commitment to the Toyota MS 150 and the Kentucky - Southeast Indiana Chapter. We are dedicated to aiding the Society in its mission to end the devastating effects of MS through this crucial fundraising event," said Nila Wells, team captain for TMMK.



The Chapter is also pleased to announce that UK HealthCare has signed on as a Gold Sponsor for the Toyota MS 150's 20th anniversary. UK HealthCare is a leader in providing health services, research, and health education to residents of the Commonwealth of Kentucky. In addition to generous cash underwriting, UK HealthCare will be providing medical

support and personnel along the route to this year's Toyota MS 150 riders.

In celebration of the twentieth anniversary of the bike tour, the Chapter is very excited to present new overnight entertainment and din-



ner options, including the new Team MS Village, at Pioneer Playhouse, Kentucky's oldest outdoor theater, located in Danville, KY. We will also be offering a new 25-mile route option on Sunday, June 4 for riders looking for a less challenging route. Riders choosing this option will start and finish at the Toyota Visitor's Center on Sunday, and will be treated to a picnic celebration and official Toyota MS 150 t-shirt upon completion of the route.

You can register to ride in the 20th anniversary Toyota MS 150 online at www. kynmss.org or by calling the Chapter office at (502) 451-0014 or 1-800 FIGHT MS. All participants are asked to pay a registration fee, and raise a minimum of \$200 (Sunday route riders are asked to raise a minimum of \$100). Prizes are offered at various levels of fundraising to reward individuals and teams who go above and beyond the call of duty.

WAMS Luncheon

he 2006 Women Against MS Luncheon was Thursday, February 16 at The Olmsted in Louisville. Guests enjoyed remarks from emcee Dawne Gee, WAVE 3 news anchor, and an inspiring keynote address from best selling author Jacquelyn Mitchard. Following the guest speaker, Jeannie Unruh, CEO MAC Construction and Excavating, delivered a special tribute to Martha Montgomery.

The Kentucky-Southeast Indiana Chapter of the National Multiple Sclerosis Society would like to recognize the following companies and individuals for their generous support of the 2006 Women Against MS Luncheon.



All expenses associated with the WAMS luncheon are underwritten by MAC Construction & Excavating. Proceeds will directly fund programs for people in our community with MS as well as national research efforts.

Special Thanks To:

Jacquelyn Mitchard, Pamela English, Dawne Gee, Jeannie Unruh, Kathy Kruer The Olmsted, Borders Book Store & Bisig Impact Group

Corporate Table Sponsors:

Norton Healthcare McCauley Nicolas Stites & Harbison Teva Neuroscience Aegon USA Nicklies Development Conliffe, Sandmann & Sullivan

New MS Support Group in Bowling Green, Kentucky!

The first meeting will be held: Tuesday, April 4, 2006 6:30 PM CST

Southern Kentucky Rehabilitation Hospital 1300 Campbell Lane Bowling Green, KY 42104

Call Laura at 270-796-8445 for more information.

Interested in volunteering?

WE NEED YOUR HELP!

If you would like more
information on our
volunteer opportunities,
contact the chapter at
502-451-0014 or
1-800 FIGHT MS option 2.

Memorials and Honorariums

Gifts have been given to the Kentucky-Southeast Indiana Chapter of the National Multiple Sclerosis Society in memory and in honor of these individuals from November 1, 2005 to January 31, 2006.

In Memory
Richard Bisch
Loretta Brown
Herbert Camp
Jim & June Conyers
Terry Thomas Courtney
Georgeann Harter
John Hughes
Anna Lou Isert
Jeana Jordan
Lois Marie Lang
Michael Barr Leone
Helen G. Levin

Cynthia Luox-Bailey

Martha Montgomery Georgie L. Phillips Lewis Schargenberger Nancy Sloan Lee Strasberg Vivian Wright

In Honor

Doug & Lorie Dressman

Clarence Graf

David Nicklies

Teresa Robinson

Terry Sakach

This Is Why...

Multiple Sclerosis is a devastating disease. *This is why* the National MS Society funds more research than any other voluntary health organization in the world. More progress has been made in the last 10 years of research than in the previous 100.

FIGHT MS Kroger Card

magine that every time you buy food for your family or need a special gift for a friend or employee, that you are also helping to find the cause and cure of multiple sclerosis!

Purchase a FIGHT MS Kroger Card today! Call the Chapter Office at 1-800 FIGHT MS.

Make Your Voice Heard! Join the MS Action Network

Join the National Multiple Sclerosis Society's advocacy efforts to maximize your impact on public policy issues affecting individuals with multiple sclerosis. MS Action Network members receive e-mail legislative alerts and federal and state updates. Sign up at nationalmssociety.org. You can make a difference!

Please contact the group leaders to ensure meetings will be held as scheduled.

