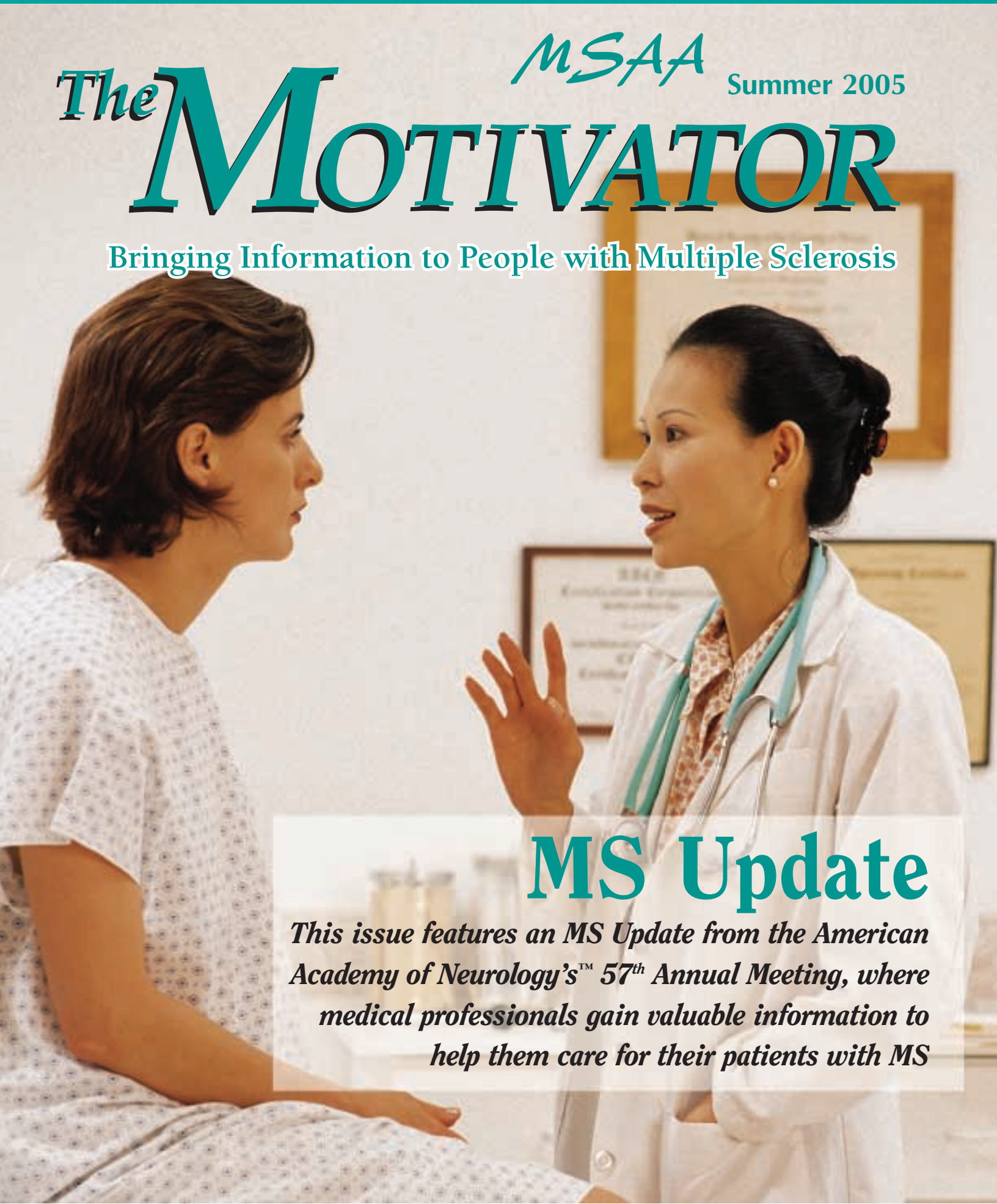
Travel the Easy Way • Coping with Heat Sensitivity

MSAA

Summer 2005

The MOTIVATOR

Bringing Information to People with Multiple Sclerosis



MS Update

This issue features an MS Update from the American Academy of Neurology's™ 57th Annual Meeting, where medical professionals gain valuable information to help them care for their patients with MS

The MSAA Motivator

Published by the Multiple Sclerosis Association of America

Douglas G. Franklin
President & CEO

Terrence McFarland
Vice President for
Development & Corporate Affairs

Robert Rapp
Vice President for Programs & Eval.

Gary Wallace, CPA
Vice President for
Finance & Administration/CFO

Jack Burks, MD
Vice President & Chief Medical Officer

MSAA Regional Directors

Linda Chaney
Susan Freund
Amanda Montague
Sue Pencoske
Adam Roberts
Renée Williams

MSAA Board of Directors

Joseph R. King, Chair
Paul Favorite, Vice-Chair
Francisco Ramirez, Treasurer
I. Ross Maclean, Secretary
Ila Bhatnagar
Jeri Canter, RPH
Tracey Edwards
James J. McGuinness
Sue Rehmus
Eric Simons
Mark L. Stine

The Motivator Staff

Andrea Borkowski, Editor
& Advertising Manager
Susan Wells Courtney, Senior Writer
Peter Damiri, Contributing Writer
Amanda Bednar, Contributing Writer

MSAA National Headquarters

706 Haddonfield Road
Cherry Hill, NJ 08002
(800) 532-7667

www.msaa.com

The Motivator's purpose is to inform and educate those with MS and their families. MSAA does not endorse or recommend any products, services, or items mentioned in articles or advertisements that appear in *The Motivator.*

Cover Story

MS Update 7
by Susan Wells Courtney
This article provides an overview of the full-day MS Update session which took place at the American Academy of Neurology's 57th Annual Meeting.

Cover Story, p. 7

Feature Articles

Travel the Easy Way, Just Pack Your Bags and Go! 26
by Christine Norris
Traveling alone and/or with a physical disability has become much easier through services to help with special needs.

Departments

Up Front 2
by Douglas G. Franklin
MSAA President and CEO Doug Franklin provides an update on the latest MSAA news. This issue's Board sidebar (written by Amanda Bednar) features Board Member Mark Stine.

Ask the Doctor 36
by Jack Burks, MD
MSAA's vice president and chief medical officer answers questions sent in by readers.

Research News 38
By Christian CD Poncet, PhD and Susan Wells Courtney
Topics are: (1) a gene required for myelin repair in mice has been identified; (2) Tysabri update; and (3) study finds that smoking may increase MS progression.

Program Notes 42
by Peter Damiri
MSAA's equipment distribution programs improve safety and accessibility.

Symptom Awareness 44
by Christine Norris
Heat sensitivity is explained and strategies to minimize the effects of heat are provided.

Health and Wellness..... 50
by Christine Norris
The importance of conserving energy is discussed, along with tips to help accomplish this goal.

Regional News 52
A listing of events, programs, and newly-formed support groups are given from each MSAA regional office.

Spread the Word 56
Three informative books from MSAA's Lending Library are outlined for interested readers.

Breaking Down Barriers
Building Up Hope

Copyright © Multiple Sclerosis Association of America, 2005. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without prior written permission from MSAA.

Up Front

by Douglas G. Franklin

MSAA is celebrating 35 years of service to individuals with MS, their care partners, and their families. To commemorate this important milestone, MSAA held a very successful fundraising gala in Philadelphia on May 19th. The evening honored MSAA's Vice President and Chief Medical Officer Dr. Jack Burks, for his 30-plus years of working, mentoring, and leadership in the field of service to individuals diagnosed with MS. Vendors, supporters, volunteers, staff, and friends, all enjoyed a wonderful evening commemorating this important anniversary, and we all look forward to MSAA's future achievements.

In June, MSAA held its Board of Directors meeting concurrently with the Consortium of Multiple Sclerosis Centers' (CMSC) annual conference. Some of MSAA's Board members, along with MSAA staff from various departments, were able to attend this informative conference. Activities included poster sessions, educational seminars, and exhibits, where MSAA had a booth to share information and public education awareness.

Together with the CMSC and the Multiple Sclerosis Foundation (MSF), MSAA co-hosted a special workshop at the conference. Focusing on the issues of children affected by MS, this was the first collaborative effort by this group of MS organizations, and the workshop topic was one of the highlights of the conference.

Joining MSAA for her first Board meeting was Sue Rehmus. Sue works for General Motors in Michigan and also heads up her own volunteer organization: Children's Hope for Understanding Multiple Sclerosis (CHUMS). Sue is a communications specialist who personally experienced MS in her family as a child and she brings a wealth of passion and dedication to our cause.

MSAA is also expanding its programs to meet the needs of the Hispanic community with MS. Thanks to a grant received from the Medtronic Foundation, MSAA's *Programs & Services Guide* has been translated into Spanish and is available now by calling MSAA at **(800) 532-7667**. A second publication, *All About Multiple Sclerosis* will also be translated. We held our first Spanish-language public education day in June in Bethesda, Maryland with Dr. Raul Mandler, and we anticipate the demand for these types of sessions to grow in the months to come.

I hope everyone is finding a way to avoid the hot summer temperatures. Those particularly sensitive to heat may benefit from MSAA's Cooling Equipment Distribution Program, which provides cooling garments free of charge. For more information, please contact MSAA at **(800) 532-7667** or visit our website at **www.msaa.com**. I would like to wish everyone a safe and enjoyable summer season.

Douglas G. Franklin joined MSAA as President & Chief Executive Officer in 1999 and has strategically guided its national outreach and corporate partnership support to unprecedented levels. Mr. Franklin is a former national trainer for the Drucker Foundation and is an internationally published expert in the field of social marketing who holds degrees from four universities. He currently serves on the national board of the Key Philanthropic Organizations Committee of the American Society of Association Executives and is a member of the Executive Committee of Health First – America's Charities Board in Washington, DC.

Meet MSAA Board Member Mark Stine

Mark Stine joined MSAA in the spring of 2001 and brought to the organization an extensive background in corporate communications and marketing. Mr. Stine, a graduate of the University of Arizona, has been involved in the communications field working with both corporate and nonprofit organizations. He has served as vice president of corporate communications/senior director of corporate affairs for Arby's, Inc. In this position, Mr. Stine worked to establish a relationship with various nonprofits and was the founding director of the Arby's Foundation.

Mr. Stine continued his work in the nonprofit sector as the director of marketing and licensing for D.A.R.E. America, a drug and anti-violence education program. In this position, Mr. Stine helped to develop successful partnerships with numerous corporations in establishing the D.A.R.E. brand. Currently, Mr. Stine is the director of business development for Nathan Adelson Hospice Group, which encompasses the Center for Compassionate Care, Nathan Adelson Hospice, and the Nathan Adelson Foundation. Mr. Stine currently resides in Las Vegas, Nevada.

As a member of MSAA's Board of Directors, Mr. Stine serves on the development committee and the nominating committee and has taken an active role in recruiting new members for the Board. One of MSAA's newest Board members, Jeri Canter, was recommended by Mr. Stine.

