

The **MSAA** **MOTIVATOR**

Published by the Multiple Sclerosis
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**Breaking Down Barriers
Building Up Hope**



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As this edition of *The Motivator* goes to press, two major natural disasters have just occurred in the Gulf region from Hurricanes Katrina

and Rita. Our hearts go out to everyone affected. In an effort to get information out as quickly as possible, we immediately listed emergency contacts on MSAA's website. This included where to call to have MS medications replaced if they were lost or damaged in the disasters. Our Health & Wellness column also gives some helpful information on how to prepare for an emergency and I encourage everyone to review this timely piece.

During the summer, questionnaires were sent to a small sample of clients as part of our clients' needs assessment project. Completed questionnaires continue to pour into MSAA, and for those who received a survey, your input is instrumental in helping both our Board of Directors and our Healthcare Advisory Council prioritize MSAA programs and services for the future. The consensus will help us determine how MSAA might best meet the most critical needs that individuals with MS face. This information will be of significant importance in ensuring that our new strategic plan in 2006 meets those needs and that every dollar we raise is used

in the most effective way. Listening to you and learning your key priorities are the first steps toward these goals.

This summer saw record numbers of equipment issued across the country. While demands for cooling equipment have tapered off with the cooler fall weather, requests for assistive devices, home modification inquiries, and MRI applications have continued to increase. Calls to our Helpline averaged more than 1,300 per month over the last quarter, and our new website has had more than 750,000 hits in just one year. Clearly, MSAA's programs and services are making their mark in the community!

Our Board of Directors met in October to review our progress to date and to discuss "life coaching" as a viable MSAA outreach project. Plans for the next meeting in January will focus on the final evaluation of the clients' needs assessment project, with collaborative input from the Healthcare Advisory Council. Our new strategic direction can then begin to take shape. This plan will be finalized in June when MSAA's Board meets at the CMSC conference.

As the holiday season is fast approaching, I would like to extend our most sincere best wishes for a happy holiday season from everyone associated with MSAA. We all have much to be thankful for, and with your inspiring support, we will continue our efforts to help more people in more places than ever before. ♦

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 Ross Maclean

Ross Maclean joined MSAA’s Board of Directors in January of 2002. With a friend who has MS and a brother diagnosed with a different autoimmune disease, Ross felt that MSAA was a good fit. “I have always believed in giving back to the community,” says Ross, who spent numerous years as a Boy Scout leader. “MSAA’s mission to enhance the quality of life for individuals with MS, speaks loudly to me.” Currently, Ross serves as secretary of the Board and is the chair of the development committee.



Since 2002, he has observed tremendous growth in MSAA and is excited about the direction that MSAA is going. “Over the past three years, I have seen our programs and services experience great demand and be delivered on a much larger national basis. I have also watched the staff take their commitment to the client to another level.”

Ross is proud of all of the programs and services MSAA offers but is most

impressed by the Helpline and the Home Modification Program. “The stories I have heard about the Helpline and what they do for our clients is something I find to be truly moving,” he states. “These

stories give us a reason to be here at MSAA every day.”

For the past twenty-plus years, Ross has worked in finance for both public and private institutions, including Merrill Lynch and First Boston. He has been married for 28 years to his wife Mary Lynn and has two sons, Ian and Sandy.

As MSAA embarks on its 36th year of service to the MS community, Ross sees great things ahead. “MSAA is in a great position to grow right now. In addition to our wonderful volunteers and generous donors, thanks also go to the staff,” he points out. “The staff is doing great things to make all these events and programs possible. The sky is the limit for MSAA; there is nothing that we cannot accomplish.”

Planning for the Future

The Importance of Advance Directives

By Christine Norris

Co-authored by Gary L. Stein, Esq., MSW and Susan Wells Courtney



How one's life will progress over the years is a mystery to us all. Few things in life are guaranteed, but many of us try to make an educated guess as to how long we might be here and how to best plan for our future. Medical decisions are important concerns as we age, and making the decisions for your future early on, while still healthy (both mentally and physically), will help to see that things go according to your wishes when you are no longer able to make such decisions.

Putting plans together in advance is a good idea for anyone (age 18 or over), since no one knows what tomorrow may bring; the same holds true for people with a chronic condition or illness, such as MS, whose course is unpredictable. MS is especially challenging, since the disease often appears when individuals are young, usually in their 20s and 30s – which is a difficult age for many to plan their medical

decisions for a time so far in the future.

