

New Research	page 2-3	Employer of Year	page 11
Apartments Available	page 4	SSDI Benefits	page 12
Tech Collaborative	page 5	Advocacy Days	page 13
Local Resources	page 6-8	Research Volunteers	page 14
Ask the Expert: The OT	page 9-10	MS Bike Ride	page 15

ms connection

Mid America Chapter

Keeping Your Cool

Overheating can aggravate a number of multiple sclerosis symptoms. Increased fatigue, weakness, and visual disturbances are just a few of the problems that may occur when the body's interior temperature rises.

This may happen when the mercury climbs on a hot summer day. It can also occur during exercise or exposure to any hot environment anywhere.

However, you don't have to be defeated! Learning to minimize the effects of heat is the key. Some common minimizers are:

Drink plenty of fluids. Water is the fluid of choice. Avoid caffeine as this acts as a diuretic.

Use fans, air-conditioning, even hand-held spray bottles. Air-conditioners can be tax deductible with a document from your physician

Exercise in a cool environment.

- * If you are exercising outside, pick the cooler times of the day, usually early morning or evening.

- * If exercising inside, using air conditioning or a fan can help maintain body temperature at an appropriate level.



- * Exercising in cool water (recommended temperature 80-84 degrees) is an excellent way to combat heat during physical activity.

- * Wear commercial cooling garments such as vests, headbands and neckbands — many athletes use them.

- * A simple damp towel can be helpful, if you do not have one of these products.

- * Traditional wide brimmed hats and light-colored, loose clothing also help.

- * Try "pre-cooling" to decrease the heating effects of exercise. Pre-cooling may increase the time it takes for the core body temperature to rise.

- * Get into a bathtub of cool water. The water temperature should be comfortably lukewarm to start. Continue adding cooler water over a period of 20-30 minutes.

- * Submersion of the upper body in cool water will provide the optimal benefit.

- * A cool bath or shower can also help reduce core body temperature following activity or exposure to a hot environment.

So, don't be discouraged by the heat of the summer months. Find the strategies that work best for you, because YOU CAN beat the heat!

Mid America Chapter

5442 Martway; Mission, KS 66205

1-800-344-4867; (913) 432-3926

Eastern Kansas Branch: (785) 272-5292**Ozark Branch:** (417) 882-8128**St. Joseph Branch:** (816) 233-1129**Chair:** Owen Buckley**President:** Kay Julian**Editor:** Nicole Long

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 using one of these medications and about strategies and effective treatments to manage symptoms. If you or someone you know has MS, please contact the MS Society today at nationalmssociety.org or 1-800-344-4867 to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

The Mid America Chapter is proud to be a source of information about MS. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendation or prescription. We do not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The Chapter assumes no liability whatsoever for the contents or use of any product or service mentioned. For specific information and advice, consult a qualified physician.

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57 NEW RESEARCH PROJECTS LAUNCHED TOTALING \$19.5 MILLION*One grant awarded to University of Kansas School of Pharmacy researcher.*

The National Multiple Sclerosis Society has just committed \$19.5 million to support 57 new MS research projects as part of its current \$45 million international effort to spur momentum in cutting-edge MS research. More than \$200,000 is allocated for a scientist in the Kansas City area. This financial commitment is the latest investment in the Society's relentless research effort to prevent, treat and cure multiple sclerosis.

Since its founding, the Society has invested over \$550 million to advance MS research, which has already led to the development of six FDA-approved therapies that affect the underlying disease process and other therapies that help in symptom management.

"With its cutting-edge research, the National MS Society is laying the groundwork to move us closer to a world free of this disease," said Kay Julian, President of the Society's Mid America Chapter. "This year, the Society will spend some \$45 million to fund over 380 new and ongoing MS research projects. This investment in critical research is paying off with new treatments and better methods of diagnosis, rehabilitation and symptom management."

To ensure the scientific merit of each research proposal selected, the National MS Society relies on expert advisory committees that include more than 70 world-class scientists who volunteer their time to carefully evaluate hundreds of proposals every year.