Mr. Stine describes his experience on the MSAA Board as "very educational, enlightening, and progressive." He explains, "It has been wonderful to see the evolution of the team at MSAA. They are doing great things such as improving and increasing our programs and services, as well as bringing *The Motivator* to a higher level. I have really enjoyed being a part of this and watching MSAA grow."

Mr. Stine is particularly proud of how MSAA makes a real difference in the MS community. "One of the first things I realized was the impact we have on the lives of those who have MS," states Mr. Stine. "By being an advocate, you realize more about the assistance MSAA provides. Once I was sitting on an airplane and the person next to me had a family member with MS. I began talking about MSAA and gave the person my business card. The client called MSAA's Helpline and MSAA was there to answer the client's questions. It's great to see how the whole process works. We are truly helping people."

MS Update

An Overview of the MS Update at the American Academy of Neurology's 57th Annual Meeting

Written by Susan Wells Courtney

Edited by Dr. Jack Burks

Introduction

The American Academy of Neurology (AAN) held its annual meeting from April 9th to 16th in Miami Beach, Florida. This is an important event attended by thousands of neurologists from around the world.

Multiple sclerosis is just one of the many neurological conditions that are discussed at the conference, and this is where neurologists receive the latest information in terms of diagnosis, treatment, experimental drugs, and MRI techniques. New findings are also presented in the etiology, pathogenesis, and pathology of MS – identifying the possible causes, development, and cellular processes involved with this disorder.

This article gives an overview of the full-day seminar, which was presented by top MS experts. The week-long meeting also featured several shorter classes to update physicians on the latest findings in MS. Additionally, poster sessions were held throughout the week. At these sessions, attendees view the posters, which are set up on easels and typically give the status or results of a research study. Often one or more of the researchers conducting the study will be present to discuss the findings with those who stop by their poster. Information from these shorter sessions and posters will be included in the next issue of *The Motivator*.

In addition to the classes and poster sessions, the annual meeting features an exhibitors' area, where many organizations and vendors set up booths to promote their cause, product, or service. MSAA participates in this exhibit area to increase awareness of the organization and its mission, as well as to expose neurologists to the programs and services MSAA provides. By doing so, physicians may return to their offices and inform their patients of MSAA programs and services that may be helpful to them.

MS Update

On the second day of the conference, a full-day update on MS was given. To follow is an overview of the information presented.

Pathogenic and Clinical Implications of the MS Lesion

The MS Update began with a session on MS pathology, which looks at the disease

processes in an effort to better understand what is occurring and why. This first segment was presented by Dr. Claudia Lucchinetti from the Mayo Clinic College of Medicine in Rochester, Minnesota.

The differences in the chronic MS lesion and active MS lesion were presented. Lesions are areas of inflammation and myelin damage within the central nervous system (CNS) as seen through magnetic resonance imaging (MRI) or under a microscope. Generally speaking, the CNS consists of the brain and spinal cord. Myelin is the protective covering or insulation to the nerves within the CNS, allowing nerve impulses to travel quickly and without interruption to their destinations. In MS, damage to the myelin occurs in these areas of inflammation (known as "demyelination"), and damage may occur to the nerves (or "axons") as well – often referred to as "axonal degeneration."

When new myelin is produced to replace damaged myelin, this is called "remyelination." Oligodendrocytes are the cells that make new myelin. While remyelination occurs more often in the early stages of MS, new myelin may also be produced during the chronic stages of MS, but this is more limited. Inflammation, more prevalent in active lesions (typical of earlier stages of MS), was also observed in lesser amounts in chronic, inactive lesions (typical of chronic stages of MS). The reduction of oligodendroctyes is just one possible explanation for the nerve's inability to regenerate myelin; a recent study suggests that the damaged nerve may not be receptive to the message of repairing damaged myelin.

Under normal conditions, the blood-brain barrier (BBB) keeps certain disease-fighting cells that exist in the blood system from passing through the walls of the blood vessels and entering into the CNS. With MS, these immune-system cells are able to cross this important barrier and make their way to the brain and spinal cord – where they cause inflammation and damage to the myelin and nerves. "Adhesion molecules" attach to the vessel walls and work like a key to open the BBB, allowing immune-system cells to cross the barrier. This was noted as an important step in the MS process.

When a body's immune system causes damage to the body's own tissue, this type of disorder is referred to as an "autoimmune" response. MS has traditionally been classified as this type of a disorder. Recent findings, however, indicate that MS may be a much more complicated process than previously recognized.

The role of inflammation in MS is still being defined through research. Most evidence supports that inflammation is a prerequisite for demyelination. It could also occur without demyelination, and may even play a role in the repair of MS lesions.

The author points out that MS differs between patients in terms of clinical, genetic, radiographic, and pathological features. Additionally, studies of MS lesions have shown that four distinct demyelination patterns occur, each with a different mechanism for causing damage to myelin or oligoden-

drocytes. Of the patients studied, each exhibited only one of the four types of active-lesion patterns. This supports the concept that different therapeutic strategies may be required for subgroups of individuals with MS.

Dr. Lucchinetti concluded by noting that both inflammatory and non-inflammatory factors contribute to the injury caused by MS. At this time, the MS lesion (associated with inflammation and demyelination) remains the target for therapy. Further research is needed to confirm the observations of the four subgroups of patients experiencing different patterns of demyelination, along with finding ways to readily identify markers which distinguish these lesion features. Such research may ultimately lead to more individual and effective therapies. Future approaches will be aimed at inhibiting demyelination, preventing nerve damage, and promoting repair.

Immune Intervention

The next session on immune intervention was presented by Dr. Samia J. Khoury from Harvard Medical School, Center for Neurologic Diseases, Brigham and Women's Hospital, Boston, Massachusetts. Dr. Khoury began by noting that MS is an autoimmune disease affecting the myelin within the CNS. As mentioned in the previous session, certain immune-system cells become activated and migrate (across the BBB) into the CNS, where they initiate an inflammatory response.

During the inflammatory response, several proteins (including myelin) may be recognized and targeted by these activated immune cells. These same cells exist in the circulation of healthy individuals, but in individuals with MS, these particular cells are in an activated state. Two theories, both relating to immune responses from a bacteria or virus, were presented as possible mechanisms for these cells to become activated in individuals with MS.

Experimental autoimmune encephalomyelitis (EAE) is an inflammatory CNS disease that is given to animals. This is done to observe how an MS-like disorder behaves in terms of symptoms as well as the cellular changes during active disease and recovery (generally the animals recover from this experimental disorder). Through such studies, researchers have been able to understand a great deal about the immune response in MS. This has also led to the therapies presently available to treat the disease.

During the past 10 years, much interaction has taken place between neurology and immunology to improve science's understanding of MS. This has resulted in the development of new therapies that target specific actions within the immune system.

The five approved therapeutic agents for MS affect the immune system in different ways. Interferon beta (which includes Avonex®, Betaseron®, and Rebif®) is a chemical that is normally produced by the body's immune cells during viral infections, explaining why individuals taking this drug may experience flu-like symptoms as a side effect. This chemical works by coun-

teracting the effects of interferon gamma, another naturally-occurring chemical that promotes inflammation. Other potential mechanisms for beneficial effects have been proposed as well.

Glatiramer acetate (Copaxone®) binds to certain molecules through various mechanisms and induces an immune response that also reduces inflammation. Mitoxantrone (Novantrone®) is a chemotherapeutic agent, which works by killing proliferating (rapidly reproducing) cells. The mechanism of action is most likely related to general suppression of the immune system.

Since the approval of these current treatments for MS, other potential therapeutic targets for MS have been proposed and experimental treatments trials are being tested. To follow are some of these targets along with a few of the associated treatments.

- **Blocking immune signals** that would otherwise activate potentially damaging cells within the immune system; a phase I clinical trial of CTLA4Ig is presently being conducted for MS.

- **Reducing the production of chemicals** (such as interferon gamma) that may promote inflammation; oral salbutamol (albuterol) is presently in a phase II study (as an add-on therapy to glatiramer acetate); Rolipram® (previously prescribed as an antidepressant) is in a clinical trial for MS; and humanized monoclonal antibodies to IL-12 are also being studied in the treatment of MS.

- **Targeting adhesion molecules** to stop immune-system cells from migrating through the BBB into the CNS; natalizumab (Tysabri®) was in phase III trials but was voluntarily suspended from the market due to adverse events.

- **Blocking other damaging processes** involved with MS pathology; Matrix-metalloproteinase inhibitors (MMPI) are being tested in other autoimmune diseases and cancers; MMPs may be involved in the BBB breakdown.

- **Reducing inflammation with statins** (statins are a group of drugs currently approved as cardiac and cholesterol-lowering treatments); a recent trial suggests that simvastatin may be beneficial for MS patients.

- **Promoting neuroprotection** (protecting the nerves from damage); "Glu receptor antagonists" may be considered for MS studies in the future; such antagonists would interfere with L-Glutamate's ("Glu") ability to excite the immune system and possibly contribute to neuronal toxicity.

Dr. Khoury concluded with the concept that modern biotechnology and an improved understanding of the immunopathology of MS have led to the development of new therapeutic targets. While animal studies do not always translate directly to humans, EAE and other animal models have made

effective treatments possible, bringing new hope to individuals with MS.

Magnetic Resonance Imaging in MS

This portion of the program was presented by Dr. Rohit Bakshi of Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts. Dr. Bakshi points out that as a result of ongoing technological advances, magnetic resonance imaging (MRI) continues to reveal new information about brain anatomy, chemistry, physiology, and pathology.

The MRI of the brain enables the neurologist to get an "inside view" of the changes that are taking place. MRI scans are vital to the initial evaluation of someone who is suspected of having MS. These are often ordered when a patient experiences an initial sign of the disease, also know as a "presenting symptom(s);" when only one symptom is experienced, this may also be referred to as a "clinically isolated syndrome" or "CIS."

An MRI is far more sensitive than clinical data when assessing disease activity. For this reason, MRI technology has also become an important tool (when needed) for measuring a patient's response to an established treatment. In addition, the worsening of MRI findings – even when a patient is not experiencing worsening symptoms (known as "clinically silent" disease activity) – may indicate long-term clinical deterioration.

Dr. Bakshi noted that MRI has an essential place in the initial evaluation of patients with suspected MS as well as in providing outcome measures in clinical trials. Through the use of a powerful magnet, the MRI is sensitive to processes that alter the water content of people's tissues, and is also sensitive to processes that constrain the motion of the hydrogen molecule. As a result, MRI images are able to show changes and abnormalities in tissues – including those which occur in the brain and spinal cord.

T2-weighted MRI images may reveal hyperintense lesions (those showing <u>increased</u> intensity) and are sensitive to lesion changes over time. This type of imaging is particularly helpful when evaluating patients at the earliest stage of the disease (such as individuals who present with a clinically isolated syndrome) as well as helping physicians to assess the effectiveness of a treatment. T2-weighted hyperintense lesions, however, cannot specifically identify underlying inflammation, edema, demyelination, axonal damage, nerve degeneration, or gliosis (scarring). Additionally, as someone's MS progresses, some hyperintense lesions tend to run together when viewed on this type of imaging. For these reasons, T2-weighted images of hyperintense lesions are less useful as one's MS advances.

