National
Multiple Sclerosis
Society

April 2004

msconnection

Greater Illinois Chapter

The National MS Society...One thing people with MS can count on.


12


16


19


23

MS Walk 2004

18,000 Stories...18,000 Walkers

The time for celebration of the advances being made in multiple sclerosis draws near – May 2 and the 2004 MS Walk presented by Serono Pfizer is just around the corner! All over the grand state of Illinois on that first Sunday of May, city and town residents surrounding over a dozen Walk sites will behold an awe inspiring sight. They will see masses of people committed to ending the devastating effects of multiple sclerosis coming together to demonstrate their resolve in the fight with both their determination and their dollars.

The sun is destined to shine on the event volunteers and 18,000 walkers and that day, as an unprecedented number of participants for the event are expected to bring in a record $2.55 million to fund local programs

(continued on page 3)

ms walk®

ms walk 2004

Sunday, May 2nd, 2004

**Start time (location specific)
9am or 1:30pm**

Register at www.msillinois.org

Repair & Recovery: Remylenation

A Cleveland Clinic study has found that new cells keep continually trying to repair the scarred brains of multiple sclerosis patients, even those who've had the disease for decades. Published in the New England Journal of Medicine, the study shows

(continued on page 4)

msconnection **APR**2004

Publication of the National Multiple Sclerosis Society, Greater Illinois Chapter

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PRESIDENT'S MESSAGE

Join Me In Welcoming Spring to Illinois!

There are many exciting things blossoming at the Greater Illinois Chapter of the National Multiple Sclerosis Society, and we invite you to join us in celebrating the excitement of the season! Spring and summer means concentration on fund raising, and there are ways for everyone to participate.

The chapter's largest event, the MS Walk, is less than a month away - May 2nd, in 13 locations across the state. Following after that will be the annual MS150 bike event, on June 26th and 27th. If you have not registered yet for these events, please do it today through the great new online system we implemented this year – it's terrific, and it's easy – www.msillinois.org.

There are a few more weeks remaining to complete your income taxes. Be sure to check off the multiple sclerosis box on your state taxes for an additional contribution. It's easy, painless, and goes to support direct services for people in Illinois with multiple sclerosis.

All of these events would not be possible without the support and hard work of volunteers. We have incredible committees who dedicate themselves to making us successful and helping us grow. On behalf of the entire MS community of Illinois – I thank each and every one of you.

And you can be a part of the growth, too, through support of our events, direct gifts to the society, or by contributing your time and talents. We are blossoming, and we would love for you to join us.

Best Regards,

Pam Swenk

Pamela L. Swenk
Chapter President

MS Walk 2004 (continued)

and research for people with MS. Given the excitement that traditionally accompanies the MS Walk, it is also expected that these 18,000+ people will also have a wonderfully good time.

If you have yet to be blown away by the new features of the MS Walk website, you should point your browsers to http://mswalk.msillinois.org as soon as possible. There you will find not only a customizable Participant Center just for you, but links to our fundraising incentive prize website and a new Storybuilder section; both the Participant Center and Storybuilder pages will allow you to tell your MS stories and inspirations, including why you're walking and fundraising tips you've found helpful.

Have you not registered yet as a participant or volunteer for the 2004 MS Walk? It's not too late to sign up and fundraise. Just visit http://mswalk.msillinois.org and click on the appropriate link to join the MS Walk as an individual or as a team.

ms walk 2004 locations

Chicago
Grant Park, 9am
Champaign
Meadowbrook Park, 1:30pm
Illinois Valley
Streator YMCA, 1:30pm
Joliet
Dellwood Park, 9am
McHenry County
Moraine Hills State Park, 9am
Naperville
Riverwalk/Downtown, 9am
North Shore
Highland Park High School, 9am
Northwest Suburban
Busse Woods, 9am
Peoria
Gateway Building, 1:30pm
Quad Cities
Middle Park, 1:30pm
St. Charles
Pottawatomie Park, 9am
South Suburban
Yankee Woods, 9am
Springfield
Washington Park Pavilion, 1:30pm

VOLUNTEER FOCUS

For all the fun that will be had and all the money that will be raised, however, we must thank all the selfless volunteers who make this event possible. If you see these 2004 committee co-chairs (or any volunteer for that matter) on May 2, be sure to show your appreciation for all their hard work!

Champaign: Kathy Kumler
Ruth Newman
Chicago: Janet Thabit
Melody Parks
Springfield: Lisa Harms Hartzler
Jane Wakeman
Illinois Valley: Julie Ramza
Joliet: Sean and Christine Whitfield
McHenry: Linda Chalmers
Naperville: Angela Marie Gotto
Suzy Cole
North Shore: Julie Shelton
Peoria: Michael Lechwar
James B. Monachino
Quad Cities: Dorothy Lemke
David & Diana Kelley
South Suburban: Caroline Huerta
St. Charles: Abbe Gunnink

Repair & Recovery: Remylenation (continued)

that the repair effort, though unsuccessful, persists much longer than had been thought, a testament to the brain's resiliency. The finding has implications for future treatments of MS, including the controversial use of transplanted stem cells to attempt similar brain repairs.

"The good news is that these data show that cells are being produced and are making a significant attempt at repair, but are falling a little bit short," said Bruce Trapp, chairman of the neuroscience department of the Clinic's Lerner Research Institute and director of the study. Rather than having to surgically transplant foreign cells, "we may be able to manipulate the [existing] cells" to finish the job themselves.

Doing that will require a better understanding of where the repair cells are coming from and what's hindering their effectiveness.