This spring, peer reviewers awarded a grant to **Teruna Siahaan, Ph.D.** of the University of Kansas School of Pharmacy for a study entitled “Suppression of EAE by modulating the immunological synapse.” It is designed to develop an experimental treatment for MS that may reprogram the immune system to ignore and not attack myelin.

Multiple sclerosis occurs when the immune system mistakenly attacks nerve fiber-insulating myelin in the brain and spinal cord. One treatment strategy that has been proposed is to force the immune system to “tolerate” myelin, such that myelin is no longer considered a target, by introducing myelin proteins as a therapy.

Dr. Siahaan is attempting to do so using a molecule called PLP-BPI, which includes components of a major myelin protein, as well as molecules that can prevent immune cell invasion of the nervous system. PLP-BPI suppressed disease progression in mice with EAE, an MS-like disease. Now Dr. Siahaan is determining its long-term effects in EAE, and is attempting to better understand the mechanism for disease suppression. This study will provide knowledge on how the immune response is modulated in MS and may serve as the basis for a new way to treat it.

“If we can improve our understanding of how this creates immune tolerance in EAE, a similar concept can also be applied to other autoimmune diseases such as type-1 diabetes, rheumatoid arthritis and multiple sclerosis,” said Dr. Siahaan. “The ultimate hope is to move closer a cure for these illnesses.”

Dr. John Neuberger, of the University of Kansas Medical Center, is currently

conducting research on residential radon exposure and MS. He is evaluating the relationship between this environmental factor and the prevalence of MS.

“It is an exciting time in MS research with hundreds of promising research projects in the pipeline,” said Julian. “Thanks to the commitment of scientists such as these and the donors who fund their work, the National MS Society is getting closer every day to ending MS.”



There are already six FDA-approved drugs that can impact the underlying disease course in people with the more common forms of MS. However, none of these drugs can stop or cure the disease. The National MS Society funded basic research that helped lead to the development of each of these drugs, and continues to advance research that will help end the devastating effects of MS.

To learn more about currently funded research and how you can get involved, log on to www.nationalmssociety.org and click on “Research.” Also see our article on page 14 about volunteering for a National research project to study multiple sclerosis over time.



Apartments Still Available!

The Melissa Anne Hanger Apartments, located in Topeka, KS, are fully-accessible, independent living opportunities for individuals with a wide range of disabilities, including multiple sclerosis. The apartments are 100% barrier-free and designed with the wheelchair/scooter user

in mind. They feature low countertops, roll-in showers, power entry doors and more.

Rent for all the units is federally subsidized and will not exceed 30% of residents' income. If people with MS apply, there is no obligation to move in. You can decline an apartment up to three different times before losing your place on the waiting list.

If you or someone you love would like to live in the Melissa Anne Hanger Apartments, either now or in the future, please give us a call today at 1-800-344-4867. You may press or say '2' and ask for Erica.

Now available...MS for Dummies

Because multiple sclerosis is an ongoing illness, most people must deal with a variety of ever-changing issues. **Multiple Sclerosis For Dummies** is a comforting guide that shows readers diagnosed with MS and their loved ones how to manage and treat the symptoms of MS and live a fulfilling lifestyle, as well as how to deal with relapses and complications so you can keep your life on track.

Discover how to:

- Get an accurate diagnosis
- Assemble your healthcare team
- Cope with advanced symptoms
- Enjoy family life with MS
- Request accommodations at work
- Explain MS to others

The authors include experts from the National MS Society. Look for **Multiple Sclerosis for Dummies** wherever books are sold.

Whether you live in Chillicothe or Cassville, Salina or Sedalia, we can provide Care Management services for you! People with MS, their families and caregivers can find the resources you need in order to live as independently as possible.

Care Management can help with:

- Transportation
- Housing
- Social Security applications
- Insurance problems
- Respite care
- Mental health issues
- Emergency financial assistance
- Durable medical equipment

The Mid America Chapter has social workers on staff to assist people with MS with these services. Call us today at 1-800-344-4867 and press or say '1' to find out how we can help!