This article presents some of the urgent medical issues that everyone should be addressing – not just those with MS – in order to make decisions that are important to each person and his or her family. Planning for the future through “advance directives” takes the burden away from family members who would otherwise need to make these same difficult decisions themselves, should a loved one be unable to make such choices at a later time.

Advance Directives

While planning for today's and tomorrow's healthcare needs, most people will make sure their healthcare insurance, long-term care insurance, disability insurance, and life insurance policies are all in place. But in addition to these important plans, people also need to look at their

end-of-life healthcare choices and prepare for these in advance.

Known as “advance directives,” these written instructions provide specific directions to doctors and family regarding a person’s end-of-life choices in advance, should this person become unable to make these decisions on his or her own when needed. While advance directives can vary from state to state, in general, advance directives typically include appointing a healthcare representative or proxy as well as creating a “living will.” (Please note that some sources refer to a living will as encompassing both instruction as well as the appointment of a healthcare representative. In this article, we have kept the two separated, as it appears with many state-regulated forms.)

Appointing a Healthcare Representative

Referred to as a Medical Power of Attorney, Durable Power of Attorney for healthcare, or a healthcare proxy, this document allows an individual to name a trusted person as his or her healthcare representative (also known as a healthcare agent, healthcare surrogate, medical attorney-in-fact, or healthcare proxy). A healthcare representative makes medical care decisions when his or her family member,

friend, or associate is dying, unconscious, incoherent, or unable to communicate. The purpose of a healthcare representative (who is often a spouse, partner, family member, or close friend) is to guide family members and physicians in deciding to use or refuse specific medical treatments when the patient can no longer communicate or make informed decisions.

When individuals do not appoint a healthcare representative, some states will create a list or hierarchy of individuals close to the patient to serve as decision makers (a person acting in this role is sometimes referred to as the “surrogate”) – dictating which individual would be asked first. For example, the list might begin with spouse, then list parent, followed by an adult sibling, and so on, until an appropriate

healthcare representative may be selected. Next-of-kin is not always top on certain state’s lists. Individuals who do not name a healthcare representative in advance (when able) are risking that someone less reliable or less familiar with their wishes will make decisions on their behalf, should they become too ill to think clearly and/or communicate.

When selecting a person to be your healthcare representative, choosing someone



who is assertive and well spoken, as well as someone who will be comfortable acting as advocate on your behalf, is recommended. A person cannot just be named as your healthcare representative; he or she needs to agree to the position. Since the role of healthcare representative can be time-consuming and emotionally draining, the person you select should be given the right to decline from taking on the responsibility. The healthcare representative must be comfortable in the role in order to be effective on the patient's behalf.

What's Involved with Being a Healthcare Representative

The healthcare representative plays an important role in end-of-life care. Generally, the law requires the healthcare representative to make the same decisions that the person they're representing would have made, if possible. To do this, the healthcare representative should fully understand and respect the person's overall values as well as his or her religious and moral beliefs. If a particular decision is not known, the healthcare representative should make the decision based on what is known about the patient's preference for care, versus the representative's personal interests or desires. The healthcare representative may choose to discuss different decisions with the healthcare team and family members for additional input.

The healthcare representative is authorized to make all medical decisions (not just end-of-life decisions), when the patient is physically or mentally incapacitated. This includes arranging for aggressive palliative care (pain treatment), if the care recipient needs this type of assistance.

The healthcare representative's job can be quite demanding. As an advocate, he or she will need to meet often with physicians to obtain clear information on the care recipient's diagnosis (what is wrong with the patient), prognosis (what will probably happen to the patient because of the disease



or injury), and the goals of care (the desired outcomes in light of the patient's prognosis).

As an advocate, the healthcare representative will be required to ask questions regarding treatment in order to make the best decisions possible. This is not always easy, and the healthcare representative will need to continue to ask questions and to speak up on the patient's behalf to ensure

that he or she is receiving the proper care. The healthcare representative may benefit from the help of a social worker, patient representative, or nurse, especially if the physicians do not provide all necessary information.

Creating a Living Will

Family and friends may think that they know what's best for their loved ones. But does anyone really know the choices that another would make at a time when various medical treatments could either be used to prolong life or withheld to allow for a more natural death? End-of-life choices are very personal and require careful planning to ensure that they are carried out in accordance with the patient's wishes. An advance directive known as a living will provides specific instructions for a person's end-of-life choices.