"Based on what we know about MS, it is surprising these cells are there," said Harvard Medical School neurologist Dr. Timothy Vartanian, who directs the MS Center at Beth Israel Deaconess Medical Center in Boston. "The findings of Trapp, [Mellen Center director Richard] Rudick and colleagues are incredibly important because they tell us for the first time that these cells exist in [MS] lesions, but are being stopped dead in their tracks."

The brain's dense network of nerve cells is connected by wiring that carries the electrical signals of thought. The wiring fibers, called axons, are insulated and nourished by a fatty coating known as myelin, just as rubber insulation protects electrical wires in your house. Without the covering, either kind of wiring - in your brain or your home - short-circuits.

Special cells called oligodendrocytes, the brain's electricians, are responsible for wrapping the axons with myelin. By toddler age, the insulating job is largely done.

In MS, the body's own immune system mistakenly targets myelin and steadily destroys it, leaving scarred areas called lesions in the brain and eventually affecting patients' ability to move and speak. The immune system also kills the myelin-making cells.

Researchers had thought until now that at this chronic later stage, the brain was no longer making new oligodendrocytes, the myelin-repairing cells. But the Clinic study found that not only are new repair cells present in the scarred areas, they are still hard at work trying to re-insulate bare axons.

The repair cells send out wispy tendrils that begin to encircle the damaged nerve fibers, the way a creeping vine wraps around a tree branch. But for some reason, the process halts before the protective sheath re-forms.

"We know very little about that," Trapp said. It's clear that in normal, developing brains, healthy axons orchestrate their own cover-up with myelin, somehow signaling their need for insulation. Perhaps the damaged axons aren't sending out that signal, Trapp said, or are broadcasting a counter message.

Either way, it's a hurdle scientists will have to get over if they are to restore the cells' healing power. Researchers also want to find a way to boost production of the repair cells, Trapp said. It's impossible to say if either can be done, or how long it might take.

"We may be able to develop a drug that will complete the repair process . . . or stimulate the production of more cells," Trapp said.

For more information on remyelination, come hear Dr. Trapp and a panel of experts discuss this on Saturday, April 17th at:

9TH ANNUAL FANNIE & CHARLES PENIKOFF RESEARCH SYMPOSIUM

THE ROAD TO
REMYELINATION

REPAIR & RECOVERY

WITH
BRUCE TRAPP, PH.D.

SATURDAY, APRIL 17
9AM - 2PM

CHICAGO • PEORIA
SPRINGFIELD

REGISTER AT
WWW.MSILLINOIS.ORG

SPONSORED BY EDUCATIONAL GRANTS FROM BIOGEN IDEC, SERONO, INC., PFIZER INC., AND TEVA NEUROSCIENCE

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10 Things to Know about Apitherapy

1) Apitherapy refers to the use of honey bee products for medicinal purposes and has been around for thousands of years. Hippocrates is said to have called it a miracle medicine.

2) Bee venom therapy is one form of apitherapy.

3) Bee venom therapy has been advocated as a treatment for a number of autoimmune conditions since 1930, including arthritis and bursitis.

4) Bee venom therapy typically involves multiple stings from a bee held by tweezers, several times a week.

5) According to Dr. Allen Bowling in Medicine and Multiple Sclerosis bee venom therapy has not been shown to have a beneficial effect in the treatment of MS.

6) Bee venom therapy could actually worsen MS. Studies conducted on mice at Alleghany University demonstrated some worsening of symptoms relative to the placebo. Dr. John Santilli will conduct research on the effect of bee venom in extract form with a MS Society grant.

7) People with MS who claim positive effects from bee venom therapy may be experiencing a placebo effect. Dr. Robert Herndon notes that “virtually every study of MS indicates a placebo effect, whereby people taking a placebo do better than they would with no treatment. Therefore, claims of success with any therapy, including alternative treatments, must be regarded with considerable skepticism until controlled clinical trials are done.”

8) Bee venom therapy is one of many complementary and alternative medicine (CAM) approaches. It is estimated that 50-60% of people with MS use some form of CAM, including acupuncture, meditation, massage, and yoga. 90% of these people also use conventional medicine. Unlike the other CAM’s bee venom therapy has never been clinically shown to have a positive effect in the treatment of MS.

9) The most prevalent substance in honey bee venom is Melittin, a potent anti-inflammatory agent, which may explain in part why bee venom therapy can be useful in rheumatoid and osteoarthritis, helping with both pain and swelling (Dr. Glenn Rothfeld, Whole Health New England). Studies on mice with the animal form of MS have shown that injections of bee venom 3 times weekly had no benefit. No large scale studies have evaluated its effectiveness in people with MS.

10) The Information Resource Center (IRC) of the Greater Illinois chapter receives calls from people with MS who want to know more about bee venom therapy. The IRC can provide information about the latest research on a specific treatment, whether conventional or alternative from its collection of pamphlets and brochures. It is important for anyone considering complementary or alternative therapies to discuss them first with a physician.

Possible Link Between Vitamin D & Reduced MS Risk Reported

A new study in nurses suggests that those with higher vitamin D intake may have had a reduced risk of developing multiple sclerosis. Kassandra Munger, MSc, and colleagues (Harvard School of Public Health, University of California at Irvine) report their findings in the January 13, 2004 issue of Neurology.

The study included 187,563 women, including 173 with probable or definite MS, enrolled in the Nurses' Health Study, which regularly surveys female registered nurses. Women whose intake of vitamin D were greater than or equal to about 400 IU/day from supplements and food, or from supplements alone, had a 40% lower risk of developing MS than women who did not take vitamin D supplements.

This study adds new information to ongoing research focused on a possible role for vitamin D in reducing the risk of developing MS. There is no information in this study to determine whether vitamin D affects the course of MS once it has begun. Further research is necessary to clarify these findings.