Mom, tune in and listen up!

Mommies with MS, a new national online radio program, is the brainchild of Tahirah Falah. Tahirah's goal is to create a forum for new moms with MS to share their stories and discuss issues related to child-rearing while dealing with the disease. Topics include coping with stress of new duties, bonding with your newborn and more.

The program is broadcast every Sunday at 3 p.m. CST. To listen and call in, go to www.blogtalkradio.com/msmommies.



MS and Employment

Multiple sclerosis can have a significant impact on every aspect of life, and the world of work is no exception. People with MS are experienced, well trained, and productive workers who often retain the ability to work long after the illness manifests itself.

If you need help making employment decisions, managing symptoms on the job, or finding reasonable accommodations, contact our Information and Referral Center (IRC) at 1-800-344-4867 and press '1.' We're here to help!

The MS Technology Collaborative: Making technology work for you

The National MS Society has recently teamed up with Bayer HealthCare Pharmaceuticals (formerly Berlex) and Microsoft Corporation to form the "MS Technology Collaborative." This exciting and unique initiative is focusing on how to better use technology so that anyone, anywhere, living with MS can maximize technology to move their lives forward and stay connected to friends, family and their community.

Visit www.MyMSMyWay.com to learn more about the Collaborative and to sign-up to participate in a first-of-its-kind survey that will explore how people with MS use technology in their daily lives. This survey will help inform future work of the Collaborative – so make your voice heard today and help all of us connect tomorrow!

Looking for some assistance as you or your child heads off to college? The National MS Society has an **annual scholarship program**. High school seniors or graduates who are the children of people with MS or have MS themselves and will attend college for the first time are eligible to apply.

Awards range from \$1,000 to \$3,000. Beginning October 1, you can find an application on the National website (www.nationalmssociety.org) or call 1-800-344-4867. Good luck!



Eastern Kansas Branch**Summer Social Bingo***Lake Shawnee**3131 SE 29th St., Topeka, KS***August 2007 - stay tuned for details**

Enjoy some good games, good food and good company with the National MS Society. Main dishes and beverages are provided. Just bring a covered dish to share with friends. Please call 1-800-344-4867 and press or say '1' to find out more.

Yoga for MS*YWCA of Topeka**225 SW 12th; Topeka, KS***Mondays & Wednesdays, 5:30 - 6:30 p.m.****Tuesdays, 12:15 - 12:50 p.m.****Saturdays, 11 a.m.- noon**

Yoga is a form of exercise that unites the mind, body and spirit through movement. This class will emphasize breathing, deliberate movements or postures, and relaxation. Yoga is designed to increase body awareness which can be helpful when dealing with MS. Please call 1-800-344-4867 and press or say '1' for more information.

Swim Fit Aquatics*YWCA of Topeka**225 SW 12th St.; Topeka, KS***Mondays & Wednesdays, 11 a.m.-1 p.m.****Fridays, 8:45-9:30 a.m. & 10:15 a.m.-1 p.m.**

Aquatics are a low-stress way to get the exercise you need in a fun environment. The MS Society will pay for half of this program's cost. Call the YWCA at (785) 233-1750 or the National MS Society at 1-800-344-4867 and press or say "1" for more information.

Kansas City Branch**Yoga in Chairs***Roger T. Sermon Community Center**201 N. Dodgion in Independence, MO***Tuesdays, 10:30-11:30 a.m.***North Lindenwood Support Center**315 North Lindenwood Drive in Olathe, KS***Wednesdays, 6-7 p.m.***Lee's Summit United Methodist Church**114 SE Douglas Street in Lee's Summit, MO***Thursdays, 2-3 p.m.**

Yoga performed in chairs is designed to allow almost anyone to participate in a very gentle form of exercise. It works the joints and muscles to increase flexibility, strength, balance and circulation. Instructors provide ideas and suggestions for adapting movements to meet participants' needs. You can join this free class at any time throughout the session, and family members are welcome to participate as well.