Also known as a "directive to physicians," a "healthcare declaration," a "medical directive," or an "instruction directive," a living will may specify a range of instructions. These may include such instructions as a desire to die at home with hospice care, or a request to withhold tube feeding. A living will goes into effect when this person can no longer make his or her own choices (when he or she is terminally ill, permanently unconscious, or dying).

A living will is best prepared before a person is seriously ill, but may be drawn up when a person is diagnosed with a terminal illness or becomes permanently disabled. Many young and/or healthy people are also discovering the importance of preparing such a document in advance.

Additionally, without evidence of a patient's wishes, medical professionals may continue life-prolonging treatment. This is not only because they're trained to do so, but also to protect them from any liability.

Individuals are advised to include instruction for their wishes regarding palliative care (which includes pain management and hospice care), as well as other end-of-life issues in a living will. Some people may want to discuss their end-of-life wishes with a spiritual or religious advisor. When you decide what to include in your living will, sharing this information with close family members and your doctor is important. Even if everyone doesn't agree with the decisions, they must be encouraged to respect those decisions. Also, by discussing these delicate matters in advance, disagreements among family members later on may be avoided.

Do-Not-Resuscitate Order

According to the American Academy of Family Physicians' website at www.familydoctor.org, a do-not-resuscitate (DNR) order is a request not to have cardiopulmonary resuscitation (CPR) if your heart stops or if you stop breathing. Patients who are most likely not to benefit from CPR are those with advanced terminal conditions.

DNR orders are written by doctors. Those who would like to have a DNR order in place are advised to discuss this with their doctor, either at the physician's office or at the hospital. Anyone wishing to have

a DNR at home (an “out-of-hospital” DNR), should also speak with their physician. An out-of-hospital DNR order must be signed by a physician to be valid and respected by emergency medical service (EMS) professionals.

For an example of New Jersey’s out-of-hospital DNR order, readers may visit the New Jersey Health Decisions’ website at www.njhealthdecisions.org and select “out-of-hospital – do not resuscitate orders” from the options on the left side. Readers without internet access may call the organization at **(973) 857-5552**.

Validating, Distributing, and Changing Advance Directives

Different states have different requirements for making the documents legally binding; these often require signatures from two witnesses or the signature from a notary. This is explained on the sample forms for each state.

Once your advance directives’ documents have been completed and signed, several copies of these documents will need to be made and given to:

- the appointed healthcare representative
- the care recipient’s physician
- the hospital
- the long-term care facility
- the care recipient’s lawyer (if involved in one’s care)

Some individuals may choose to share a copy with another family member or their spiritual or religious advisor.

Additionally, the healthcare representative should keep the originals in a safety

deposit box and also keep one copy at home where it’s easy to find. Of course, the patient should have a set of copies kept in a safe, easy-to-find location as well. As mentioned in the earlier listing, if the patient goes to the hospital or to a long-term care facility, copies should be given to the appropriate staff and placed in the patient’s medical records.

Gary L. Stein, Esq., MSW, executive director of New Jersey Health Decisions, explains that advance directives (Medical Power of Attorney, living will, etc.) may be cancelled or replaced with new ones at any time simply by informing all of those given the previous documents and destroying the old documents. All individuals with the previous copies will need to be given copies



of the new documents. (While this is the case in most states, readers are advised to confirm what laws apply in their own state; these are usually noted with the forms for the individual state – mentioned later.) For many individuals, knowing that they may change their advance directives is very important. One's condition or outlook, as well as medical treatments available, may change over the years.

Working with a Lawyer

Gary Stein notes that forms for advance directives in each state are usually self-explanatory and most families do not need to consult a lawyer unless one anticipates problems with their family, medical team, or healthcare facility. For those who choose to use a lawyer, consulting one who is well versed in elder or healthcare law is recommended. To find one locally, individuals

Starting the Dialogue: A Guide for Family Members

Discussing end-of-life wishes with a loved one is not easy, but doing so will enable loved ones to know your wishes. Caring Connections at www.caringinfo.org offers the following advice on how to start a conversation about end-of-life wishes:

If you can begin to talk about the end of life while people are healthy, you will have made a significant contribution to your family, and will discover important information for yourself. Communicating with family includes understanding hopes and fears around illness and dying.