The U.S. government-issued "Adequate Intake" level of daily vitamin D for adults is 5-15 micrograms or 200-600 International Units. Excessive intake of supplemental vitamin D can have serious, toxic effects on the body.

MS Clinical Trials Update

The Clinical Trials feature of the National MS Society's website has been recently updated. Following is a summary of the articles and website address. You may also access the information through the website home page at: nationalmssociety.org – click on "Research" and "Clinical Trials".

- The list of "Agents in Clinical Trial for MS". This document lists more than 160 ongoing, planned, or recently completed studies of agents under study for MS.
- An expanded version for health care professionals contains extensive information on possible mechanisms of action for each agent, as well as study results, if these are available.
- "Clinical Trials in MS — Getting Involved, Getting Results". This spotlight highlights the latest news related to clinical trials, studies funded by the National MS Society, and the profile of Ruth Ann Marrie, MD, a Society-funded Sylvia Lawry Physician Fellow, who is being trained to conduct clinical trials.

Research Progress

The year of 2003 saw rapid research progress in the fields of science and medicine that impact our understanding of the unpredictable neurological disease of multiple sclerosis. Significant advances have been made in both clinical and laboratory studies in MS. In addition, nearly 160 clinical trials are underway around the world, and still other experimental drugs are in the pipeline. A few of the highlights of the year include:

- Promising results were published from an early-phase clinical trial of the monoclonal antibody Antegren® (natalizumab) in relapsing forms of MS. Those treated with Antegren for 6 months had fewer relapses and areas of myelin damage than those treated with placebo. Larger-scale trials are underway to determine if it can safely benefit people with MS.

- Italian researchers reported that immature nerve cells (adult mouse neural stem cells, or neurospheres) injected into the blood or brain cavities of mice with MS-like disease can move throughout the brain and spinal cord to sites of tissue damage, promote repair of nerve-insulating myelin, decrease damage to nerve fibers, and reverse clinical disease. If confirmed, this may help find a way to repair nerve tissue damage in people with MS.

- The U.S. FDA approved revised labeling of Betaseron® (interferon beta-1b) to extend its use to treat “relapsing forms of MS,” including individuals with secondary-progressive MS who experience relapses, or acute attacks. The FDA also extended the labeling of Avonex® (interferon beta-1a) to include those who experience their first clinical episode and have MRI-detected brain lesions consistent with MS.

- A small study found that the cholesterol-lowering pill Zocor(r) (simvastatin) safely reduced the number of new brain lesions in 30 people with relapsing-remitting MS. Larger, controlled studies are planned.

- The oral drug Aricept(r) (donepezil hydrochloride) modestly improved performance on a memory test in 69 individuals with MS with mild to moderate cognitive impairment. Larger studies are needed to confirm the safety and benefits of this medication.

- Researchers reported that in a study of more than 20,000 Norwegians, the risk of developing MS was nearly twice as high among smokers than people who never smoked. Further study is necessary to confirm and to explain this risk.

- Results from a clinical trial of oral marijuana derivatives for the treatment of MS symptoms, involving 657 people across the UK, showed that these agents did not provide objectively measured improvement in spasticity experienced by persons with MS, but confirmed prior suggestions that patients using marijuana felt better in ways that could not be measured by their physicians.
- The Society launched three new Collaborative MS Research Centers, five-year, $825,000 awards for expert scientists and clinicians from a variety of fields to team up on promising avenues of research. Projects funded in 2003 involve the search for MS genes, developing better diagnostic technologies, and testing possible strategies for myelin repair.

MS Cluster Study Begins in Northern and Central Illinois

Last summer MS Connection announced a study to determine the prevalence of MS, or the number of individuals with MS, in five small communities in northern and central Illinois where environmental hazards exist, Morrison, Savanna, Paw Paw, Lewistown, and DePue. The Agency for Toxic Substances and Disease Registry (ATSDR) selected the University of Illinois College of Medicine at Rockford as one of five national projects. Other projects are being conducted in Massachusetts, Oregon, Missouri, and Texas. The prevalence for ALS or Lou Gehrig's disease will also be investigated.

Approvals have now been obtained from the Center for Disease Control and Prevention and the University of Illinois Institutional Review Board to protect the privacy and confidentiality of the study subjects which allows the study to move forward. The project is now recruiting participants living in these five communities. Participants will complete a questionnaire about their health history, family history, and occupations and will give consent for their medical records to be reviewed according to the McDonald criteria for MS diagnosis.

Participants must be 18 or older, have lived in the study zip codes anytime between 1998-2002, and have had a physician visit for MS or ALS during that time.

For further information or to participate in the study please contact Health Systems Research, University of Illinois College of Medicine at Rockford, at 1-800-854-4461 or Barbara Sjostrom, Project Coordinator, at barbsjos@uic.edu.

Novel Technology Tested for Making "DNA Vaccine Cocktail" to Fight MS in Mice

Researchers are using advanced technology to design vaccines to treat EAE, an MS-like disease in mice. William H. Robinson, MD, PhD, Lawrence Steinman, MD (Stanford University, CA) and colleagues report the results of a novel study in Nature Biotechnology (2003 Sep;21(9): 1033-1039).

Research has indicated that "epitope spreading" may play a role in the immune attack on nerve-insulating myelin in MS. This means that although one protein in myelin may trigger the attack, the resulting immune response may spread to additional segments of that protein or other proteins. Investigators designed customized DNA vaccines containing "cocktails" of the genetic material that instructs several myelin proteins, which would induce maximal immune system "tolerance." The vaccines succeeded in reducing relapse rates in the mice, as well as epitope spreading.

In an accompanying editorial, Eli Sercarz, PhD (Torrey Pines Institute for Molecular Studies, San Diego) suggests that further studies are needed to establish the usefulness of these exciting results in devising therapies for people with MS. Bayhill Therapeutics notes in a press release that it plans to enter clinical studies in 2004 with a therapy for MS.