All facilities are fully accessible. In Olathe, this program will be led by Michelle Warner. In Lee's Summit and Independence, Shelly Lynn is the instructor. For more information, call 1-800-344-4867 and press or say '1.'

YMCA MS Wellness Program*Red Bridge YMCA**11300 Holmes Rd.; Kansas City, MO***Wednesdays, 1-2 p.m. Land class****Fridays, 1-2 p.m. Aquatics class**

Aquatics are a low-stress way to get the exercise you need in a fun environment. Please call the YMCA for more information at (816) 942-2020.

Project WOW! (Workout On Wheels)

Do you want to be more physically active? Do you use a manual wheelchair? Researchers at the University of Kansas and the University of Kansas Medical Center are seeking manual wheelchair users to enroll in an exercise study.

Participants will adopt a home-based activity program and will be followed another 6 months after the intervention ends to assess maintenance of activity. For more information, call (913) 588-7382 or (913) 588-5000, ext. 1324. This is your chance to begin an exercise program that is right for you!

Bates County, MO Transportation Resource

Bates County Memorial Hospital is pleased to offer "CARE-A-Van," a transportation service for the local community. The hours of operation are 7 a.m. - 4 p.m., Monday through Friday, with no holiday coverage.

The "CARE-a-Van" is provided for medical appointments (outpatient clinics, dialysis, etc.) There is no charge for transportation for medical needs, and the service is not to be used for emergency transportation. To schedule "CARE-a-Van" please call the hospital at (660) 200-7100.

United Way 2-1-1

Don't know where to turn? The United Way is now providing an online directory of health and human services for an expanded Kansas City metropolitan area. Find help for basic needs, health concerns, employment issues, volunteering and much more! Dial 2-1-1 or visit www.kcunitedway.org. It's free, confidential and easy.

Interested in attending an Aquatics, Tai Chi or Yoga class in your area? We want to expand our Wellness programs. Let us know what type of class you are interested in. Email us at info@nmsskc.org.

Ozark Branch**MS Aquatics Classes**

St. John's Sports Center

4331 S Fremont Ave.; Springfield, MO

Tuesdays and Thursdays

8:30-9:30 a.m. and 5:30-6:30 p.m.

Aquatics are a simple, low-impact way to keep exercise in your daily routine. Contact us to find out how this class can help you. Call 1-800-344-4867 and press or say '1.'

Chronic Illness Therapy Group

Ozarks Counseling Center

Galleria Shopping Center

1550 East Battlefield, Suite A

Springfield, MO

Tuesdays, 10 - 11 a.m.

Learn to cope with the difficulties of living with chronic pain. There is no cost to attend. Please call (417) 869-9011 to register and find out more.

Southwest Center for Independent Living

2864 South Nettleton Avenue,

Springfield, MO

The mission of SCIL is to promote a barrier-free environment for all disabilities through public education and advocacy for social change. They also strive to provide a full range of independent living services which will assist each person in meeting his or her goals for independence. Call (417) 886-1188 to find out more about this local resource.

Begin with MS Learn Online

Fearful, depressed, confused? A person can feel all of this after an MS diagnosis. But perspective—and hope—are available in the **MS Learn Online** webcast “Where do I begin? Newly Diagnosed with MS.”

Three people, with more than 30 years of living with MS between them, talk about their lives and recall their feelings at the time of their diagnosis. They discuss relationships and support, becoming one's own health-care advocate, and the possibility of reinventing oneself while managing life with a chronic illness.

To view the 23-minute webcast anytime and explore the full roster of **MS Learn Online** offerings, go to nationalmssociety.org/mslearnonline.

Three's A Crowd Couples Retreat
Mark your calendars to join us October 13-14 at The Elms Resort and Spa in Excelsior Springs, Missouri for a weekend all about relationships. Cheryl and Len Chatman will lead us in learning ways to enrich our relationships through their experience living with MS. Cheryl was diagnosed in 1990. She and her husband have spent years inspiring other couples to see the disease as an obstacle that can be overcome.