There are many events and openings that can help you get started. If you want to start the conversation, think about some of the issues and then watch for a good opportunity. You will be surprised at how many possibilities you find.

Conversation triggers include:

- The death of a friend or colleague
- Newspaper articles about illness and funerals
- Movies

- Sermons
- Television talk shows, dramas and comedies
- Financial planning
- Annual medical checkups
- Family occasions such as baptisms, marriages and (especially) funerals
- Magazines and books

Both personal experience and current events, as well as art and culture, offer trigger points for conversations. Once you realize how many “conversation triggers” there are in daily life, you will be ready to start your own conversation. And starting is the most important part. Too often, these conversations don't take place until there is no time left for honest discussion, reflection and planning.

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may contact their local Area Agency on Aging (AAA), which may be found in the blue pages of the telephone book under Human Services. Such lawyers may also be found by visiting the National Academy of Elder Law Attorneys website at www.naela.org, which lists a registry of specialists in elder law.

If you need a lawyer but are unable to afford the legal costs of preparing advance directives, some elder law attorneys work at reduced rates for seniors or persons with disabilities unable to pay their usual fees. Call your local AAA for information and referrals. AARP also offers its members and their spouses reduced fees for work conducted by attorneys specializing in elder law, via its Legal Services Network at www.aarp.org/lbn. *The Consumers' Guide to Legal Help* on the internet (sponsored by the American Bar Association) also has resources for obtaining reliable legal assistance at www.abanet.org/legalservices/findlegalhelp/home.cfm.

Resources for Forms and Additional Information

Forms for healthcare representatives and living wills are available through the internet and through various agencies. Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative that seeks to improve care at the end of life. By visiting their website at www.caringinfo.org, individuals may download and print their state's advance directives (including forms to appoint a

healthcare representative and make a living will). This website provides information on state-specific guidelines and sample forms for setting up advance directives.

While these forms for advance directives may have different names in different states, their overall purpose remains the same – in general, to appoint a healthcare representative and create a living will. The website mentioned lists each state separately, and once selected, the documents may be downloaded to your computer, along with complete instructions for filling them out and distributing them in accordance with state law.

Supported by a grant from The Robert Wood Johnson Foundation, Caring Connections provides free information on end-of-life care. In addition to advance care planning, they also offer free resources on caregiving, pain, financial issues, hospice and palliative care, as well as grief and loss. Individuals may also contact NHPCO for information and free publications by calling **(800) 658-8898**.

The American Bar Association (at www.abanet.org) has published a guide entitled, *The Consumer's Tool Kit for Advance Health Care Planning*. This helpful publication assists with creating advance directives and provides information on such topics as: how to select your healthcare representative, personal priorities and spiritual values, conversational scripts to promote family discussion of advance directives, guide for healthcare representatives, and additional resources. This guide may be downloaded and printed by going to www.abanet.org/elderly/toolkit/home.html. The phone number

NEW YORK HEALTH CARE PROXY – PAGE 1 OF 2

INSTRUCTIONS

PRINT YOUR NAME
PRINT NAME, HOME ADDRESS AND TELEPHONE NUMBER OF YOUR AGENT

(1) I, _____, hereby appoint:

(name, home address and telephone number of agent)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. My agent does know my wishes regarding artificial nutrition and hydration.

This Health Care Proxy shall take effect in the event I become unable to make my own health care decisions.

(2) Optional instructions: I direct my agent to make health care decisions in accord with my wishes and limitations as stated below, or as he or she otherwise knows.

(3) Name of substitute or fill-in agent if the person I appoint above is unable, unwilling or unavailable to act as my health care agent.

(name, home address and telephone number of alternate agent)

(4) Donation of Organs at Death: Upon my death:
 I do not wish to donate my organs, tissues or parts.
 I do wish to be an organ donor and upon my death I wish to donate:

ORGAN DONATION (OPTIONAL)

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Shown below are Healthcare Proxy and Living Will sample forms from New York. Forms may be found for every state on the Caring Connections™ website at www.caringinfo.org. (Copyright © 2005 National Hospice and Palliative Care Organization. All rights reserved. Reproduction and distribution by an organization or organized group without the written permission of the National Hospice and Palliative Care Organization is expressly forbidden.)

NEW YORK LIVING WILL – PAGE 1 OF 2

This Living Will has been prepared to conform to the law in the State of New York, as set forth in the case *In re Workmaster County Medical Center*, 72 N.Y.2d 517 (1988). In that case the Court established the need for “clear and convincing” evidence of a patient’s wishes and stated that the “ideal situation is perhaps a ‘living will.’”