Study Confirms Disease Risk Level for Co-Twins When One Has Multiple Sclerosis

Published in the Proceedings of the National Academy of Sciences by Drs. C.J. Willer, George C. Ebers and colleagues from the Welcome Trust Centre for Human Genetics at the University of Oxford, along with collaborators at Stanford University, the University of British Columbia and the Canadian Collaborative Study Group, this study is an important confirmation of both the genetic underpinnings of MS and of the fact that a person must encounter some other, non-hereditary factor to develop the disease.

A large, long-term study involving 370 Canadian twin pairs in which one or both have MS, confirmed the risk of a twin developing MS when his or her co-twin has MS. The overall risk for identical co-twins is 25% (1 in 4), is lowest when both identical twins are male (about 5%) and highest when both are female (34%). The risk for non-identical twins was 5.4%.

More research is ongoing to understand gender differences in MS and discover the genes that make people susceptible to developing this unpredictable neurological disease.

Test of ACTOS for Treatment of MS

Research opportunity in Chicago Area

Doctors at the University of Illinois in Chicago are seeking subjects to participate in a Pilot Study to test if the FDA-approved oral anti-diabetic drug ACTOS will be safe in MS patients. Pre-clinical studies suggest that ACTOS may influence the course of MS, however the effects of this drug in MS patients has not yet been tested. Participants must have diagnosed relapsing-remitting (RR) form of MS, and must currently be taking either Avonex or Rebif to treat their MS symptoms. The study will last approximately 18 months.

This study (UIC Protocol #2003-0547) will be performed at the Department of Neurology at the University of Illinois Hospital under direction of Dr. Douglas L. Feinstein in the Department of Anesthesiology, University of Illinois, 1819 West Polk St, Room 544, MC519, Chicago, IL, 60612. He can be reached at 312-355-1665 or by email at dlfeins@uic.edu.

If you are interested in participating, or to obtain more information, please contact Winnie Dollear in the Department of Neurology at 312-413-5780; or Dr. Claudia Kaiser in the Department of Anesthesiology at 312-996-0052, for further information about this research study.

Explaining Chronic Illness to Your Child

How to "normalize" the illness, no matter the child's age

As a parent, if you become ill, your illness has a profound effect on the entire family system. In spite of your own increased stress, confusion and anger, your children will look to you to maintain or return to normal family routines as soon as possible. If you or your spouse present an image of feeling overwhelmed or being consumed with the illness, your children will feel as if life is spiraling out of control.

As parents, it is often instinctive to want to protect our children from hurt or pain. We want them to be carefree and experience the joy and happiness that only childhood can offer. However, as much as we don't acknowledge it, children do experience the same kinds of losses and disappointments that we, as adults, experience.

We, as the nurturers and protectors, must explain and "normalize" these experiences in the best way that we can.

No matter what the age of your child, it is helpful to know and understand developmental stages and how children at each stage can be expected to respond to stress and change.

Developmental refers to the concept that a child's behavior, like his or her physical growth, develops in patterned and predictable ways. The age and goals of your child at each stage will guide you in how and when you need to intervene when your family goes through a crisis.

INFANCY – AGE 2

The first developmental stage is probably the easiest in terms of knowing how to respond. The primary developmental goal is to establish trust. The child is completely dependent on the mother (or primary caretakers) to have basic physical and emotional needs met. With love and nurturing, the infant will thrive and grow.

Adults generally assume that a baby is too young or unaware to notice a change in a parent or family. However, infants and babies are extremely intuitive and can sense when a parent is upset or anxious. Any change in daily routine can throw a baby into a fretful state. When a crisis occurs, you may see the following behaviors: increased crying and irritability; changes in appetite and sleep schedules; clinging behaviors and regression. Separation anxiety, which occurs routinely, becomes exaggerated. The baby will develop offensive behaviors. Treat regressive behaviors casually and return to a normal routine as soon as possible.

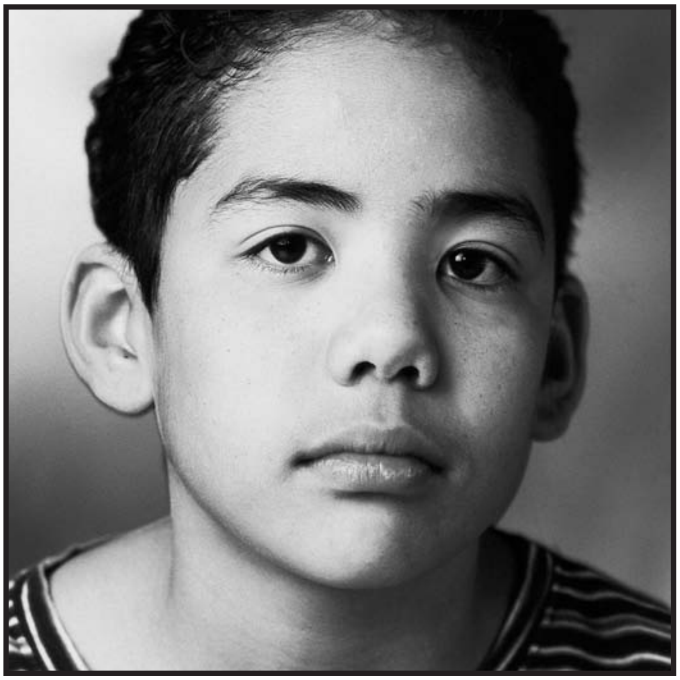
If your toddler asks a question about your illness, answer openly and honestly. A rule of thumb is: never offer more information than the child has requested. Concealing the illness or whispering about what is happening will not help. Children always suffer more from the tension of not knowing than from knowing the truth. Allowing the child to act out fears and frustration through play or art is also an excellent help.