Invest in your relationship!
This weekend event is only \$50 per couple which includes lodging, most meals and valuable information to maintain and improve your relationship. The historic setting adds a little romance to the weekend and the stage is set for an uplifting, empowering experience. Space is limited and fills up quickly so call today to register 1-800-344-4867 and press or say ‘1’.

Relationship Matters: A Program for Couples Living with MS

When you know how to take charge as a couple, MS doesn't have to rule your relationship. With this proactive approach, you and your partner can learn how to improve communication and resolve conflicts, have greater fulfillment in your relationship, manage MS as a team and help your relationship thrive.

Do you feel MS is like an 800-pound gorilla that has moved into the middle of the room, but whom no one wants to talk about? Through a series of interactive courses, the **Relationship Matters** program helps you learn and apply skills to deal with challenges related to multiple sclerosis. Topics include:

- * Communication and Conflict Resolution
- * Managing MS as a Team
- * Financial Planning for a Life with MS
- * Career Crossroads: Facts and Fiction
- * Having Fun Together
- * Intimacy: Enriching your Relationship

Most courses are offered in a tele-course or online learning format. Working in collaboration with a MS Navigator, you and your partner will create a personalized education plan. Register now for this effective program by calling 1-800-344-4867 or emailing couplesprogram@nmss.org.



I'm experiencing increasing weakness in my hands and fingers. Will exercise make my hands strong again? What exercises are best for this problem?

Our hands are the “doing” centers for many of our everyday tasks. Many of the jobs we need to do become frustrating and difficult when hand strength and coordination decrease. The hand weakness you experience as a result of MS is due to reduced nerve conduction rather than weakened muscles. Therefore, the primary goal is not necessarily to increase hand strength (although for some people the hands do become stronger), but to maintain existing dexterity and muscle strength and, to the extent possible, prevent further deterioration. Your OT will prescribe active range of motion, coordination, and mild resistance exercises that may include therapy putty exercises. The exercise program needs to be individualized so that the appropriate muscles are involved, especially if you are experiencing stiffness or spasticity.

It seems to take so much effort just to get up in the morning and deal with bathing, dressing, and breakfast. Is there something I can do to make those tasks easier and less tiring?

The primary goals to keep in mind with all of your activities of daily living are to simplify your life and manage your energy wisely. When MS fatigue interferes with your ability to perform the basic physical tasks, take time to think

about your routine. Experiment with ways to simplify and reorganize your routine to conserve your energy. Examples of energy conservation might include such simple changes as taking a shower in the evening so that you have less to do in the morning, and building two-to three minute rests into your schedule so that you do not get overly exhausted. If you are heat-sensitive, consider taking a cool or lukewarm shower rather than a fatigue-producing hot shower. Use of a shower chair instead of standing can minimize the amount of energy used. Consider selecting your clothes for the next day and putting them on a bedside chair before you go to bed in the evening. As you purchase clothes now and in the future, try to select items that are easy to take on and off and require a minimum of energy to maintain. Similarly, plan your breakfast the night before, and leave the nonperishable items and dishes on the counter or table so that they are ready to use in the morning.



I enjoy my work, but am finding it increasingly difficult to maneuver around my office and manage my fatigue over the course of the working day. I'm afraid I won't be able to stay at this job if it gets any worse.

continued on next page

Taken from *Multiple Sclerosis: The Questions You Have, The Answers You Need*. These questions were answered by Cynthia Gackle, OTR/L. The text was edited by Rosalind C. Kalb, Ph.D., Director of the National MS Society's Professional Resource Center. This resource may be purchased from demosmedpub.com.

continued from previous page

Work simplification is the key to enhancing comfort and productivity on the job. Work simplification involves:

- * Making sure that your work space, furniture, and office equipment are designed and situated in such a way as to promote correct body mechanics, physical comfort, and reduce fatigue.
- * Organizing your workspace to eliminate unnecessary reaching, lifting, and walking.
- * Re-examining your approach to tasks to ensure that you are doing them in the simplest, most energy-efficient, and least time-consuming way.
- * Becoming familiar with the tools and/or adaptive devices that are available to simplify your tasks and enhance your comfort.
- * Arranging your schedule to make the best use of high-energy times and build in short rest periods.