Gadolinium (GAD) is a "paramagnetic" contrast agent that may be given to an individual via intravenous (IV) injection prior to an MRI. The gadolinium adheres to areas of acute inflammation which occur around the blood vessels (known as "perivascular inflammation"). These areas of acute perivascular inflammation indicate

Attention: Federal Employees

People with Multiple Sclerosis depend on MSAA as a…

LIFELINE FOR A LIFETIME

Incurable and unpredictable, MS is diagnosed earlier and earlier…even in pre-teens!

MSAA works with people as they cope with:

- teen years, education, dating, career planning
- marriage, family life, changes in MS

MSAA programs and services include:

- Toll-free Helpline, Equipment Distribution, Publications
- Home modification, Diagnostic and Follow-up MRI
- Cooling, Networking, Lending Library, Support Groups

YOU CAN BE A LIFELINE FOR A LIFETIME

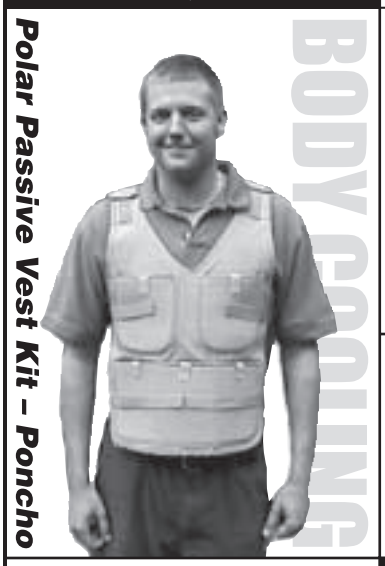
When completing your CFC form, please remember **#9509** for MSAA

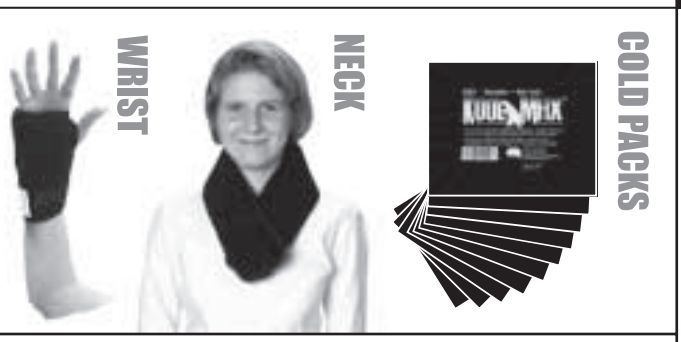
Multiple Sclerosis Association of America
706 Haddonfield Road, Cherry Hill, NJ 08002
1-800-532-7667 www.msaa.com

Relief from Heat

POLAR Body Cooling SYSTEM KITS

Cold Pack Cooling Systems





Each System Kit Includes:

- *Fully adjustable vest with 10 Kool Max cold packs*
- *2 wrist wraps w/ cold packs*
- *Neck collar w/ cold packs*
- *Extra set of cold packs for wrist wraps, neck collar and vest. Keep In Reserve!*

Lightweight & Comfortable

1-800-763-8423
WWW.POLARSOFTICE.COM

Worn Under or Over *Clothes*

where the BBB has been compromised and immune cells may be entering the CNS.

When an MRI is performed, these areas of inflammation stand out since they have been enhanced by the contrast agent (GAD). While GAD-enhanced lesions are a weak predictor for short-term change in terms of disability, they do provide a measure of long-term disease activity as well as therapeutic efficacy in clinical trials.

T1-weighted images showing hypointense lesions (those of lower intensity) have been used recently as an outcome measure in clinical trials. Newly formed T1-hypointense lesions likely reflect inflammation, edema, demyelination, early remyelination, axonal changes, and glial activation (which forms scars). Approximately half of these lesions will resolve within six months. Permanent lesions may help to predict accumulating clinical symptoms.

Magnetic resonance spectroscopy (MRS) is used primarily as an investigational tool to examine lesions as well as normal-appearing brain tissue. This technology is able to detect various compounds within the tissue, which may potentially include products that result from the breakdown of myelin. MRS may be more sensitive than MRI in identifying abnormal tissue in MS, but MRS is still being validated as a measure in terms of clinical correlation and sensitivity to therapeutic effects.

Magnetization transfer imaging (MTI) is another technique that may detect demyelination, gliosis, and inflammation that may not be identified through a conventional MRI. The magnetization transfer ratio (MTR) is reduced when tissue damage (demyelination, axonal loss, etc.) occurs in MS. MTR actually declines a few months before GAD-enhancing lesions may be observed, and declines further as the lesion begins to enhance. While still exploratory at this time, MTI has the potential as a measure of long-term disease progression and treatment monitoring in MS.

The involvement of the spinal cord was also included in the presentation. According to Dr. Bakshi, hyperintense lesions on T2-weighted images may be observed in the spinal cord in many individuals with MS. Spinal cord lesions may relate more specifically with one's physical disability. For individuals with a "clinical picture suggestive of MS," but who have a normal brain MRI, lesions in the spinal cord may be visible in roughly five to 15 percent of these individuals. Spinal cord lesions may also be visible in some individuals presenting with a clinically isolated syndrome.

Article reprints on the role of MRI in MS, written by Robert Zivadinov and Rohit Bakshi, were included in this presentation on MRI. The presentation also included extensive information on MRI techniques as well as countless MRI images to assist neurologists with more precise analysis of disease activity.

Diagnostic Criteria for MS

The MS community is aware of the challenges involved with determining whether or not someone has MS. Individuals experiencing symptoms often must go through a long period of

uncertainty before this diagnosis may be confirmed.

Dr. Brian G. Weinshenker of the Mayo Clinic College of Medicine in Rochester, Minnesota, outlined the criteria needed to diagnose MS, along with some of the pitfalls that may occur. Specific diagnostic criteria for MS were first proposed more than 50 years ago and since then have been updated many times. The majority of these updates resulted from advances in technology, particularly in regards to cerebrospinal fluid (CSF) analysis and MRI. Although many revisions have introduced new features, several basic principals were retained.

According to Dr. Weinshenker, a diagnosis of MS requires:

- lesions (such as those on an MRI) must be disseminated in time and space – meaning that at least two lesions must occur at different times as well as in different locations

- upon examination, the physician must observe "abnormalities" (in terms of a patient exhibiting one or more symptoms)

- the patient must also experience either relapses lasting at least one day and separated by at least one month, or a progressive disability worsening over at least six months

- no other diagnosis to explain symptoms (in earlier versions of the criteria, the diagnosis was limited to individuals between the ages of 18 and 50, but the medical community has since discovered that individuals with MS may be younger or older at onset)

MRI results, evoked potentials, and spinal fluid analysis were first integrated into diagnostic criteria for MS in 1983, through the work of Poser and others. This was the most widely used criteria until recently. The McDonald criteria are the newest version of diagnostic criteria for MS. Created by a committee in London and published in 2001, these criteria are based on lesions disseminated in time and space. It also removed arbitrary criteria (such as age), enabling some to be diagnosed sooner and possibly benefit from early intervention. The Barkhof criteria have also been adopted, adding MRI specificity to the McDonald criteria, with the intent of minimizing the possibility that inconsequential MRI changes would be misinterpreted.

Dr. Weinshenker notes that a better understanding of the role of MRI, along with enhancements in CSF analysis, have resulted in an improved diagnosis of MS, allowing physicians to better differentiate this disorder from other demyelinating diseases. While the present diagnostic criteria are of great value, they lack specificity. As the understanding of MS evolves, further modifications to the criteria may be appropriate.

Current Therapeutic Strategies

Dr. Dean M. Wingerchuk of the Mayo Clinic College of Medicine in Scottsdale, Arizona, summarized the recent advances in several aspects of therapy for demyeli-

nating disease. He included the treatment of exacerbations, clinically isolated syndromes, and the different types of MS, using specific study results to support his conclusions.

Individuals experiencing an acute exacerbation, which is one that causes moderate or severe symptoms, are usually treated with corticosteroids. Dr. Wingerchuk points out that a short course of parenteral (administered non-orally) corticosteroids, will speed recovery from attacks. A meta-analysis of trials has shown that intravenous administration (IV) of methylprednisolone at 1,000 mg/day for five consecutive days may be the optimal treatment at this time. The value of oral prednisone for treating relapses is not known.

Individuals with very severe exacerbations who do not respond to corticosteroids may respond to plasmapheresis. Plasmapheresis, also know as plasma exchange or "PE," is a procedure where the blood is circulated through a cleansing machine and returned to the body. A study showed that 42 percent of individuals receiving this therapy experienced significant clinical improvement. Individuals with severe optic neuritis who do not respond to corticosteroids may also benefit from this procedure. [Editor's note: while some individuals respond to plasmapheresis, the treatment effect may be temporary, the procedure is expensive, and plasmapheresis has side effects that should be taken into consideration.]

MSAA Needs Volunteers!

Volunteering assignments include:

- Public Education Ambassadors
- Support Group Leaders
- Professional Volunteers (including lawyers, occupational therapists, and physical therapists)
- Independent Volunteer Fundraisers
- Resource Detectives
- Sweeten the Season Ambassadors

Please contact **Malcolm Friend at MSAA**
Phone: (800) 532-7667, ext. 8
Email: volunteering@msaa.com
Website: www.msaa.com/volunteer.html

(When sending an email, please include areas of interest for volunteer work and any contact information)

Body Cooler®
Body Warmer™

Cooling neck wraps, therapeutic collar with spinal attachment, foot wrap, cooling vests, skull pad and many more styles.

NEW MAXIMUM ACTIVITY COOLING VEST™

Using NASA Spin-Off Technology, it will keep you cool for many hours. As with all our products it is reasonably priced.

VEO-8

AKEMI, INC. Houston, TX
www.bodycooler.com
info@bodycooler.com
Toll free 1-800-209-2665 (cool)

Dr. Wingerchuk notes that while such treatments are important for patients in order to speed recovery from a severe exacerbation, no treatment approach has been shown to improve long-term recovery. In other words, regardless of whether or not a patient received treatment for a relapse, studies show that his or her long-term outcome may not be altered.

Individuals diagnosed with relapsing-remitting MS (RRMS) often begin with a clinically isolated syndrome as their first episode, such as optic neuritis. Two studies ("CHAMPS" and "ETOMS") have shown that early treatment with interferon beta-1a may delay conversion to clinically definite MS and reduce disease activity in the brain as measured by MRI. Since the study was short term, researchers do not know if this early treatment has any beneficial effects on future disability and disease progression.

The three interferon drugs and glatiramer acetate are the main therapies in the treatment of RRMS. Dr. Wingerchuk's interpretation of the pivotal trials is that all three interferon (IFN) drugs reduce relapse rate by approximately one-third, and both of the IFN beta-1a drugs have at least one study that demonstrates an effect to slow the progression of disability. A pivotal IFN beta-1b study did not show a statistically significant change in EDSS measures (for progression of disability). Glatiramer acetate also shows a reduced exacerbation rate by approximately one-third, but studies did not show a significant impact on the progression of disability. [Editor's note: differences in trial design may prevent these trials from being directly compared.]