PRESCHOOL

Preschool, ages four to five years, is the age of expansion. Preschoolers are ready to move out of the safety zone of home and into a broader social arena. There is an increased reliance at this stage on "magical thinking". Anything that happens, good or bad, is related to them and their behavior. If a parent becomes ill during this stage, the preschooler's view will be: "Mommy is sick because I told her she was mean."

In response to stress and change, preschoolers often present with extremes, either being all good or all bad. This is the child's attempt to maintain a sense of control and to feel less frightened. Regressive behaviors are likely to occur, especially an increased reliance on a favorite security object (blanket, teddy bear, and thumb-sucking).

To help preschoolers, it is essential to assure them that the illness is not their fault. Returning to a security object should be encouraged, rather than discouraged. Answer all questions honestly, including those about death.



SCHOOL AGE

The primary developmental goal of the school-age stage (six to ten years) is achievement. The focus is school, activities and developing strong peer relationships. While parents and family are still central, the biggest concern is: "What will happen to me if you are ill?" This self-centeredness is normal.

By the age of eight, children realize that illness may not be their fault. However, they still aren't mature enough to remove themselves completely from the situation. The thinking now is: "If I'm good, mommy will feel better and things will be fine."

Under normal circumstances, adolescents are known for their emotional volatility and moodiness. When crisis occurs, you may see and hear even more expressions of anger, hurt and confusion. The opposite extreme is also common (continued on next page)

Explaining Chronic Illness To Your Child

continued from page 13

- they may withdraw completely and not want to discuss your illness or their feelings about what's happening.

There will be ambivalence about helping you. Acceptance by peers will be much more important than appearing helpful to the family. It is normal for them to be embarrassed by the illness and not want to discuss it.

This is an essential time for parents to fine-tune their communications skills. It is imperative to listen to and understand the volatile outbursts of the adolescent. Accept these feelings without overreacting to their tone. Continue to set limits, rules and boundaries, but keep the task of separation in mind. These outbursts are often fear-based. At a time when they often feel out of control, teenagers cling to the hope that parents and family will remain structured and safe.

Remember, even though he or she appears grown, your adolescent needs as much love and reassurance as your younger children. In discussion about your illness, be prepared to give more detailed information, especially all the facts about the illness. A major concern or fear will be: "Will I get it, too?"

Some adolescents (ones who withdraw) may not want to hear about or discuss your illness. They may express anger or disappointment toward the ill parent. These behaviors serve to diffuse their own feelings of inadequacy in controlling the changes that are occurring or may occur in the future. Honest and open discussion of your own feelings may help them to express their own feelings.

One of the most difficult obstacles is the expectation that the adolescent will be mature enough to handle the situation and to provide support. In actuality, they are overburdened with their own concerns and too vulnerable to carry the burden of adult concerns.
In conclusion, the following reminders are offered to help you during times of crisis:

- Your children, like mirrors, reflect adult stress and behavior.
- Be assured that most children experience times of high stress, confusion and frustration, yet still manage to develop and maintain a healthy sense of personal worth.
- Your children still need limits, rules and structure. Be the same parent you were before the illness.
- Discuss plans and decisions with your children commensurate with age and level of understanding. The more a child is included in planning, the more your relationship will be safeguarded.
- Do not assume the problem behaviors that a child exhibits in times of high stress will be permanent. However, if behaviors persist or worsen over time, seek professional help for the child and family.

Workplace Giving: A Win/Win Situation

Corporate philanthropy has long been recognized as a great way for businesses to make a name for themselves in the community, but the recent economic slump has made it increasingly difficult for companies to maintain a consistent level of charitable giving. A simple solution does exist, however, which promotes a positive company image without stretching the budget.

Community Health Charities®
WORKING FOR A HEALTHY AMERICA

Workplace giving programs allow employees to support a charity of their choice through payroll deduction, one time gifts or credit card donations. These programs are free for employers and add another component to benefit packages, but more importantly, they grant employees the satisfaction of making a direct contribution to a cause that is important to them.

Running a workplace giving campaign is incredibly easy for companies to do when they team up with an outside organization such as Community Health Charities of Illinois. CHC, of which the Greater Illinois Chapter is a member, is the largest workplace giving program dedicated solely to health charities. Their organization provides all the materials needed to establish and maintain a workplace giving campaign, and will even assist in planning a kick-off event to get employees excited about the new opportunity. Once in place, CHC handles all the financial processing, including the distribution of checks to member charities, and also supplies an expert staff for support. For more information about Community Health Charities, visit www.healthcharitiesillinois.org or contact Sarah Greenwald, Director of Corporate Relations, at 312-939-6275 or sarah@healthcharitiesillinois.org.

Direct Assistance

There are many issues that people with MS must face. It is often difficult for individuals and families to get the services they need without also experiencing a financial burden. Services or supplies, such as transportation, counseling or supplies for incontinence, are not covered by Medicare and are often not included in insurance plans.

Services like transportation for a routine visit to the doctor, can for some, be financially taxing. Counseling is another service that may be a necessity for someone learning to the live with MS. While this is an important service, and one that may assist with one's adjustment to the disease, it is often cost prohibitive. The Income tax check off campaign is designed to assist people with MS who (continued on page 17)

Transportation in Illinois

by Kim Albin

When I started this transportation research back in September, I was not even sure there would be enough information available to make it worth my while. Here it is the middle of March, and I'm still learning about the lack of handicap-accessible transportation in this state and working with the Advocacy and Government Relations Committee to figure out a plan of action to resolve a problem that seriously affect those of us living with MS.I have made some valuable contacts at the Illinois Department of Transportation and at PACE who are also frustrated with the lack of funding available for those requiring handicap-accessible transportation. It is a monumental problem and one that will take a great amount of work to overcome.