You can schedule an appointment with an OT to evaluate your workplace and recommend ways to simplify your tasks and help you be more comfortable and productive on the job. Many of the adaptations he or she might suggest are considered “reasonable accommodations” under the Americans with Disabilities Act. The OT can help you formulate your requests for accommodations from your employer.

My hands feel weak and clumsy most of the time. Is there anything to help tie my shoes and button my shirt?

A variety of products are now available to help with frustrating tasks such as tying shoes and buttoning shirts. Several options are available if you are able to bend over and reach your shoes, including “no-bows,” a spring-loaded lace tightener, Velcro™ shoe closures, and even one-handed shoe-tying techniques. If you are not able to reach your feet, you can replace your cotton shoelaces with elastic ones that will turn your tie shoes into slip-ons. Once the elastic laces are tied in place, have a shoemaker stitch the shoe tongue to the top of the shoe so that it won’t move around, and use a long-handled shoehorn to put on your shoes. A shoemaker can also sew a loop on the back of the shoe so you can pull it on with a long-handled hook. Another simple solution is a well-fitting pair of slip-on shoes. If you are also finding it tiring and difficult to pull on socks, an assistive device called a sock aid helps to pull the sock over the toes and up the calf of your leg.

Buttoning is made simpler with a buttonhook, which is used to pull the button through the buttonhole with a minimum of strength and dexterity. Some people prefer to wear shirts with large, easy to grasp buttons, pullovers, or polo-type shirts that have very few buttons. Mail-order catalogs and Internet Web sites containing these and other products are available for consumers. You will discover numerous ways to streamline many aspects of your daily routines as you begin to look for ways to conserve time and energy.

Lockton Companies Named National Employer of the Year



Lockton Associates Accepting Employer of the Year Award

The Mid America Chapter of the National Multiple Sclerosis Society is proud to announce that Lockton Companies, LLC headquartered in Kansas City, Mo. has been named the **2006 Employer of the Year** by the National Multiple Sclerosis Society.

This award distinguishes employers throughout the United States who have made significant contributions toward the hiring and retention of workers with multiple sclerosis as well as other disabilities and serves as a role model in advancing disability rights. Past notable recipients include Target, Proctor & Gamble and Turner Construction.

The nomination came from Roslyn Dryden, a Lockton associate who has MS, who stated, "Lockton Companies has a foundation like few other organizations. It's built on a philosophy that acknowledges associates as the most important asset. There is no regard for disease or disability. Community service and family involvement is a guiding principle. There is simply no end to the support and generosity of Lockton executives and associates."

Lockton Companies, LLC provide a variety of accommodations to associates including flexible work schedules, a private first aid room for injecting MS therapy medications, a full service gym for rehabilitation and strength training, and last year, they purchased a scooter for their Associates with mobility issues. To find out more, log onto www.lockton.com.

The Mid America Chapter's 2006 Annual Report is now available online. It outlines the financial overview and focus of the Chapter. In addition, it highlights some of the people who have heightened the Society's mission through their fundraising efforts.

To download your copy, go to www.msmidamerica.org and click on "Annual Report."

Filing for SSDI Benefits

If you have MS and are unable to work due to an MS-related disability and/or other conditions, you may be entitled to **Social Security Disability Insurance (SSDI)** benefits. To receive these benefits, you must have worked at least five of the 10 years immediately before the disability and paid FICA taxes. The disability or impairments must be expected to last for at least 12 months.

Step One: Get familiar with the process. See “Loosening the SSDI Knots” in the April-May 2007 *InsideMS*. Go to nationalmssociety.org, click on Library in the gray menu bar in the upper right hand corner, and then on *InsideMS* in the box on the left-hand side—or call us for a copy.

For a more detailed review, check out the Society’s new SSDI Guidebook for People with MS at nationalmssociety.org/SSDI. If you do not have Web access, call us.