Scientific trials (the "INCOMIN" and "EVIDENCE" studies specifically) show some evidence for a dose effect with the interferon drugs, i.e., an increased dose resulting in an increased effect. Any change in dose, however, should only be determined by one's physician. An additional small study demonstrated that patients who remained on a standard dose of IFN beta-1b had a lower relapse rate than those who switched to a weekly dose of IFN beta-1a.

Studies have demonstrated that IFN beta-1b and IFN beta-1a are effective in slowing the rate of progression in SPMS patients over a two-to-three-year period. Critics, however, note that this improvement was very limited. Other studies with the interferons did not show an effect on disability progression in SPMS, but did show a treatment effect on multiple secondary outcomes, including relapse rate, relapse severity, and MRI measures of disease activity and total burden of disease.

With the use of interferon drugs comes the long-standing controversy over the possible impact of neutralizing antibodies (NAbs) on treatment efficacy. Formed by the body as a response to these types of drugs, some studies have indicated that persistent NAbs may have a negative effect on some clinical benefits of IFN treatment. Relapse rates have been higher during NAb-positive periods, but this did not affect progression as measured by EDSS. While brain MRI T2 volume changed during this time as well, MRI results were still better than for those on placebo. The clinical importance of NAbs has not been determined.

Natalizumab (Tysabri®, formerly known as Antegren®) was anticipated to be a strong line of treatment for individuals with RRMS. The drug was approved for treatment of MS in the United States in November 2004. Due to the diagnosis of an often-fatal brain disorder in two MS trial participants, however, the drug was voluntarily suspended from the marketplace in February 2005.

Phase II studies of this drug showed a 90-percent reduction in the number of GAD-enhancing lesions and more than a 50-percent reduction in clinical relapses. These led to the phase III "AFFIRM" study (Tysabri versus placebo) and "SENTINEL" study (Avonex plus Tysabri combination versus Avonex plus placebo). One-year data from the AFFIRM trial showed that the treated group experienced 66 percent fewer relapses and 92 percent fewer GAD-enhancing lesions. Determined by clinical and MRI measures, 46 percent of the treated group versus 14 percent of the placebo group were without disease activity during this first year.

Mitoxantrone (Novantrone®) was noted as a treatment option for worsening RRMS and secondary-progressive MS (SPMS). A small trial demonstrated that some individuals with worsening RRMS and SPMS may be stabilized when given this treatment, which is administered intravenously (IV). Individuals with SPMS are most likely to respond if they are: (1) in transition between RRMS and SPMS or (2) are still experiencing relapses or inflammatory disease activity. The study had a high dropout rate (along with other study-design issues), which may have affected the outcome. Numerous combination studies with mitoxantrone are either being planned or are ongoing. [Editor's note: this drug also has a two-to-three year, lifetime limit for treatment, given the potential for heart damage.]

Dr. Wingerchuk concluded his session with a discussion of unresolved issues. He covered topics such as: what evidence should be used to make treatment decisions; what long-term benefits are gained through reducing inflammation; how are treatment responders and nonresponders identified within trials; and how should treatment failure be defined.

Symptom Management

This session of the MS Update addressed symptom management, presented by Dr. Elliot M. Frohman, University of Texas Southwestern Medical Center at Dallas, in Dallas, Texas. Given space limitations for this article, information from this section will be included in upcoming "Symptom Awareness" columns in *The Motivator*, as well as other articles as they relate to the treatment of different MS symptoms.

New Directions in MS Therapeutics

This session of the MS Update discusses the many challenges involved with finding treatments for a disease where the cause and mechanisms of action are still not fully known. The information was presented by Robert J. Fox and Richard M. Ransohoff, both from The Mellen Center for Multiple Sclerosis Treatment and Research in Cleveland, Ohio.

Basic immunological research has enabled scientists to have a much better understanding of what they suspect may be happening within the central nervous system (CNS). This knowledge has led to the development and assessment of dozens of immune-based therapies for the treatment of MS.

The different types of MS pose one of the many challenges which arise in its study and successful treatment. Relapsing-remitting MS (RRMS) involves periods of demyelination, inflammation, scarring, edema, and nerve loss. In contrast, progressive forms of MS, including secondary-progressive MS (SPMS), appear to be largely degenerative (deterioration and loss of nerve cells), with little immunological or inflammatory involvement.

The distinct periods of relapses and remissions, characteristic of RRMS, allow for much easier detection of disease activity in terms of observable symptoms and active lesions (as shown on an MRI). This type of immune-system activity allows researchers to conduct studies with various agents and determine short-term results rather quickly. For this reason, most approaches to MS have been focused on the early stages of MS, with the hopes that early treatment will slow or stop the development of disability.

With progressive types of MS and their neurodegenerative component, changes are much harder to detect. Treatment trials for progressive MS require longer periods of time and outcomes are often difficult to determine. The presenters of this update explain that future research into treatments for progressive types of MS will be greatly assisted by (1) appropriate animal models to study the process that occurs in post-inflammatory demyelinating disease, and (2) more advanced clinical imaging techniques to observe this process.

The question still exists as to whether or not MS is an immunopathological disease (resulting from an immune response) or a neurodegenerative disease (resulting from some other cause of nerve damage). A third possibility is that MS evolves over time, changing from an abnormal immune response to a neurodegenerative process. The bottom line, however, is that therapies under development must be precisely targeted to those specific processes found to be involved with MS, whether inflammatory, neurodegenerative, or some other process.

Manufacturers of the STACOOL VEST™

Toll Free: 1-866-782-2665
www.stacoolvest.com

An important aspect of MS research involves the animal models used to (1) evaluate the MS-like behavior of the immune system and inflammatory response, as well as (2) test the efficacy (effectiveness) of various treatments to interfere with the disease process. The most commonly used model is experimental autoimmune encephalomyelitis (EAE), a lab-induced disorder showing that autoimmunity to myelin can produce inflammatory damage to the CNS in animals along with resultant episodic paralysis.

While EAE has been extremely productive in terms of clarifying the different mechanisms that lead to CNS damage similar to MS, treatments do not always carry over well to human studies. Several therapies that have been successful in slowing or stopping the effects of EAE, were later found to have no effect or even a damaging effect on MS. Additionally, the two main lines of treatment for MS today were both found in round-about ways. Interferon beta therapies were originally tested to treat a chronic viral process. After being approved for MS, they were later found to be mildly effective in EAE. Glatiramer acetate was tested on EAE with the idea that it would exacerbate the disorder, but when found that animals with EAE improved, it led to trials in MS.

A wide range of drug therapies are currently under consideration for the treatment of MS. Many different types of therapies are being studied because of the numerous potential targets. Some of these treatments are in early development, while others are in later stages of clinical testing. The fact that some potential treatments may result in an **increase** of disease activity stresses two points: (1) the complexity of the immune dysfunction and (2) the importance of small studies for safety.

In addition to testing treatments that are injected or administered intravenously (IV), several studies with oral agents are in the planning or trial stages of development. Among others, these include cholesterol-lowering drugs (statins) and a drug named "SAIK-MS" (laquinimod). Oral treatments have obvious advantages, including patient comfort and convenience.

In conclusion, researchers and physicians continue to meet the challenges presented by the complexity of processes involved with MS. At this point in time, treatment has been largely focused on early, active MS versus later or progressive forms of MS. With the latter, including late SPMS, no therapy has been proven effective, although many studies are in progress. For example, intermittent (or "pulsed") corticosteroids may potentially help later-stage MS, but more studies are needed to confirm this finding as well as the long-term safety of this treatment. Protecting neural tissue from secondary degeneration following inflammatory injury is another vital area of research.

Given the vast number of therapies currently being studied for the treatment of MS, the presenters note that better therapies will surely be available in the years ahead. The research gives individuals with MS much hope for the future.

In the Next Issue of *The Motivator*...

This article on information presented at the AAN's annual meeting will be continued in a **special Research News section** in the Fall 2005 issue of *The Motivator*. At that time, highlights of the educational seminars and poster sessions will be listed (often giving specific study findings not yet published). The next issue of *The Motivator* will also feature an article on the **Consortium of MS Centers' Annual** Meeting. This will include an overview of the information presented, with topics such as: a full approach to managing symptoms; exercise and rehab; nursing perspectives; ethno-cultural issues; coping with illness and nurturing children; and using assistive technology devices. ◆

Correction

On page 37 of the Spring 2005 issue of *The Motivator*, the Beaumont Foundation of America was listed as a source for recycled or free computers. Please be informed that the Beaumont Foundation no longer offers individual grants for this purpose. This organization should not be contacted with regards to obtaining a computer. We apologize for any inconvenience this may have caused to our readers as well as the Beaumont Foundation of America.

HISPANIC OUTREACH PROGRAM

PROGRAMA DE TOMA DE CONCIENCIA HISPANO

When/Fecha:
Saturday/Sábado, August 27 Agosto, 2005
9:00 am - 12:00 pm

Where/Lugar:
Hyatt Regency Coral Gables
50 Alhambra Plaza
Coral Gables, Florida

A continental breakfast is included
Incluye un desayuno continental.

Dr. Carlos Ramirez, a recognized expert in multiple sclerosis, will discuss current treatments, symptom management, and overall healthcare for MS patients and their care partners.

This program is provided **free of charge** by the Multiple Sclerosis Association of America through an educational grant from the Medtronic Foundation.

For more information or to register for this program, please call Helpline Consultant Richard Palacio at **(800) 532-7667**, extension 108.

El Dr. Carlos Ramirez, un reconocido experto en esclerosis múltiple, nos informará sobre los últimos tratamientos, el manejo de síntomas, y la atención médica integral para el paciente con EM y el socio en su cuidado.

Este programa **gratuito** está suministrado por la Asociación Americana de Esclerosis Múltiple (MSAA) a través de un fondo educativo de la Medtronic Foundation.

Para registrarse para este programa, por favor llame al **(800) 532-7667**, extensión 142.

Travel the Easy Way...

Just Pack Your Bags and Go!

By Christine Norris

This geyser at the Yellowstone National Park is a popular place to visit. Photo courtesy of Access Tours, 2005.

Some individuals with MS are skeptical of traveling due to their physical limitations. Others relish the independence and confidence that comes from the rewards of seeing a new part of the world. If you have always wanted to travel but are afraid of handling the logistics due to your disability, you may be surprised at some of the services available to help you on your journey. From all-inclusive resorts to group-guided tours, the world of travel has become savvy to the needs of the disabled. This article lists some great options for individuals with MS who are looking to take a vacation.

If you're afraid of traveling alone, don't worry. You'll find many others that feel the same way, and remember, going alone doesn't have to mean being alone. Group or escorted tours offer varying degrees of excitement and freedom for travelers of all ages and abilities. These group-organized activities give the single traveler ample opportunity to meet other people.

"You can also learn a lot. It's nice to have someone tell you what you're looking at – especially when it's your first time abroad," says Andrea Fox, a former travel agent who has traveled all over the world solo. "Tours are good for people who don't want to structure everything themselves. Tours make traveling alone easier, and you can always strike up a conversation with someone whenever you like."