We were fortunate enough to secure a meeting with Speaker of the House, Dennis Hastert, right before Christmas. It was a little disheartening to discover that the third highest-ranking legislator in our country is unaware of how large this problem is, even in his own district, Kane County. He is under the assumption that the gasoline taxes that each county gets, goes toward transportation when in reality that money is strictly earmarked for road repairs and construction. Our next step should be to let our government know that there is no funding available for additional handicap-accessible transportation and the challenges facing counties, especially rural, who want to offer services but do not have the resources.

I want to thank those facilitators who took the time to send in the transportation surveys and to assure all of you who deal with transportation issues in your community, that we are committed to doing all we can to shed light on this problem. The AGRC will be making its annual trip to Washington D.C. June 1st, and as your delegate, I am looking forward to meeting with those representatives that might be able to answer the question we all have: why don't handicap enjoy the same opportunities as every other American living in this country?

If you have any questions or comments, please call me at (630) 510-1189.

Navigating the Employment Maze

Upcoming Employment Events:

- **April 13, 2004**
  Working with MS & Disclosure
  A Teleconference with a Nationally known employment specialist, Steve Nissen, M.S., CRC.
- **April 16, 2004**
  Partners for Inclusive Employment will be hosting a job screening workshop at the University of Illinois at Chicago-this program will help you to focus on the skills needed to prepare for looking for employment.
- **April 24, 2004**
  Partners for Inclusive Employment will host a Job Match Fair, this Job Fair is invitation only you must attend the Job screening workshop on April 16, 2004 to be invited -Employers and Businesses attending this Job Match Fair will have job openings and be prepared to offer on the spot interviews.
- **May 11, 2004**
  Working with MS & the ADA
  Chat live with Dr. Phil Rumrill and Mary Hennessey from the Multiple Sclerosis Employment Assistance program at Kent State about your employment issues. Peter Breg, from the Great Lakes Disability & Business Technical Assistance Center will answer technical questions about the Americans with Disability Act (ADA).

Please Contact Celestine Willis at (800) 922-0484 or via email at celestine.willis@ild.nmss.org for more information or to register for any of these programs.

Direct Assistance

continued from page 15

are not able to afford needed services. By simply checking line G (step 10) of the 2003 Illinois tax return, money will be allocated for the Direct Assistance Program of the Greater Illinois Chapter of the National Multiple Sclerosis Society. 100% of donations go to the Assistance Fund and can help to provide direct service benefits for the more than 18,000 Illinois residents living with MS. Services currently provided include transportation, individual and family counseling, and incontinence supplies. For more information on the Direct Assistance Program call the Information Resource Center at 1-800-FIGHT MS

Multiple Sclerosis Assistance Fund
2004 Illinois Income Tax Check-Off

Kathy Harper, Peoria, IL (Central Region)

Kathy Harper is a National MS Society volunteer who lives in Peoria, and has three different volunteer roles with the Greater Illinois Chapter at the present time. Kathy is Chair of the Communications Sub-Committee, for the MS WALK in Peoria Committee; Co-Facilitator of the Peoria evening MS support group; and a volunteer MS Ambassador in the Central Region of the Chapter.

"I enjoy volunteering with the National MS Society because it allows me to help others, who like myself, are living with multiple sclerosis. I was diagnosed with MS four years ago."

Kathy has been volunteering with the Chapter for a few years already, and has gotten her husband to join in. Wally Harper is on the MS WALK Committee, is a TeamMS Captain, and also a volunteer MS Ambassador.

"I've been volunteering for more than three years with the Greater Illinois Chapter. I went to a support group meeting and found people who were not willing to give up, but rather help themselves and others with this disease. I decided pretty quickly that I needed to volunteer to help others."

Kathy's volunteer spirit doesn't end with the National MS Society. She is a community volunteer, and one of her ongoing efforts is to crochet and donate baby blankets to the local crisis nursery.

When asked what she does in her spare time, Kathy said that she enjoys spending time with her grandchildren. She also enjoys attending the semi-pro indoor football games in Peoria, to cheer on the Peoria Pirates!

Kathy Harper is a dedicated volunteer and a spirited community member. She actively supports the programs, advocacy, and fundraising efforts of the National MS Society. Kathy shares her enthusiastic spirit, and commitment to ending the devastating effects of MS, with everyone that she meets!

Excellence in Communications Award

The Greater Illinois Chapter received an Excellence in Communications Award for its campaign to publicize the Multiple Sclerosis Assistance Fund, an Illinois state income tax check-off that allows Illinois taxpayers to support the fight against multiple sclerosis through contributions from their 2002 Illinois Individual Income Tax Form. The state-wide campaign involved the use of a Peoria-based integrated communications firm, Hult Fritz Matuszak, to create a branded identity for the campaign and help develop key messages and strategies about the check-off opportunity for newspapers, radio, television and the Internet. The chapter realized more than $146,000 from the campaign, surpassing its goal of $100,000 and securing the position of multiple sclerosis on the 2003 Illinois Individual income Tax Form.

Volunteers of the Quarter

Mary Jo and George Viero

Mary Jo and George Viero are longtime and dedicated members of Multiple Solutions for MS, an auxiliary group of the Greater Illinois Chapter of the National MS Society. Membership is composed of young professionals dedicated to fostering awareness of MS in the greater Chicagoland young adult community and building an ongoing membership to provide both volunteer and financial support for the Chapter. Mary Jo and George started with the Southport Pub Crawl for MS in Chicago several years ago and the event has grown over the years, raising in excess of $85,000 since it began. The husband and wife team worked tirelessly over the 2003 holiday season on the 7th Annual Pub Crawl, despite the fact that Mary Jo was six months pregnant!