The exact requirements for SSDI are detailed in the Social Security Administration’s Blue Book (SSA No. 64-039, or www.ssa.gov/disability/professionals/bluebook).

Step Two: Get prepared
Keep a detailed journal of your MS symptoms and how they limit your ability to work. Visit your doctor and let her/him know you plan to apply for SSDI benefits.

Offer your doctor the Society’s template letters to make the documentation of your symptoms easier. (Go to nationalmssociety.org/SSDI and scroll down to “Worksheets and Sample Letters.”)

Step Three: Strengthen your chances
Don’t hesitate to ask for help from an SSA representative, a family member, staff in your doctor’s office, or a knowledgeable person at the Society.

Don’t delay if you can’t complete certain general information on the application. Sufficient medical information is the most important.

The best source of your medical information is your doctor. Be sure your doctor is aware of all of your symptoms.

Step Four: The waiting game
Recent data indicates that nationwide roughly 62% of initial claims for SSDI were denied, and that most applicants who went on to file a written appeal called the “reconsideration” were also turned down. Only 16% of these second-level claims were approved.

The third level provides a face-to-face hearing before an administrative law judge called the ALJ hearing. Nearly 60% of recent hearing decisions were in favor of the person seeking benefits.

A final level is also available: the Appeals Council of the Social Security Administration. This rarely results in an award of benefits. Beyond this point, a person may file a complaint in the U.S. District Court.

Contacting the SSA
Toll-free: 800-772-1213, 7 am to 7 pm, M–F
TTY: 800-325-0778, 7 am to 7 pm, M–F
On the Web: www.ssa.gov

Kansas Advocacy

Twenty-three committed individuals visited Topeka on March 7. The group met with 11 senators and 23 representatives to discuss the following agenda:

We support the Governor's Fiscal Year (FY) 2008 Budget recommendation for the Social and Rehabilitation Services Department which meets many significant needs. We also encourage the funding of unmet needs including attendant care reimbursement, prevention of a waiting list for Physical Disabilities, Home and Community Based Services (HCBS) and more.

At the State level, we support the inclusion of all accepted MS therapies on the drug formularies of private and public health plans as well as fair co-payments for all of these therapies; improving access to health insurance for all Kansans; and other vital related issues.

We support an increase in the Kansas minimum wage, the efforts to increase mass transit initiatives and the efforts to allow stem cell research in accordance with federal, state and local laws. We oppose legislative efforts to restrict any such approved research.

Finally, we visited all legislative offices to deliver MS Awareness items that introduced our new logo, brand and tagline. In addition, Kansas Governor Kathleen Sebelius signed a proclamation declaring March as MS Awareness Month.

Missouri Advocacy

Missouri Legislative Action Day was a major success. Forty-four Legislative Ambassadors from across Missouri met at the Capitol in late February and participated in meetings with more than 120 members of the General Assembly. The opportunity to have face-to-face dialogue with legislators was valuable in advancing all of our legislative concerns.

The objectives of our legislative meetings were:

- * Providing information about MS and deepening elected officials' understanding of the challenges that many people with MS experience.
- * Participating in the dialogue on MO HealthNet (Medicaid reform, SB 577). Our top priorities include assuring access to specialists, coverage for disease modifying drugs, durable medical equipment and therapies, and increasing Medicaid physician reimbursements.
- * Supporting the reestablishment of a Ticket to Work Medicaid buy-in program in Missouri (HB 39).
- * Urging establishment of a tax credit for home accessibility modifications (SB 8). For several years, the MS Society has supported providing a tax credit to help offset the costs of home modifications for families with moderate incomes.



NATIONAL RESEARCH STUDY NEEDS VOLUNTEERS

The Sonya Slifka Longitudinal MS Study, sponsored by the National MS Society, has collected information from some 1,600 people with MS since 1999. Because the Slifka Study provides such valuable information to the MS community, it has just been expanded and extended for another five years. Now it needs 2,500 more people with MS.

Specific populations with MS will be “oversampled” in this phase of the study to ensure that their experiences are adequately represented. The target populations are African-American, Hispanic, and people diagnosed with MS after September 2006.