I, _____, being of sound mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below:

I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying, if I should be in an **incurable or irreversible mental or physical condition with no reasonable expectation of recovery, including but not limited to: (a) a terminal condition; (b) a permanently unconscious condition; or (c) a minimally conscious condition in which I am permanently unable to make decisions or express my wishes.**

I direct that my treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment.

While I understand that I am not legally required to be specific about future treatments if I am in the condition(s) described above I feel especially **strongly about the following forms of treatment:**

I do not want cardiac resuscitation.
 I do not want mechanical respiration.
 I do not want artificial nutrition and hydration.
 I do not want antibiotics.

However, I do want maximum pain relief, even if it may hasten my death.

CROSS OUT ANY STATEMENTS THAT DO NOT REFLECT YOUR WISHES

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for the American Bar Association’s service center is **(800) 285-2221**.

The Division of Bioethics at the Montefiore Medical Center/Albert Einstein College of Medicine has a guide entitled, *Making Health Care Decisions for Others: A Guide to Being a Health Care Proxy or Surrogate*. This guide may be found by going to http://eph.aecom.yu.edu/web/division_details.aspx?id=3 and clicking on the guide name at the lower portion of the page. If unable to access the guide, a copy may be obtained from MSAA by calling **(800) 532-7667**.

Another good resource is AARP’s website at www.aarp.com. End-of-life information may be found by going to the section labeled “Family, Home and Legal” and then selecting “End of Life” from the options on the left. AARP may also be contacted by calling **(888) 687-2277**.

The Eldercare locator may be found at www.eldercare.gov, or you may also reach them by calling (800) 677-1116. Here you can find state and county area agencies on aging. The site also offers resource information on reputable lawyers in your area that may charge lower fees or work pro bono (at no charge) to help seniors or people with disabilities to draft living wills. Legal advice may also be found through the National Academy of Elder Law Attorneys at www.naela.org or by calling (520) 881-4005.

Conclusion

Gary Stein states, “People may recall highly publicized cases, such as those of Karen Ann Quinlan from New Jersey or Terri Schiavo from Florida, who were kept alive for extended periods of time through artificial means. Many people in this type of condition would not want to live indefinitely on breathing machines or through tube feeding. This preference has been supported through many public opinion polls. Additionally, many may worry that disagreements can tear their loved ones apart.

“This scenario may be avoided by planning ahead. I cannot overstate the importance of appointing a trusted family member or friend to advocate on your behalf. In addition, expressing your wishes for your care and then documenting these wishes in your advance directives, best ensures that you get the kind of care you want.”

About the Author

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

Helpful Resources

Heffelbower, Ruth, D. *What Happens After We're Gone? Estate and Life Planning for Families in Which a Dependent Member Has a Disability or Mental Illness*. Mennonite Mutual Aid, Advocacy, and Education Resources, 1996.

Kalb, Rosalind, C. Ph.D. *Multiple Sclerosis: The Questions You Have. The Answers You Need*. Demos Medical Publishing, LLC, 2004.



In the next issue of *The* **MOTIVATOR**:

Many of you may remember that we requested inspirational stories to be mailed in by our readers for a future article in *The Motivator*. We just want to let you know that our cover story in the upcoming

Winter 2006 issue of *The Motivator* will highlight the many inspirational stories we have received. Please do not send any additional stories at this time. Thank you to all who sent in their stories!

Palermo, Michael. *AARP Crash Course in Estate Planning: The Essential Guide to Wills, Trusts, and Your Personal Legacy*. Sterling Publishing, 2004.

Pond, Jonathan. *Your Money Matters: 21 Tips for Achieving Financial Security in the 21st Century*, The Berkley Publishing Group, 1999.