Cruise lines and all-inclusive resorts make the trip as smooth as possible for the disabled traveler. Meals, many activities, and entertainment are included in their cost. Best of all, since you sleep in the same cabin

Traveling can offer new challenges and exciting adventures, such as river rafting. Photo courtesy of Access Tours, 2005.

or room each night, you don't have to pack and unpack as you would when traveling from one hotel to another. This conserves energy for more pleasurable pastimes such as "people watching" on the Riviera or sampling wine and cheese at a village winery.

Before deciding on a group tour to explore the ancient jewels along the Nile or an independent trip to take in the latest plays in London, think about what you want to get out of your vacation. Do you need to unwind? Would you like to meet people or be alone? Are you interested in a challenging adventure? Or do you crave a change of scenery?

To help you discover what you really want to get out of your vacation, it's best to contact a tour operator or travel agency that specializes in planning trips for people who are physically challenged. Staffed with trained professionals, these agencies can provide information, plan an itinerary, and ensure that you will have the accessibility you need to travel comfortably with your disability. If you prefer, with their guidance, you can plan your own trip. To follow are some of the top tour groups to contact. They have all been in business for over a decade and specialize in accessible travel.

Shown here visiting India, the late Dr. Kate Zee leaves behind a book and a scholarship fund for disabled travelers (see page 34 for details). Photo courtesy of Accessible Journeys, 2005.

The largest group cruise operator in the world for slow walkers, travelers with wheels©, their families, and friends, is Accessible Journeys. They also offer individuals with physical disabilities special group vacations, independent travel, and itinerary planning. What makes this service unique is its staff of professional companions, including registered nurses, therapists, and physicians, to make your trip experience more comfortable.

Accessible Journeys specializes in international travel. Trips planned for 2005-2006 include excursions to: New Zealand and Australia, Costa Rica, and Ireland; a South African safari; and luxury tours of Italy and England. The organization also offers its customers a vast array of disability resources regarding desti-

nations, services, access, barrier-free travel, and traveler supplies. For more information on Accessible Journeys, visit **www.disabilitytravel.com** or call **(800) 846-4537**.

Flying Wheels Travel, based in Owatonna, Minnesota, has been arranging escorted group tours, accessible cruises, and customized itineraries for disabled travelers with able-bodied companions for more than 30 years. Founded in 1970 by Barbara Jacobson and her late husband, Judd Jacobson, who was a quadriplegic, Flying Wheels Travel specializes in international travel for the disabled. Jacobson recently received The Conde Nast Traveler award for her tireless efforts to improve accessibility for her disabled clients. She travels constantly to research accessibility and to find new opportunities for her clients to travel safely.

People taking a road trip with Access Tours might travel on an accessible tour bus such as the one pictured. Photo courtesy of Access Tours, 2005.

For example, Jacobson recently accompanied a person with MS on a new cruise ship that traveled along the Nile. The cruise ship featured four wheelchair-accessible cabins. She believes that the key to opening more of the world to individuals with disabilities, is to educate the suppliers. For more information on Flying Wheels Travel, visit **www.flyingwheelstravel.com** or call **(507) 451-5005**.

Contact Access Tours, based in Idaho, if you want to see the great American West. A service of Access Institute (a volunteer, nonprofit organization), Access Tours specializes in small, all-accessible tours. Since most tours only include 10 to 11 people, advance reservations are recommended. This year's tours include the Southwest Tour (to Tucson, Tombstone, Sedona, Kartchner Caverns, Spanish Mission, Mexico, Indian Ruins, and Biosphere 2); Canadian Rockies (including Glacier Park in Montana, Lake Louise, Banff, and Waterton Lakes National Park); Mount Rushmore National Park; Santa Fe, Mesa Verde, and Arches National Parks; and Yellowstone and Grand Teton National Parks.

According to Clint Grosse, director for Access Institute, "I have always felt that travel is

Travelers stop by a lake to admire the view. Photo courtesy of Access Tours, 2005

therapeutic and that we all need some R&R [rest and relaxation]. Our guests tell us all the time that their travels with us really provide these benefits. Some of those who have never traveled before with a disability, suddenly realize that if they can go all the way out west, they can do a lot more things at home.

"Many of our guests have MS, and we plan our tours according to their needs," notes Clint. "For instance, with heat regulation often being a problem for individuals with MS, we set our tour dates in warm weather, but try to avoid hot weather. We also don't usually start our day until after 9:00 in the morning, and typically don't continue past late afternoon, in an effort to minimize fatigue." For more information, please visit **www.accesstours.org** or call **(800) 929-4811**.

If you prefer a vacation where you can explore the great outdoors with experienced guides, contact Wilderness Inquiry Outdoor Adventures. This nonprofit organization based in Minneapolis runs accessible canoe, kayak, raft, hiking, and dogsled adventures all over North America. Recent trips have included a five-day canoe trip through northern Minnesota's million-acre Boundary Waters canoe area, a family friendly adventure to the Black Hills of South Dakota, a five-day trip by horseback through Colorado's High Country, and a 10-day sea kayak trip to Costa Rica. For more information on Wilderness Inquiry Outdoor Adventures, please visit **www.wildernessinquiry.org** or **call (800) 728-0719**.

All of the services mentioned give individuals with physical challenges some great options for travel. Whether going west to ride a raft down Snake River or traveling half-way across the world to sit atop the Great Wall of China, these services can help you to plan an unforgettable trip. Through the assistance of guides, accessible transportation, and medical professionals, as well as having other travelers along, you'll ensure that your vacation is safe, enjoyable, and fun!

Photo courtesy of Access Tours, 2005

Airport Alert

The Transportation Security Administration (TSA), part of the Department of Homeland Security responsible for protecting the nation's transit system, recently posted updated guidelines for air travelers. These include guidelines for those with disabilities regarding security screening procedures.

This information describes the rights of passengers with disabilities and necessary screening procedures. The update also includes guidance concerning different types of disabilities and assistive devices. These tips are posted on the TSA website at **www.tsa.gov**. TSA may also be reached by calling **(866) 289-9673**.

Editor's note: the agencies mentioned have been helping individuals with disabilities for many years to see the world in the safest and most enjoyable ways possible. Please note, however, that MSAA is not affiliated with these agencies and is not responsible for any issues that may arise. Anyone interested in using these services for their travel plans should take the usual precautions (both financial and personal) as they would when hiring any outside travel agency. Additionally, individuals with a medical condition (such as MS) who are planning to travel should check with their physician in advance to be sure that all activities are approved and do not present any dangers to one's health or wellbeing.

About the Author

A former editor of *The Motivator*, Christine Norris is now a freelance writer specializing in health and wellness issues.

Helpful Resources

Smitner, P., *Access for Disabled Americans - A Guide for The Wheelchair Traveler*, Disabled Travel Series, 1996.

Steves, R., *Easy Access Europe 2004: A Guide for Travelers with Limited Mobility*, Avalon Travel Publishing, 2004.

Walsh, A., *The Real Guide: True Stories by and for People with Disabilities,* Prentice Hall, 1994.

CLEAN THAT CLOSET
AND BENEFIT MSAA

MSAA has colorful Clothing Recycling bins throughout the Delaware Valley.

As you find clothing, shoes, and other fabric items you are no longer using, please bring them to collection boxes at one of more than 90 locations in New Jersey and Pennsylvania.

You'll be doing yourself and MSAA a favor.

Call (800) 532-7667, ext. 113
for Clothing Recycling locations near you.

RELIEF FROM
MULTIPLE SCLEROSIS'
HEAT RELATED SYMPTOMS

BENEFITS

* Improved coordination
* Diminished fatigue
* Improved speech
* Improved vision
* Diminished Spasticity
* Enhanced physical performance and endurance

THE MOST ADVANCED PERSONAL COOLING SYSTEMS UTILIZING SPACE TECHNOLOGY WITH BENEFITS PROVEN IN CLINICAL STUDIES.

For information and studies results, contact us at:

LIFE ENHANCEMENT TECHNOLOGIES, INC.
Phone (800)779-6953
Fax (408)330-6949
Internet: http://www.2bcool.com

LET
LIFE ENHANCEMENT TECHNOLOGIES

Schwarz, S.P., *300 Tips for Making Life with Multiple Sclerosis Easier*, Demos Medical Publishing Inc., 1999.

Roth, W., *Easy Access to National Parks*, Random House, 1992.

Please note: some of these books may be ordered through **www.amazon.com** or Barnes & Noble at **www.bn.com**. Barnes & Noble may also be reached by calling **(800) 843-2665.**

Travelin' Talk is an internet network of disabled people in thousands of locations worldwide that share accessible information on travel. To join for $19.95, visit **www.travelintalk.net.** ◆

View of Grand Canyon, photo courtesy of Access Tours, 2005.

Leaving Behind a Book and a Legacy

Despite being diagnosed with MS and breast cancer, former emergency physician Kate Christie Zee, MD, PhD (pictured on page 27) had a remarkable zest for life, adventure, and travel – going on to write a book about her experiences. Titled *Disappearing Windmills: A Waist-High View of the World's Hot Spots*, this writing gives an exciting account of her journeys around the world.

Having traveled to 47 countries, Kate visited 21 of them while in a wheelchair, including China, India, Nepal, Russia, Vietnam, Cambodia, Brazil, and Tanzania. Intertwined with her international adventure stories are discussions of social issues that face all of us who go through a major change in life, whether it be adapting to a disability, growing older, losing a spouse, or moving to a strange city.

Sadly, Kate passed away in 1999 following a two-year battle with bladder cancer. Prior to her death, Kate established a scholarship fund to provide free travel opportunities to disabled travelers who are unable to afford the cost of travel. The proceeds from her book sales as well as outside donations fund this scholarship. For more information on her book or the scholarship, please go to **www.disability-travel.com/windmills.htm** or call Accessible Journeys at **(800) 846-4537.**

Ask the Doctor

Dr. Jack Burks
Vice President & Chief Medical Officer for MSAA

Q: I have been diagnosed with MS and I take an immunomodulating medication for its treatment. A recent MRI didn't show any new, active lesions, and I have not experienced any new symptoms. How often should a patient have an MRI done?

A: The "official" recommendation by neuroradiologists states that MRI's should not be done routinely on MS patients. MRI's should only be considered if a change in therapy is contemplated and the MRI will help in making a treatment decision. Many neurologists, however, feel that an MRI is a valuable tool to evaluate disease activity that may not be evident during routine checkups. Therefore, many MS experts recommend an MRI every one to three years. One rationale is that MS medications cost between $15,000 and $20,000 per year, so why not spend $1,000 on an MRI to see how well the therapy is working? Opponents of this position point out that an MRI can change dramatically from month to month, and a single MRI may not accurately reflect ongoing brain damage. On the other hand, a very recent presentation from Italy indicates that new damage on the brain MRI (using a contrast material known as gadolinium) may predict a sub-optimal response to treatment. So, the debate continues.

Q: Is there any research about how MS affects various ethnicities differently?