Most participants will be selected at random from the National MS Society’s database. However, to ensure that the study adequately covers people with MS who are **African-American, Hispanic, and/or are very recently diagnosed**, we are asking for volunteers. If you are a member of one or more of these groups, please consider joining this important study. Call **1-800-305-8013**.

Participation involves telephone interviews every six months, plus keeping a log of your health status, the medical services and therapies you use, the money you spend on MS-related needs, and the impact MS has on your life. The calls are made in English, so volunteers need to be comfortable talking on the phone in English.

All the information collected is confidential. Those who use data from the study will not be able to identify individual participants.

MS researchers are already using data from the first phase of the study to identify ways to improve quality of life and manage MS symptoms more effectively. The study data also helps the Society advocate for public policies that address the issues most important to people with MS.

The second phase of the study will lead to more important information about how people live with MS over time.



Beverly, diagnosed in 2001



SVAA Fall Show Fundraiser

The Springfield Visual Artist Alliance (SVAA) will be holding their annual Fall Show on November 10 from 10 a.m. until 4 p.m. The Fall Show will be held at South Street Christian Church, located at 500 South Street in Springfield MO. A portion of the sales will benefit the National MS Society. For more information, please call 417-882-8128 or 1-800-344-4867 or go online to <http://svaaarts.org>.

MS BIKE RIDE COMING SOON

With your help, we can Start to Finish MS

In September 2007, the Mid America Chapter will host three MS Bike Rides to get us closer to a world free of multiple sclerosis. In Kansas City, we'll ride on Sept. 8 & 9. On Sept. 15 & 16, we'll host the Ozark MS Bike Ride presented by FedEx Freight. And on Sept. 22 & 23, the Eastern Kansas MS Bike Ride will take over Topeka.

More than 4,000 riders will join together and raise over \$2 million for local programs and national research. You could be one of them! If you or a loved one is up for two days of cycling, sign up online at www.msmidamerica.org.



For people with MS who don't ride in our events, YOUR CHANCE to get involved is through our Champions Against MS program! We pair up MS Bike Ride participants and people with MS and their care partners. The Champions offer encouragement and support as participants strive to meet their tremendous goals. They share their stories of struggles and joys in dealing with MS. Participants often credit their new friends as the inspiration to continue training and fundraising.

All it takes is a little time and the willingness to reach out. You can be an active part of our fight against this disease. If you are interested, please contact the Mid America Chapter at 1-800-344-4867 (press or say 2) or at info@nmsskc.org.

Introducing the MS Society's Car Donation Program

Trying to figure out what to do with that old car, truck or van that's sitting in the driveway? Consider donating it to the Mid America Chapter. Whether your car is running or not, we can eliminate all of the hassles associated with selling your vehicle.



To find out more or to begin the donation process, visit our web site: www.msmidamerica.org and click on the Donate tab, or call Leslie Hansen at 1-800-344-4867, press 2.

More Cool Tips for Hot Days

- * Keep a plastic water bottle half filled in the freezer. Top it off and you'll have a drink that stays cool all day.
- * Herbals teas—fruity blends, peppermint, and ginger—are good chilled and have little or no calories if you make your own. Avoid sugary drinks. They leave you thirstier—and heavier too, because of all the calories.
- * Drink fruit juice the light way by extending with ice, water, or a fruity herbal tea.
- * Smoothies and slushies pack a cool nutritional punch. In a blender, combine banana, melon, strawberries, or peaches with low-fat milk or fruit juice. Then pile in the ice. Add a few drops of vanilla for an exotic touch.
- * Keep your car cooler with reflective shades for the windshield and fabric car seat covers. Available at auto supply stores.
- * Commercial cooling garments, such as vests, bra inserts, and headbands, can help you stay cool for hours. Search ABLEDATA (www.abledata.com or call 800-227 0216) or call us for referrals.
- * For information on heat sensitivity, go to nationalmssociety.org/sourcebook. Click on heat/temperature.



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