Helpful Websites for More Information

www.americangeriatrics.org/education/forum
www.bazon.org
www.kidney.org
www.medicalalert.org
www.neriscience.com
www.uslivingwillregistry.com
www.caringinfo.org ♦

<p><i>Relief</i> from Heat</p>	<p>POLAR <i>Body Cooling</i> SYSTEM KITS</p>	<p>Cold Pack Cooling <i>Systems</i></p>
<p>Polar Passive Vest Kit - Poncho</p>  <p>BODY COOLING</p>	<p>WRIST</p>  <p>NECK</p>  <p>COLD PACKS</p> <p><i>Each System Kit Includes:</i></p> <ul style="list-style-type: none">• 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!	<p>BODY COOLING</p>  <p>Polar Passive Vest Kit - Zipper</p>
<p>Lightweight & Comfortable</p>	<p>1-800-763-8423 WWW.POLARSOFTICE.COM</p>	<p>Worn Under or Over Clothes</p>

The Consortium of Multiple Sclerosis Centers' Annual Meeting

Introduction

The Consortium of Multiple Sclerosis Centers (CMSC) held its 19th annual meeting this past June in Orlando, Florida. This five-day conference is a collaborative effort between the CMSC, the International Organization of Multiple Sclerosis Nurses (IOMSN), and the Latin American Committee for Treatment and Research in Multiple Sclerosis (LACTRIMS).

Using the theme of “Navigating the World of Multiple Sclerosis,” this year’s meeting provided information about the MS disease process and the immune system; basic fundamentals of MS care as well as advanced concepts in care and research; progress in diagnosis and MS treatment; strategies for addressing disease progression; and symptom management as well as rehabilitation for individuals affected by the disease.

The CMSC is the largest professional MS organization in the world, seeking to develop and sustain a specialized team approach to meet the needs of those with MS. The CMSC promotes a comprehensive model of MS care, striving to address all of the different ways in which MS affects individuals who are diagnosed with the disorder. This includes the physical aspects of diagnosis, disease progression, symptoms, and treatments, as well as the psychological, emotional, and social impact. The group also looks at other important factors,

including family and care partner issues; along with the need for advocacy.

Its members are professionals from all areas of MS care. The list includes neurologists, nurses, physiatrists, counselors, rehabilitation professionals, psychologists, neuroradiologists, clergy, neuropsychologists, educators, social workers, and others. The CMSC’s annual meeting gives everyone an opportunity to learn about the latest findings in research, treatment, and rehabilitation, while sharing new ideas for various strategies to help individuals to cope with and overcome some of the challenges which MS presents.

Presentations and Abstracts

Presentations at this year’s meeting included:

- **Fundamentals of MS care and management**, from diagnosis to rehabilitation, encompassing: an overview of MS; disease-modifying treatments and managing relapses; MS rehabilitation; cognition, swallowing, and speech issues; the psychosocial impact of MS; and hope for the future
- **Lectures** on: whether or not MS is a neurodegenerative disease; if MS is different in Latin America; and the potential for remyelination in MS

- **Symposia** covering: the focus and accuracy of diagnosing MS in 2005; the evidence shown by MS rehabilitation (including the effectiveness of energy conservation education and the management of communication problems); pregnancy and MS; the diagnosis and prognosis of primary-progressive MS; neurocognitive retraining in MS; alternative medicine and MS; the evolution of MS lesions; the history of MS; neuroprotection and neurogeneration; MS research and care in Latin America; along with understanding and treating pediatric MS
- **Workshops and mini-courses** covered a range of subjects, from sleep disorders, rehabilitation, and legal issues, to the African-American perspective, mobility aids, and cognitive therapy, along with several other relevant topics

In addition to these sessions, more than 140 abstracts were presented. These too covered a full range of topics relating to MS research, treatment, and ongoing care.

The “Powerpoint” or slide presentations from many of the sessions, as well as the abstracts from the scientific platform and poster presentations, are available to the public by going to the CMSC’s website at www.mscares.org. Visitors may find these by clicking on the 2006 upcoming meeting, then clicking on annual meetings, and then scrolling down to and clicking on the 2005 annual meeting. The direct address is: www.mscares.org/members.cfm?doc_id=35.

The MS Coalition’s Workshop for Nurturing Children

Of particular interest was the workshop entitled, “Nurturing Children: Coping with Chronic Illness.” This was presented by Lara R. Krawchuk, MSW, LSW, MPH, from the Conill Institute for Chronic Illness, and Helen Link Egger, MD, from the Duke University Medical Center. The workshop was planned through the newly formed “MS Coalition,” a group of three MS organizations – the CMSC, MSAA, and the Multiple Sclerosis Foundation (MSF) – whose mission, by working together, is to increase opportunities for cooperation and to leverage the effective use of resources for the benefit of the MS community.