A: Ethnicity issues in MS have been recognized for several decades. For example, Caucasians are at a greater risk for MS than African-Americans, Asians, Native Americans, and others. Northern European heritage is a risk factor. Therefore, genetics are clearly related to risks of getting MS. However, the overall risk is still small in the population at large. Recent research has shown that those of African descent, while less likely to get MS, may have more aggressive clinical disease course (and may not respond to treatments as well as Caucasians). Also, while Asians may have less MS, they get another diagnosis more frequently (neuromyelitis optica or Devics syndrome). This disease involves myelin damage in spinal cord and optic (visual) nerves. In the near future, research should add more clarity to these important issues.

Q: What medications are available to manage pain and when should someone move on to pain patches and opiate therapy (without risk of sleepiness or addiction)? How can acute pain be brought under control?

A: I divide MS pain into two categories. The first is "neuropathic" pain, which is

often described as "burning," "painful pins and needles" feeling, "lightning-like" sensations, and/or "stabbing," and "searing" sensations. The cause is myelin damage and/or inflammation in the brain and spinal cord. Medications used for this pain usually begin with anti-seizure drugs, although this pain is not associated with epilepsy. Neurontin® is often the first line of treatment, followed by Tegretol®, Dilantin® or Depakate®. Tricyclic antidepressant drugs, such as Elavil® can also be tried. Biofeedback is helpful with some patients. Narcotics and pain patches (lidocaine) are usually not very helpful. Steroids for acute attacks of MS may provide relief, and sedation may "take the edge off" temporarily. Usually "neuropathic" pain lessens after a few months.

The second type of pain is "neuromuscular," secondary to imbalances from poor coordination, tremors, stiffness, and weakness, but not from direct myelin damage. This pain is best treated by rehabilitation techniques as well as medications for stiffness, for example. Stretching, cooling, warming, strengthening, and balance programs may be helpful. Assistive devices such as a cane or walker may reduce joint pain from limb weakness. Muscle relaxants are used cautiously because of potential side effects such as sedation, fatigue, and fuzzy thinking, etc. Narcotics and pain patches are usually not the long-term answer for most patients, but they may help decrease the acute pain in selected patients. Exercise programs under the supervision of a physical therapist trained in MS are usually recommended. ◆

Jack Burks, MD, is a neurologist who specializes in MS. He is vice president & chief medical officer for MSAA, as well as president of the Multiple Sclerosis Alliance. Additionally, Dr. Burks is a clinical professor of medicine in neurology at the University of Nevada School of Medicine in Reno, Nevada, and a member of the Medical Advisory Board of the National MS Society. He has edited two textbooks on MS, and in the 1970s, Dr. Burks established the Rocky Mountain MS Center in Colorado, one of the nation's first comprehensive MS centers.

MSAA IS ONLINE!

Visit MSAA's website at

www.msaa.com

for resources, program information, news updates, and much more!

To Submit Questions to Ask the Doctor…

Many of these questions were submitted by readers. If you have a question that you would like to ask, please submit your question to:

MSAA
Questions for Ask the Doctor
Attn: Andrea Borkowski
706 Haddonfield Road
Cherry Hill, New Jersey 08002

Readers may also send in questions via email to aborkowski@msaa.com. Please be sure to write "Ask the Doctor" in the subject line.

Research News

The Gene Olig1 is required for Myelin Repair within the CNS in Mice

Multiple sclerosis (MS) causes destruction within the central nervous system (CNS) of the nerve's insulating material called myelin. Currently, the strategy to fight the effects of multiple sclerosis consists of preventing and suppressing inflammation. Researchers are now considering an additional therapeutic option: the repair of myelin.

To prevent or limit exacerbations, disease-modifying treatments are aimed at interfering with the destructive events which occur in patients already diagnosed with MS. All of the drugs available today to fight MS focus on this anti-inflammatory process. They are immunomodulators, such as Betaseron® (interferon beta-1b), Avonex® and Rebif® (interferon beta-1a), and Copaxone® (glatiramer acetate), as well as the immunosuppressant Novantrone® (mitoxantrone).

A different way to treat MS focuses on repair. While repairs of the myelin sheath occur naturally after brain or spinal cord injuries (including attacks from MS), new myelin growth is not sufficient to completely repair the damaged tissue and re-establish full myelin function. Consequently, successive exacerbations lead to major destruction of the myelin sheaths, interrupting the flow of nerve impulses, and ultimately causing a loss of function. Despite the importance of myelin repair, little is known clinically and scientifically.

Recently, a study published in the journal Science[1] indicated the discovery of a key role played by a gene in the myelin repair. This gene, called Olig1, is required for the repair process. Olig1 produces a protein called a transcription factor. Transcription factors function by regulating the activity of other genes within the nucleus of the cell.

Using mice as a study model, researchers were able to localize the protein produced by this gene. They found that, after damage occurs in the adult nervous system of mice, this protein relocates from the cell body to the nucleus of the cell. This new distribution of the protein into the nucleus indicates that the protein works as a gene regulator. Interestingly, post-mortem studies conducted on six patients with MS revealed, as well, the nucleus localization of this protein in the cells located in regions affected by lesions.

Furthermore, to understand the function of Olig1 in mice, researchers deactivated the gene by genetic technology. This mutated gene was then unable to produce the protein. They discovered that, after artificial brain lesions were developed, these mice lacking Olig1 were incapable of repairing the damaged nervous system. Normally, adult mice are able to repair, to some extent, the damaged nervous system.

These findings clearly indicate that the gene Olig1 is required to repair the damaged myelin. By understanding the molecular process of repair, it may be possible to design specific drugs to stimulate remyelination.

For individuals diagnosed with MS, this ability to repair the injured myelin after an exacerbation episode would limit some of the consequences of the injury.

This fundamental discovery provides a fantastic hope for members of the MS community. It is also a step forward to better understand the repair process of the myelin after brain and spinal cord lesions.

- By Christian CD Poncet, PhD
Reviewed by Dr. Jack Burks

Comments and questions are welcome:
christianponcet@hotmail.com

Reference:

[1]bHLH transcription factor Olig1 is required to repair demyelinated lesions in the CNS. HA Arnett et al, *Science*, Dec 2004, Vol. 306, 2111-2115. ◆

Tysabri Update: Evaluation Underway, Possible Early Test for Virus, Potential Risks Remain

Suspected cases of PML not confirmed; safety evaluation being conducted

Several articles on the topic of Tysabri® (natalizumab) and the possible development of progressive multifocal leukoencephalopathy (PML) were posted on the *New England Journal of Medicine*'s website (at **http://content.nejm.org/**) in June 2005. While these case studies and editorials were originally to be published in July 2005, news of a suspected fourth case of PML in a Tysabri-treated patient prompted the journal to post the articles in advance online. Soon after, a possible fifth case of PML was announced in the media.

As of this writing, neither of these "suspected cases" has been officially announced by the FDA or Biogen Idec Inc. and Elan Corp. (makers of Tysabri), so readers are cautioned to wait until these media reports may be confirmed. Additionally, readers should keep in mind that at this time, PML has not been confirmed in anyone taking Tysabri aside from the original three people.

Biogen Idec is conducting a large safety evaluation of thousands of patients who took Tysabri. Any unusual responses to the drug will be investigated and reported to the FDA. Results of this evaluation are expected to be available by the end of the summer.

Background on Tysabri and PML

To review, Tysabri was given early approval in November 2004 by the Food and Drug Administration (FDA) for the treatment of MS. The drug had shown initial success in clinical trials and was expected to be a strong candidate for the treatment of MS. The drug was suspended, however, in February 2005 after PML (an often-fatal brain disorder caused by the activation of the JC Virus) was confirmed in two patients taking both Tysabri and Avonex® (interferon beta-1a).

The first patient died and the second patient is reported to be improving. A third case was discovered upon the re-examination of data on a patient who took Tysabri in the treatment of Crohn's Disease and died in 2003.

Early test for virus may provide hope for Tysabri's return

A letter from doctors at Biogen Idec may also be viewed on the *New England Journal of Medicine*'s website. They state that while little is known about PML and JC virus, studies suggest that PML is not uniformly fatal, and cases of PML may be preceded by the activation of the JC virus.

The letter also notes that a test may be able to determine the presence of the JC virus in a patient's plasma. The doctors speculate that through early JC Virus detection, Tysabri treatment could be discontinued in time to allow patients to recover, providing hope for some that Tysabri may return to the marketplace.

Risks may still exist

According to *The Wall Street Journal* press release dated June 9, 2005, Dr. Joseph Berger from the University of Kentucky Medical Center has some concerns. He warns that while the idea of early diagnosis and recovery is a possibility, the JC virus may still carry associated risks.

For instance, the MS patients with PML were only on Tysabri for two to three years. The risk of developing PML could potentially increase with longer term therapy. Additionally, Tysabri remains in the body for three months after treatment is stopped, which could continue the risk of developing PML, even if the treatment is discontinued following the discovery of the JC Virus. Speculation is not a substitute for data; waiting for the full analysis before making any conclusions will ensure accuracy.

Information for this writing was obtained from the *New England Journal of Medicine* (at **http://content.nejm.org/**), Reuters, and *The Wall Street Journal*. ◆

—Written by Susan Wells Courtney
Reviewed by Dr. Jack Burks

Smoking May Increase Progression of MS

In April 2005, WebMD Medical News reported that researchers from the Harvard School of Public Health have found that individuals with MS who smoke (or smoked previously) appear to be at a much greater risk of experiencing a quicker progression of their disease. While cigarette smoking has already been found to increase one's risk of developing MS, this new research suggests that current and previous smokers are more than three-and-a-half times as likely to progress from relapsing-remitting MS (RRMS) to secondary-progressive MS (SPMS) within a five-year period as compared to patients who never smoked.

Continued on page 43

Program Notes

Different MSAA Programs Share Goal of Improving Home Safety and Accessibility

MSAA offers a number of programs and services aimed at improving safety and accessibility in the home. The three most frequently utilized programs to address client needs in this area are: Equipment Distribution, Portable Ramps, and Home Modification. Knowing the difference between the programs can help individuals choose the program that best suits their particular needs.

The **Equipment Distribution Program** offers clients a wide array of safety and home accessibility products as well as daily living aids. Recognizing that bathroom safety is a top concern among individuals with limited mobility, the program features an extensive selection of durable medical equipment including grab bars, shower chairs, transfer bench, and other items for the toilet and bathtub. These pieces of adaptive equipment offer simple, yet very effective solutions to common safety issues and help alleviate the need to undertake costly and disruptive home renovations. The program also provides a selection of specialty products, such as "reachers" (lever-controlled pinchers to take hold of items out of reach) and easy-grip eating utensils, to help with common household chores and daily functions.

MSAA's Equipment Distribution Program provides a varied inventory of equipment to clients at no charge.

Another frequent request is the need to address home access with a ramp. MSAA offers two programs to assist with this need. The Portable Ramp Program is a division of the Equipment Distribution Program and offers a range of ramp sizes to address small inclines such as door thresholds and curbs. The program does offer larger, folding ramps up to 12 feet in length. However, this type of ramp will usually only cover one to two steps, as federal safety guidelines specify that for every inch of vertical rise there must be one linear foot of ramp. Therefore, a 12-foot ramp is only suitable for a 12-inch rise. For ramps larger than 12 feet in length, individuals are encouraged to apply to MSAA's Home Modification Program.