Elizabethtown

Two Meeting Times Bridge Community Church Last Tues each month 6:30 pm 2nd Mon of each month noon Contact Tom 270-360-8415

Frankfort

Frankfort Regional Medical Center Multi-purpose room 2nd Fri each month 6:30 pm Contact Michelle 502-223-1306

Franklin

Calvary Baptist Church 1st Mon each month 7 pm Contact Linda 270-598-0669

Lexington

St. Luke's United Methodist Church 2nd Mon of each month 7 pm Contact Leslie 859-269-4036

Newly Diagnosed Group People diagnosed 2 years or less Meeting Locations Vary Last Mon each month 6:30 pm Contact Jenny 859-263-3643

Louisville

St. Stephen's Baptist Church 3rd Thurs each month 7 pm Contact Chapter

Younger Persons with MS 4th Mon each month 7 pm Northeast YMCA Contact Tom 502-376-5832

Martha Montgomery MS Support Group Pitt Academy 3rd Thurs each month 7pm Contact Tonya 502-543-2025 Multiple Sclerosis Praise and Prayer Group Lyndon Baptist Church 1st & 3rd Wed each month 1 pm Contact Mary 502-426-4784

London

First United Methodist Church 4th Tues each month 7 pm Contact Shirley 606-864-5326

Madisonville

Trover Clinic, 8th Floor 4th Mon each month 6:30 pm Contact Carolyn 270-639-5679

Morehead

St. Claire Medical Center Room B 4th Tues each month 7 pm Contact Judy 606-784-8044

New Albany, IN

Providence Nursing Home 3rd Mon each month 6 pm Contact Regina 502-541-8069

Paducah

Western Baptist Hospital 3rd Sat each month 2 pm Contact Karen 270-247-4064

Jellico, TN

Jellico Community Hospital 3rd Mon each month 1 pm Contact Beth 865-470-9933

Harrogate, TN

4th Mon each month 7 pm Contact Beth 865-470-9933

To inquire about starting your own group, contact Sonya Sandridge at 1-800 FIGHT MS or 502-451-0014.

Action Alert

Action Alert is the grassroots program of the National Multiple Sclerosis Society. Each chapter develops its Action Alert list—a group of people who will quickly and reliably respond to requests for advocacy action. Possible requests for advocacy action might include: writing letters, e-mails, calling and/or visiting elected officials or executive agency staff.

All Action Alert members automatically receive the monthly federal and state advocacy updates as well as all federal action alerts published by the advocacy programs department.

If you would like to add your name to the Action Alert list, please contact the Chapter at 1-800 FIGHT MS or kyw@nmss.org

MS Learn Online

MS Learn Online is an internet-based educational program designed to deliver quality information to your computer. To connect to MS Learn Online, go to www. nationalmssociety.org and select "Educational Programs".

DATES TO REMEMBER

2006 MS Walk Louisville April 15, 2006 Waterfront Park

2006 MS Walk Lexington April 15, 2006 Kentucky Horse Park

2006 MS Walk Paducah April 22, 2006 Noble Park

<u>2006 Toyota MS 150</u> June 3 & 4, 2006

2006 MS Walk Morehead September 9, 2006 Don Greenhill City Park

2006 MS Walk Columbia September 9, 2006 Columbia Baptist Church

2006 MS Walk Elizabethtown September 9, 2006 Freeman Lake Park

2006 MS Walk Bowling Green September 9, 2006 Greenview Regional Hospital

Best of Louisville Bash
September 22, 2006
Bowman Field
Louisville Aviation Hangar

2006 Dinner of Champions October 19, 2006 Churchill Downs

AQUATIC EXERCISE

Glasgow YMCA 1 YMCA Way Glasgow, KY 270-651-7599

Mary T. Meagher Aquatic Center 201 Reservoir Avenue

Louisville, KY 502-897-9949

Northeast YMCA 9400 Millbrook Road Louisville, KY 502-425-1271

Baptist East/ Milestone Wellness Center 750 Cypress Station Dr. Louisville, KY 502-896-3900 www.baptistmilestone.com

Shawnee High School 4018 West Market Louisville, KY 502-485-7664 Pool is located behind school, next to the football field. Mon-Wed 10-11 am \$2/class

EXERCISE CLASSES

Eastern Kentucky University Moberly 202 Richmond, KY 859-622-1891 louisa.debolt@eku.edu

North Lexington YMCA Mon/Wed 3-4 pm 859-622-1891 louisa.debolt@eku.edu

YOGA

Yoga East Holiday Manor Center 502-585-2070 www.yogaeast.org

Staying Connected

Confidential email reminders about upcoming programs in your area are available by sending an email request to: kyw@nmss.org

Keep S'Myelin

Keep S'myelin, a newsletter for children about MS. is available through NMSS chapters as well as on the National MS Society's website. Designed for children 5-12 years old, who have a parent or loved one with multiple sclerosis, Keep S'myelin includes regular articles about different aspects of MS, puzzles and games, photos, book reviews, tips, and more.

For a copy of the latest issue call 1-800 FIGHT MS, or to access the newsletter through the Internet, go to nationalmssociety.org, scroll down the front page.

SPRING2006

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www.kynmss.org

Publisher's Printing underwrites all printing costs for the MS Connection. The support this business provides to the Kentucky-Southeast Indiana Chapter of the NMSS ensures our clients will receive timely information and that funds raised will support client services, educational programs, and research to find a cure to end the devastating effects of multiple sclerosis.



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