Members of the MS Coalition had identified a problem reported by many MS professionals, including doctors, nurses, rehabilitation therapists, and others. As these specialists came in contact with their clients who have MS, and went about their work, a number of clients would often express their concern for their children and the problems they were encountering. While these particular MS professionals were skilled in areas of disease and symptom management or rehabilitation, they did not have the background to offer informed feedback to their clients about family counseling and the problems that their children may be experiencing.

The Coalition decided to offer a workshop at the CMSC’s annual meeting that would provide information about children learning to cope with a parent’s illness. This

would give MS professionals the facts they needed to talk with their clients and provide valuable advice. To follow is an overview of this workshop.

The workshop began with information about depression in individuals with MS. It noted how individuals with MS were at an increased risk of both depression and suicide. Symptoms and causes of depression were noted, along with a reminder that the care partner (often the other parent) may be at greater risk of depression as well.

Certainly depression not only impacts one's quality of life and emotional as well as physical health, but can also impact one's children. Depression can limit a parent's physical and emotional capacity to parent with consistency and patience, which can have a significant effect on a child's cognitive, social, and emotional development. Getting the adequate treatment for depression can greatly improve the situation and diminish or avoid some of these issues related to depression.

Emotional reactions that children may experience when a parent is sick include guilt, anger, fear and anxiety, embarrassment, sadness, and feelings of helplessness and neglect. Unfortunately, few studies have been conducted to determine the effects of parental MS on child adjustment. The effects of maternal depression, however, are documented; maternal depression can cause increased rates of behavioral problems, social and emotional maladjustment, and a deficit in cognitive functioning.

Disorders that children may be experiencing were explained. These included symptoms of childhood depression, psychi-

atric or anxiety disorders, attention deficit disorder, and oppositional behaviors.

Parents need to know that these occur in children whose parents have no illness – and MS is often not the cause. Any child exhibiting unusual behavior should be seen by a physician, evaluated, and given treatment if needed, to help improve the child's emotional, mental, and physical wellbeing.

Parents can help their children by: providing a safe and loving home; developing a good relationship which encourages good communication when upset; teaching the importance of accepting limits; and seeking help when needed. Educating one's children about MS and depression (through age-appropriate conversation) and maintaining an honest and open relationship helps to minimize children's worries and fears.

For More Information

The workshop described above was just one of many informative presentations that were held at the CMSC's annual meeting. These were all aimed at helping the MS professional to understand all aspects of the illness, from research and treatments to social needs and family issues, enabling these MS specialists to play an important role in providing comprehensive MS care. As mentioned earlier, slides of these presentations may be viewed by going to the CMSC's website at www.mscares.org.

We were unable to include more information in this issue from the many presentations given at the CMSC's annual meeting. When possible, we will try to incorporate some of this valuable information in future articles of *The Motivator*. ♦

New Medicare Drug Program

The Medicare Part D Prescription Drug Program officially begins on January 1, 2006. Anyone enrolled in Medicare is eligible. This program is voluntary for most Medicare recipients. You do not need to participate if you have a better plan already in place or available to you, whether through your employer or other health insurance provider. If you receive Medicare as well as Medicaid, you must enroll in the Medicare Part D plan to keep your prescription drug coverage.

Individuals who enroll in Medicare Part D must choose one of the several private prescription drug plans that Medicare has approved. These plans meet certain minimum coverage criteria, but vary in terms of what drugs they cover and how much they pay – so individuals need to look at their options carefully.

In general, participants will be required to pay a small monthly premium (approximately \$32) as well as a \$250 deductible, although some plans will waive that deductible. Participants must then pay 25 percent (\$500) of the next \$2,000 in eligible drug purchases. A gap in coverage requires the participant to pay the next \$2,850 (if applicable) in eligible drug purchases, before the plan kicks in again with 95 percent coverage (known as the Catastrophic Benefit).

Individuals who are on Medicaid will only need to pay a small co-payment for their prescription drugs, and some states will provide coverage through Medicaid to cover the cost of that co-payment. Individuals who are not on Medicaid, receive a limited income

(\$14,355 for a single person; \$19,245 for a married couple living together), and have limited resources, may qualify for extra help through the Social Security Administration.

Please note that Medicare Part D has strict deadlines that must be followed. Individuals who are eligible to enroll in Medicare Part D and wait to enroll after the May 15, 2006 deadline may be given higher rates to pay as a penalty. This penalty may be waived if you have prescription drug coverage through an employer-sponsored plan.