The **Home Modification Program** coordinates a home assessment to learn about a client's needs and pays for various modifications (where approved) up to a budgetary limit. Once it has been determined that the client's needs cannot be met through the Equipment Program, MSAA will help offset the cost of various home projects including large ramps, wider doorways for wheelchairs and scooters, and reasonable bathroom alterations for shower stalls and sinks.

The Home Modification Program is more time consuming than the first two programs. From start to finish, the client (or his or her care partner) participates in a step-by-step process to apply for the program and enable MSAA to assess the needs, obtain estimates, and complete the work. Adding safety and convenience to one's home is an invaluable service and well worth any extra time involved.

MSAA's home modifications can range from the purchase of adaptive equipment such as grab bars and shower chairs, to the construction of ramps (pictured at left) and wider doorways.

Those interested in any of these or other MSAA programs may contact MSAA at **(800) 532-7667** or visit the website at **www.msaa.com**. Applications for the Equipment Program and Portable Ramp Program can be downloaded from MSAA's website. Requests for the Home Modification Program may be sent via email by visiting the program's web page within the website. ◆

— Peter Damiri

Research News

Continued from page 40

These findings came from a study using a national health database from the United Kingdom to identify 179 patients originally diagnosed with RRMS, examining their medical records prior to their diagnosis, confirming their smoking status through computer records, and following their progress. While these findings need to be confirmed though additional research, it does lend support to the value of not smoking.

Researchers have different theories as to why smoking may affect MS. One theory is a link between nitric oxide (a chemical found in cigarette smoke) and MS. Within the body, nitric oxide is a free radical that is suspected of being involved with oligodendrocyte and neuronal injury in MS.

Whether or not the course of one's disease may be changed by quitting cigarettes is not known, but medical professionals agree on the other health benefits derived by not smoking. Further research is needed to confirm the specific dangers of smoking and MS. ◆

—Written by Susan Wells Courtney
Reviewed by Dr. Jack Burks

Symptom Awareness

Heat Sensitivity

During the hot summer months most people complain about feeling tired and listless. But for individuals with heat-sensitive MS, staying cool in the heat is a necessity. Studies have shown that nerves with damaged myelin are sensitive to changes in temperature. A rise in temperature may cause the body not to transmit necessary signals from the brain to the body and a reduction in temperature may allow more signals to be carried across the damaged nerve. Excessive heat sensitivity can cause symptoms to temporarily worsen, including cognition and motor function.

"When your body temperature rises, the impulses cannot pass easily through the nerves affected by MS. This may cause you to feel more tired and fatigued," says Stacey Sjoquist, a physical therapist with the Franciscan Skemp/Mayo Health System Holmen Clinic in Holmen, Wisconsin.

To follow are some important tips:

Rethink your routine. During the warm months exercise or run errands early in the morning or later in the evening when temperatures are at their coolest.

Be aware of your body temperature. According to Ms. Sjoquist, body temperature is usually lower in the morning and higher in the late afternoon.

Be prepared. The best defense against heat sensitivity is a good offense. Visit **www.weather.com** daily during the warm summer months to check your local area's heat index. For a description of the heat index and how it impacts health, please visit **www.nsis.org/weather/heatindex.html**. To find out what the heat index is in your area, visit **www.wunderground.com/US/Region/US/HeatIndex.html.**

Television weather forecasts often show when the heat index has reached a dangerous level. What level of heat may be tolerated varies from one person to another, so speak with your physician about the heat index and when you should take extra care. If the heat index is too high, try to stay indoors with air-conditioning or fans.

The Humidity/Thermometer Stopwatch is a handy device that measures temperature along with humidity and calculates the heat index. When the heat index is too high, the watch sounds an alarm. This product is available from Extech Instruments Corporation (not affiliated with MSAA) for $39.95. Interested readers may go to **http://www.extech.com/instrument/products/alpha/HW30Humidity.html** or call **(781) 890-7440** for more information.

Watch the humidity. "Remember, the humidity can be as draining as the heat. Even if it doesn't feel very hot but it's humid, you should be very careful and take it as easy as possible," says Adam Roberts, director of MSAA's South-Central Regional Office in Mesquite, Texas.

Drink enough water. To properly hydrate and to keep your body temperature as low as possible, experts generally recommend drinking six to eight, eight-ounce glasses of

water each day. Individuals should check with their own physician regarding how much water is advised for them specifically.

Use cooling devices. Both "active" cooling garments called cool suits, also known as liquid-cooled garments, and "passive" cooling garments, which include bandanas, skullcaps, and vests, can greatly help people with MS by lowering their body temperature to provide temporary symptom relief. While reducing heat sensitivity, cooling devices have been shown to temporarily help energy level, cognitive processing, and motor function.

Developed with the help of NASA, cool suits work by pumping a cool liquid through a network of small tubes sewn inside of the garment. These tubes of cool liquid help to remove heat and cool the body. Passive cooling garments do not contain an active cooling mechanism. Rather, they work via the transfer of heat by wearing a hat or other piece of clothing that contains a cooling source.

"You can make use of different cooling devices depending on your personal circumstances. You don't need to choose just one," notes Linda A. Lucuski, MPT, an administrator/physical therapist at Magee-MossRebab at Voorhees in Voorhees, New Jersey. "For example, a lightweight passive vest for riding in the car may be sufficient, but an active cooling garment could be better for a picnic on a hot summer afternoon. The most suitable cooling garment depends on a number of factors including the air temperature, your level of physical activity, and your personal sensitivity to heat."

People with MS also should consider using the cool suit for short periods of time, says Roberts. "It can be extremely advantageous. For example, wear your cool suit while doing housework."

Don't overexert yourself. If you must exercise on hot days, only do so under your physician's supervision and go easy with your workout. A better choice (again under a doctor's supervision), is to exercise in water. You'll stay cool and reap the benefits of aerobic exercise in relieving symptoms. For more information, see Health & Wellness on page 50.

Stay in an air conditioned area. According to Roberts, even in the hot, humid, southern states, some individuals with MS do not have air conditioning in their homes. To beat the heat, he advises them to run cool water over their wrists, keep their heads covered when out in the sun, and keep fans running continuously. "It's also a good idea to rest whenever you can," he says.

- By Christine Norris

About the Author

--A former editor of *The Motivator*, Christine Norris is now a freelance writer specializing in health and wellness issues.

For More Information

For information on MSAA's Cooling Program that offers the free use of cooling garments, please call **(800) 532-7667**. When calling, readers may request a copy of MSAA's *Multiple Sclerosis and Cooling*. This booklet may also be viewed or downloaded from MSAA's website at **www.msaa.com.**

Health and Wellness

Conserving Energy

As anyone with MS knows, when energy conservation pops up in conversation, it's not an environmental issue. It's a personal struggle, one that must be managed daily to prevent overexertion and fatigue.

According to a recent compilation of studies on energy conservation and MS conducted by researchers at the College of St. Catherine, the University of Minnesota, and the University of Illinois at Chicago, 75 to 90 percent of individuals with MS experience chronic fatigue and up to 50 percent identify it as their worst symptom. The good news is that studies show chronic fatigue can be prevented or lessened by reducing stress and exposure to heat, and most importantly, by learning to conserve energy.

According to Linda A. Lucuski, MPT, an administrator/physical therapist at Magee-MossRehab at Voorhees in Voorhees, New Jersey, people with MS must learn to conserve energy. Otherwise, their symptoms may worsen, limiting their ability to function while at work, home, and when participating in leisure activities. She adds that as a result, "individuals may have lessened mobility and decreased clarity of thought."

To follow are some tips to help conserve energy. Try at least a few of them so that you can enjoy your favorite activities and prevent symptoms from worsening while the mercury is still high.

Tips to Conserve Energy

Move Your Muscles. Certain types of "easy exercise," such as gardening and yoga (with your doctor's approval), have been shown to boost energy levels, reduce stress, improve joint range of motion, help manage spasticity, and increase strength. "You should also consider water exercise programs that are specific for people with MS," says Ms. Lucuski. "If your local fitness center or physical therapy facility does not offer such a program, ask them to consider initiating a program. Make sure that you conserve energy by taking the most direct route to the locker rooms. Wear your bathing suit to the pool to save time and energy."

Because of its natural buoyancy, water allows many men and women with MS to perform exercises they cannot do outside of the pool. Water exercise helps increase flexibility, strengthen the upper and lower extremities and trunk, improve ambulatory skills, increase coordination and balance, and condition the overall body to raise endurance levels and lessen fatigue. As with any exercise program, Ms. Lucuski says to start slowly with 15-minute exercise increments and to perform the exercises in a safe manner, stopping if symptoms worsen.

Take advantage of a scooter and rolling walker. Adam Roberts, director of MSAA's South-Central Regional Office in Mesquite, Texas explains, "I tell my clients that you only have a dollar's worth of energy to spend in a day. Try to conserve your energy to do something that you really want to do instead

of something that you think you ought to do. For example, some people have a really negative view of using their scooters; but, if they used them, they would have more energy to do the things that they really love doing, such as spending time with family or shopping at the mall."

Pat Provance, PT, is a physical therapist at Kernan Hospital (part of the University of Maryland Medical System) and a member of MSAA's Healthcare Advisory Council. She suggests a rolling walker when traveling short distances. "Rolling walkers with large swivel wheels, a seat, and hand brakes can be extremely helpful when bilateral support is needed and endurance is limited," she notes.

Consider telecommuting. A great way to conserve energy is to reduce the amount of time spent traveling to and from work. Ask your employer about working part of the week from home. (For more information on telework and other ways to make work less taxing on your health, please see "Employment Strategies," pages 9 to 23, in the Spring 2005 issue of *The Motivator*.)

Take fewer steps. "Try to take care of as many things as possible in one room to eliminate multiple trips," says Ms. Lucuski. "Make sure everything you need to prepare for the morning is accessible in your bedroom or bathroom. Consider carrying a bag or knapsack to move objects from one room to another. If you use a walker, attach a carry bag or basket to the walker."

Use adaptive aids. Reachers, dressing aids, and other adaptive equipment can significantly help conserve energy when dressing, bathing, and performing other household and personal activities. Many of these items may be obtained through MSAA's Equipment Distribution Program. Please call **(800) 532-7667** for more information.

Consider shopping from home. Get out your catalogs and start dialing or ordering items online. Besides avoiding the crowds as well as the wear and tear on your body, you can try clothes on at your leisure when your energy level is highest. Many grocery stores also offer online ordering with either free delivery or a minimal charge for delivery.

Don't get overheated. This can cause fatigue. Wear your cool suit or other cooling device and try to go outside either early in the morning or later in the evening when temperatures are at their coolest. (For more information on cooling management techniques, please see Symptom Awareness on page 44.)

Learn to delegate. If cooking, shopping, cleaning, and doing the laundry saps your energy, talk with family members about sharing the load or consider hiring a cleaning or laundry service to take care of some of the chores. Let your family and friends know that you are counting on them for support, and tell them specifically what they can do to help. Remember, everyone benefits when your symptoms are lessened by conserving your energy.