Mary Jo and George have also been major team players for Slugfest Against MS since its start in 2001. Slugfest is a one-day, 16-inch, coed softball tournament with 32 teams of 15 players each – representing neighborhood establishments, corporations and individuals all playing against each other for an important cause. In 2003, the 3rd annual Slugfest raised in excess of $30,000. We are grateful for the spirit and commitment that Mary Jo and George Viero have shown in the fight against MS, and for that reason we would like to recognize them as Volunteers of the Quarter.

Whitney Young Students Volunteer for MS

If you visit the Chapter's Chicago office in the afternoon, chances are you may see a group of energetic teenagers laboring over the photocopier, hard at work on a mailing, or in our stock room helping to inventory our event T-shirts. They are volunteering through the Whitney Young Magnet High School Chapter of the National Honor Society. To be considered for membership to a group of one million outstanding high schoolers across the country, these juniors and seniors are not just good students - they are have also exhibited the core values of leadership, service, character, and scholarship to their community. The Greater Illinois Chapter of the National MS Society is a partner agency in the out-of-school service program, and while school was in session in 2003, 76 students served over 200 hours in the Chapter's Chicago office. Ready and willing to help, these volunteers brighten our office and lighten our workloads.

News from the Tour de Farms

Cyclists across the state have already begun training in preparation for the MS 150 Tour de Farms weekend on June 26 & 27, and the National MS Society is doing its best to prepare for them. The route for this year's event will take some 2,000 riders through some of the most scenic areas of northern Illinois, but it will take the efforts of hundreds of volunteers to make the trip safe and enjoyable, as well as incredibly beneficial to those people living with multiple sclerosis.

The National MS Society is looking for volunteers to cover duties as varied as truck driving, massage therapy, accounting, check-in/out management, and good ol' moral support (indomitable cheer required). To find out how your special talents can help make the Tour de Farms '04 an unforgettable event, register to volunteer online at http://ms150.msillinois.org.

Pedal Partners has become one of the most important links between MS 150 Tour de Farms cyclists and the people with MS for whom they ride. Cyclists who sign up for the program are riding specifically for someone with multiple sclerosis, and in their honor riders wear a brightly colored bandanna signed by their Pedal Partner. For those participants who do not have a personal connection to MS, this can provide a great motivation to reach the finish line.

ms 150 bike tour®

To be a pedal partner, sign up when you register for the Tour de Farms at www.msillinois.org, or for more information about the Pedal Partners Program, call us at 888.343.1179.

Do you like challenging bike rides? Do you enjoy pastoral beauty and cyclist camaraderie? Then the MS 150 Tour de Farms is the event for you. Sign up as an individual, or gather your friends and co-workers to form a team. Registration can even be done online at ms150.msillinois.org.

MS 150 Tour de Farms

June 26th & June 27th, 2004

Waubonsee Community College, Sugar Grove to Northern Illinois University, DeKalb

To register, www.msillinois.org

Sponsors include:

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MS Wellness Days

Health is not simply a characteristic of the body – but the mind as well. One way to cope with the changes from MS is to recognize the powerful "connectedness" of the body and mind, and its influence on health. The Greater Illinois Chapter of the National MS Society is proud to sponsor two upcoming "Wellness Days," in Quincy and Bourbonnais Illinois, both on April 3, 2004 from 9:00 am to 1:30 pm. Each program is designed to enhance wellness in all areas of your life: mentally, emotionally and physically.

"The Mind-Body Approach to Managing MS" will be held in Quincy, Illinois. The guest speaker for this event is Rev. Judith Taylor who will speak on "Positive Attitudes – Life with MS." Other featured presenters will include Lilie Long, a physical therapist with the Hannibal Regional Medical Center, who will present "Exercises at Home," Margaret Williams, Associate Professor at the Blessing-Rieman College of Nursing who will provide information on "Nutrition and MS" and Jan R. Barrett, a certified Iyengar Yoga Instructor who will speak on "Yoga and MS."

The MS Awareness and Wellness Workshop in Bourbonnais will feature Dr. Barry Arnason, a Professor of Neurology at The University of Chicago, who is an expert in the diagnosis and treatment of multiple sclerosis. Loriann Mehmel, a certified yoga instructor will present "Yoga for MS" and Gary Paruszkiewicz will show "Theraputic Tai Chi for Multiple Sclerosis". Mr. Paruszkiewicz is a certified Stress Management Educator and certified Tai Chi instructor. This program is a joint initiative with Riverside Health fitness Center and is sponsored by an educational grant from Berlex Laboratories.

Come and join these experts to learn how to empower yourself to be proactive in managing your "wellness" needs. More information on each program and registration information in available on our website.

April 3rd

9:30am - 1:30pm

Riverside Health Fitness Center
100 Fitness Drive, Bourbonnais, IL

Pre-registration required
Sponsored by an educational grant from Berlex Laboratories

April 3rd

9:30am - 1:30pm

Holiday Inn
201 S. Third Street, Quincy, IL

Pre-registration required

Camp MS

Come and join us for some outdoor fun and activities at Camp MS! From May 18th to the 21st, we'll be having a great time together while participating in events such as Archery, Horseback Riding, Canoeing, Swimming, Yoga and Tai Chi.

Space is limited. Priority given to first-time attendees. Registration fee is based on financial need. Call **1-800-FIGHT MS** or visit **www.msillinois.org** for an application.

First Look for Charity Moment

Mr. And Mrs. R. Randall Onstead take moment for a snapshot during this year's Chicago Auto Show First Look for Charity at McCormick Place.

Symptom Management Support Group Program

with Randy Schapiro, MD

Saturday, May 10th, from 7pm-9pm

Carmichaels Steakhouse, 1052 W. Monroe St., Chicago, Illinois

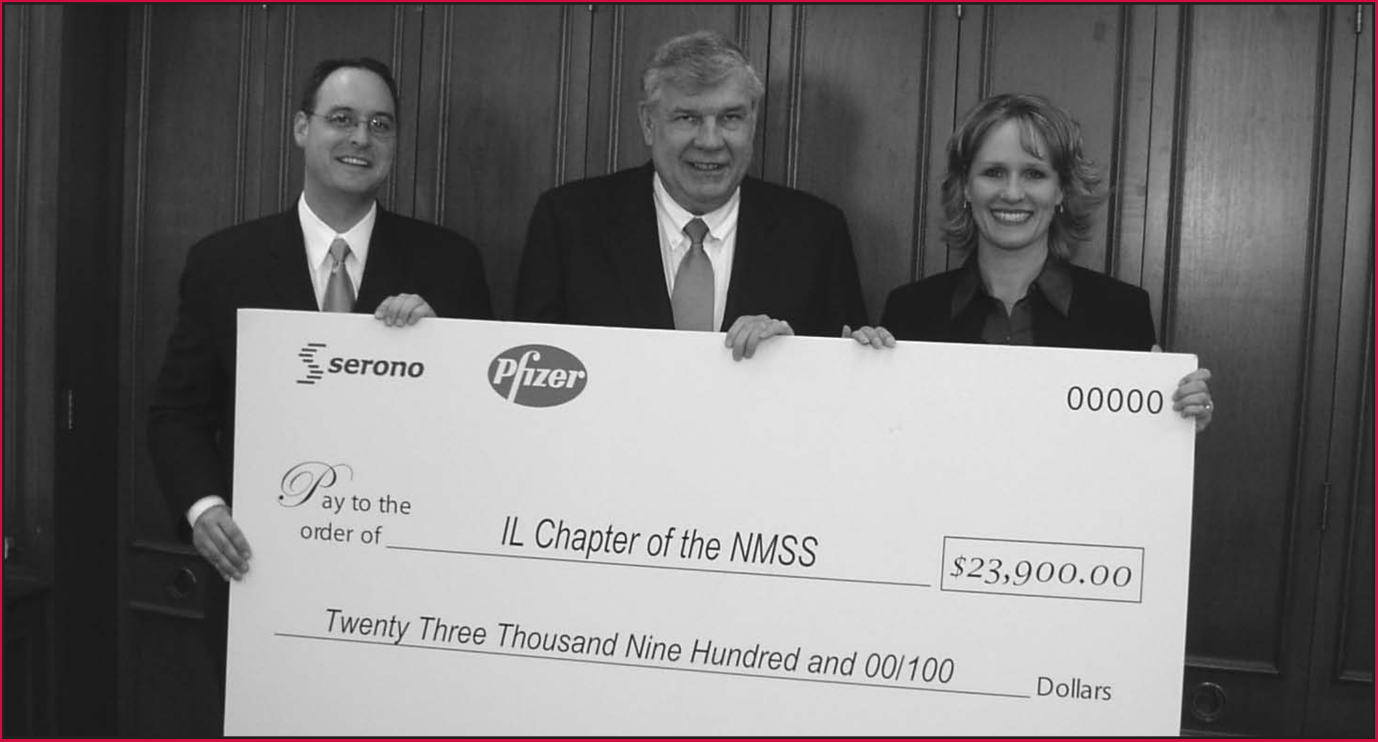
Please join Dr. Randy Schapiro, on May 10th, for a look at Symptom Management, as part of our new statewide initiative to create larger statewide opportunites with experts in the MS field. Dr. Schapiro is the founder and director of the Fairview Multiple Sclerosis Center and Minneapolis Clinic Multiple Sclerosis Program. He is Clinical Professor of Neurology at the University of Minnesota and on the board of Directors at the Jimmie Heuga MS Center in Colorado. Dr. Schapiro is a member of the National MS Society's Medical Advisory Board and a chair of the Clinical Advisory Committee.You will also receive a free copy of his book, Symptom Management in MS, signed by Dr. Schapiro himself.

For more information, please visit www.msillinois.org. Pre-registration is required, and space is limited, so don't wait, sign up now!

Make sure to keep on the look out for other Symptom Management & Living with MS programs throughout the state, including April 30th in Carol Stream, IL and June 10th in Elmhurst, both featuring Dr. Daniel Wynn.

Programs sponsored by an educational grant from Serono, Inc. & Pfizer, Inc.

Serono Pfizer Check Presentation Ceremony



Chuck Connors, the Chapter's Chairman of the Board of Trustees, accepts a check from Serono's Denise Wolff and Pfizer's Dan Bell; Serono and Pfizer have donated $43,900 towards underwriting the 2004 MS Walk, enabling more of the fundraising dollars brought in to be applied towards programs and services for people with MS in Illinois.

ms walk®

on May 2, 2004

Without the generous support of all our event sponsors, the National MS Society could not have made our events as successful as they've become. Our sincerest gratitude goes out to all these companies and organizations.

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CALENDAR

April

3 - MS Awareness Day & Wellness Workshop in Bourbonnais, IL
17 - Research Symposium (Chicago, Springfield & Peoria)
30 - Symptom Management with Dr. Daniel Wynn (Carol Stream)

May

2 - MS Walk
10 - Symptom Management with Randy Schapiro, MD (Chicago)
13 - Men's Fishing Trip & Dinner
18 - Camp MS
22 - MS Awareness Day in Highwood, IL

June

10 - Symptom Management with Dr. Daniel Wynn (Elmhurst)
26 - MS 150 Tour de Farms

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