-By Christine Norris

About the Author

A former editor of *The Motivator*, Christine Norris is now a freelance writer specializing in health and wellness issues.

Continued on page 55

Regional News

For information on events and newly formed support groups, please call the phone numbers listed. When specific numbers are not given, please contact the MSAA Regional Office appearing below each listing. Established support groups are held in many other cities; please call the nearest MSAA Regional Office for details. All activities are free of charge unless otherwise noted. Times listed are in the local time zone for the region or location of the event.

Northeast Region

Upcoming Events:

- September, Educational Workshop sponsored by Berlex; Atlantic City, New Jersey (date and location to be determined)
- September, Educational Workshop sponsored by Teva; Atlantic City, New Jersey (date and location to be determined)
- September, Educational Workshop for Care Partners, Hagerstown, Maryland (date and location to be determined)
- Wednesday, September28th, Wine Tasting Fundraiser, Cherry Hill, New Jersey; please visit www.msaa.com/calendar/northeast.html for further details

Newly Formed Support Groups:

- Holbrook, New York; contact Jaime Cummings at (613) 472-5045
- Scranton, Pennsylvania; contact Debbie Niehuus at (570) 961-2268

Support Groups Coming Soon:

- Cherry Hill, New Jersey
- Columbia Falls, Maine
- Newark, New Jersey
- Windham, Connecticut

MSAA Northeast Regional Office:
Susan Freund, Director
706 Haddonfield Road
Cherry Hill, New Jersey 08002
(856) 488-4500
(800) 532-7667, ext. 106

MSAA New Hampshire Field Office:
John Robinson
Client Services Coordinator
13 Elwood Road
Londonderry, New Hampshire 03053
(603) 434-0176
(800) 532-7667, ext. 151

Southeast Region

Upcoming Events:

- Saturday, August 13th, "Treatment Updates, Orals & Latest Trials," Asheville, North Carolina; please visit www.msaa.com/calendar/southeast.html for further details
- Thursday, September 22nd, "Treatment Updates, Orals & Latest Trials," Ocala, Florida; please visit www.msaa.com/calendar/southeast.html for further details.
- Friday, October 14th, "Treatment Updates, Orals & Latest Trials," Deltona, Florida;

please visit www.msaa.com/calendar/southeast.html for further details

- Saturday, October 15th, "Treatment Updates, Orals & Latest Trials," Palm Coast, Florida; please visit www.msaa.com/calendar/southeast.html for further details
- Saturday, October 22nd, "Neurology Expo," hosted by the American Academy of Neurology and its Foundation, World Congress Center, Atlanta, Georgia, 10:00 am to 4:00 pm; for free tickets contact Kim Schofield at (404) 381-6731 or kschofiled@bellsouth.net; for expo information visit www.thinkneurologynow.org
- Scuba Diving Certification
  Scuba diving is not only great aquatic exercise, but it can also be challenging and inspirational! For individuals with MS, it may provide the feeling of being free from disease for a short time, and may increase one's quality of life. A medical release form is needed, but readers should not be discouraged; the instructors are highly trained, and even people who depend on a scooter may be able to participate! Although a fee is charged, this program is presently offering a "buy-one, get-one free" special. Space is limited. Please contact Linda Chaney at (727) 367-1137 for more information.

Newly Formed Support Groups:

- Gainesville, Florida; contact Sarah Maurer at (352) 367-9660
- Greenville, South Carolina; contact Octavius Arnold at (864) 220-2592
- Salem, Virginia; contact Danny Huff at (540) 387-9179

Support Groups Coming Soon:

- Decatur, Georgia
- Kinston, Alabama
- West Palm Beach, Florida

MSAA Southeast Regional Office:
Linda Chaney, Director
PO Box 66565
St. Petersburg, Florida 33736
(800) 532-7667, ext. 154

Midwest Region

Upcoming Events:

- Thursday, September 22nd, "MSAA Day at the Comedy Club," Cleveland, Ohio; in addition to entertainment, an MS specialist will speak at this event
- Saturday, October 29th, MSAA Halloween Party, Cleveland, Ohio; in addition to the party, an MS specialist will speak at this event
- Check MSAA's website (www.msaa.com/calendar/midwest.html) regularly for information on more upcoming events.
- Readers may call their nearest MSAA support group or contact the regional office for information about upcoming "Holiday Socials."

Newly Formed Support Groups:

Contact the Midwest Regional Office for information on existing MSAA support groups or to start a local support group.

MSAA Midwest Regional Office:
Renée Williams, Director
13938A Cedar Road, #243
University Heights, Ohio 44118
(216) 320-1838
(800) 532-7667, ext. 140

South-Central Region

Upcoming Events:

- August through December, "MS: Behind the Scenes," presented by Richard G. Pellegrino, MD, PhD, in Dallas, Houston, and San Antonio, Texas; Baton Rouge, New Orleans, and Shreveport, Louisiana; Kansas City and St. Louis, Missouri; Tulsa and Oklahoma City, Oklahoma; and Denver, Colorado (dates and times to be determined)
- Friday through Sunday, October 7th through 9th, "Ruston/Monroe Retreat," Lake D'Arbonne State Park, Farmerville, Louisiana, space is limited, so please call early to check availability

Newly Formed Support Groups:

- Arkansas City in Cowley County, Kansas; contact David Goff at (620) 442-0737

Support Groups Coming Soon:

- Breckenridge, Colorado
- El Dorado, Arkansas
- El Paso, Texas
- Fayetteville, Arkansas
- Hot Springs Village, Arkansas
- Knoxville, Tennessee
- Mansfield/Arlington, Texas

MSAA South-Central Regional Office:
Adam Roberts, Regional Director
1515 N. Town E Boulevard
Suite 138, Box 320
Mesquite, Texas 75150
(817) 480-2125
(800) 532-7667, ext. 153

MSAA Arkansas Field Office:
Judith Bennie, Client Services Coordinator
107 Avonshire Terrace
Hot Springs, Arkansas 71913
(501) 262-9380
(800) 532-7667, ext. 137

Northwest Region

Upcoming Events:

- Friday, August 12th, "35th Anniversary Luncheon," Indian Creek Golf Course, Elkhorn, Nebraska, 11:30 am
- Thursday, August 18th, "Managing and Living with Multiple Sclerosis," with Dr. Steven Pugh, Walla Walla General Hospital, Walla Walla, Washington, 6:30 pm
- Sunday, September 11th, "Celebration Picnic," Sons of Norway Hall, Great Falls, Montana, 1:00 pm
- Saturday, September 24th and Sunday, September 25th, "Parade of Homes," Great Falls, Montana, 10:00 am to 5:00 pm

Newly Formed Support Group

- Minot, North Dakota; contact Brian Stein at (701) 852-2115

Support Groups Coming Soon:

- Bozeman, Montana
- Casper, Wyoming
- Hettinger, North Dakota

MSAA Northwest Regional Office:
Sue Pencoske, Director
600 Central Plaza, Suite #13
Great Falls, Montana 59401
(406) 454-2758
(800) 532-7667, ext. 131

Western Region

Newly Formed Support Group

- Fossil, Oregon; contact Jean Rumble at (541) 763-4042
- Portland, Oregon; contact Jeff Fortner at (503) 245-2997

Support Groups Coming Soon:

The Western Regional Office is hoping to start support groups soon in the following cities: Los Angeles, California (both Spanish and English-speaking support groups); San Francisco, California; and Las Vegas, Nevada. Those interested in joining a support group in any of these areas or starting a support group in another area, please contact Amanda Montague, western regional director, at amontague@msaa.com or (800) 532-7667, ext. 155.

MSAA Western Regional Office:
Amanda Montague, Director
1819 Polk Street, Mailbox #326
San Francisco, California 94109
(415) 260-6420
(800) 532-7667, ext. 155 ◆

Continued from page 51

Helpful Resources

The following publications are available through MSAA's Lending Library. Please see page 56 for more information.

Schwartz, S.P., *300 Tips for Making Life With Multiple Sclerosis Easier*, Demos Publications Inc., New York, 1999.

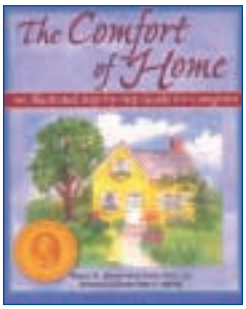
Schapiro, Randall T., *Managing the Symptoms of Multiple Sclerosis,* Demos Publications Inc., New York, 2003.

Please note: Some of these books may be ordered through **www.amazon.com** or Barnes & Noble at **www.bn.com**. Barnes and Noble may also be reached by calling **(800) 843-2665**.

For More Information

For information on MSAA's Equipment Distribution Program (which provides mobility aids and assistive devices at no charge) and MSAA's Cooling Equipment Distribution Program (offering the free use of cooling garments and a variety of cooling accessories to individuals with MS) please call **(800) 532-7667**.

Spread the Word

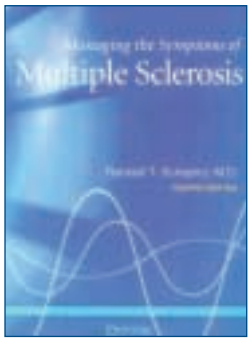


The Comfort of Home (second edition)
Written by Maria M. Meyer with Paula Derr, RN
Published by CareTrust Publications LLC
MSAA Book #119

This illustrated, step-by-step guide for caregivers covers the many issues involved with caring for someone at home. Topics include financial management, preparing the home, therapies (physical, occupational, speech, massage, etc.), diet and nutrition, and handling emergencies, among many others. This book is also available in Spanish (see below).

La comodidad del hogar
Escrito por María M. Meyer con Paula Derr, RN
Publicado por CareTrust Publications LLC
MSAA Book #230

Esta guía ilustrada y detallada de cuidado y asistencia trata muchos temas relacionados con el cuidado de la persona en casa. Los temas incluyen la preparación del hogar, terapia (física, ocupacional, del habla, de masage, etc.), la dieta y nutrición, el manejo de emergencias, entre muchos otros. Este libro está disponible también en inglés.



Managing the Symptoms of Multiple Sclerosis (fourth edition)
Written by Randall T. Schapiro, MD
Published by Demos Medical Publishing, Inc.
MSAA Book #242

This is the latest edition of Dr. Schapiro's invaluable reference on managing symptoms. This book first provides information about MS, the immune system, and managing the disease process. It then continues with several chapters devoted to the individual symptoms of MS and their treatments. The book concludes with guidance for total health, including diet, exercise, and sexuality.

MSAA Lending Library

If you would like to borrow any of the books featured in this column or any other book in MSAA's Lending Library, please send us your name and address. We will send you an application and a list of books for the Lending Library. MSAA and its clients greatly appreciate any donations made to help build the Lending Library. If you would like to donate a book to the Lending Library you need only send it to us at the address below. Please address all correspondence to:

MSAA Lending Library
Attn: Woody Dyer
706 Haddonfield Road
Cherry Hill, NJ 08002
(Please reference book number)