Deadlines are:

November 15, 2005: Enrollment begins for Medicare Part D.

January 1, 2006: Drug coverage begins for those who enrolled with the new program.

May 15, 2006: Last day to enroll without a penalty, unless you qualify for an exception; those who have yet to begin Medicare may enroll in the new drug program when they initially sign-up for Medicare.

For more information, please visit or call: AARP at www.aarp.org/medicarerx, (888) 687-2277; Medicare at www.medicare.gov, (800) 633-4227, TTY at (877) 486-2048; Social Security Administration at www.socialsecurity.gov, (800) 772-1213, TTY at (800) 325-0778; and State Health Insurance Assistance Program (SHIP) at www.shiptalk.org to find the toll-free phone number for your state. Please call MSAA's Helpline at (800) 532-7667 if you need further assistance.

Ask the Doctor

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



Q: I am not able to undergo an MRI because of my claustrophobia. I have tried a variety of sedatives which haven't worked. My doctor won't allow me to go totally under anesthesia,

but I don't know why I couldn't do this. What options are available that you would suggest?

A: When doctors recommend a test (or treatment), they must weigh two issues: the potential benefits versus the potential risks. What are the benefits and risks of an MRI? While the MRI has been very helpful in diagnosing of MS, its role as a “routine” test to follow the progress of the disease is not uniformly accepted. In fact, one group of MRI and MS experts did not recommend “routine” MRI’s for MS patients. Therefore, ordering an MRI may not be indicated unless the doctor is considering a change in treatment and MRI results would influence that decision.

Since the value of a “routine” MRI is not fully established, what are the risks? While the risks of an MRI are minimal, the risks associated with anesthesia are worrisome. Some MS patients do not tolerate anesthesia well. Therefore, why expose the patient to the risk of anesthesia unless the test results are going to be extremely valuable?

Apparently, your doctor may not feel that the potential MRI value warrants your risk of anesthesia.

What are your options? An “open” MRI, which does not require being placed “in a tube,” is an option. However, the MRI results from “open” MRI’s are not as detailed as the regular MRI results. Therefore, the limited value of “routine open MRI” may not justify the test.

In my experience, sedatives are helpful in reducing anxiety caused by claustrophobia. I recommend that you have another discussion with your doctor (maybe in conjunction with an anesthesiologist), to assess the potential value of the MRI and the risks of anesthesia. The result may be another sedative that you have not yet tried (versus anesthesia) if your doctor believes that an MRI is crucial to your care.

Q: I was diagnosed with MS 13 years ago. Five years later, I suddenly developed severe allergies, mainly to food, that result in the itching of my eyelids; itching, swelling and welts all over my face and now my chest; as well as itching and peeling of skin on my fingers to the point that they bleed. After seeing many specialists, none can determine the cause or cure. Can this be related to MS?

A: Multiple sclerosis does not “cause” allergies. However, MS and allergies, are both autoimmune diseases and people with one autoimmunity are at greater risk for a second

autoimmune disease. As you have discovered, food allergies are a common cause of skin reactions. I assume that you have consulted an allergy specialist and discontinued any of the foods that could aggravate your condition, and that you continue to monitor any other foods for possible reactions.

Environmental triggers are also common, and these may include pets, plants, molds, dust, laundry detergents, and soaps, to name a few. Through lab work (skin or blood-sensitivity tests) and sometimes testing each item separately (by removing and then bringing back the potential allergen), individuals suffering from these types of allergies need to make whatever modifications necessary to limit their exposure to such allergens.

Medications can also cause allergic reactions in certain individuals. These include both the disease-modifying treatments for MS, as well as medications used to treat the different symptoms of MS. If your physician suspects that medications may be the cause, he or she may have you stop and later restart each drug (if needed) to see if any are causing the reaction. Please note that any changes to one's treatment regimen should only be done under the advice and

supervision of his or her doctor.

Lastly, when I evaluate MS patients with skin allergies, I test for systemic lupus erythematosus (lupus), especially in women. Blood tests can usually diagnose lupus, which can mimic MS symptoms. ♦

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.

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.

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Visit MSAA's website at

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

Research News

Tysabri® Update

Good news for patients previously on Tysabri... no new cases of PML

Biogen Idec and Elan Corporation, makers of Tysabri® (natalizumab), have conducted a safety evaluation of patients who previously took Tysabri. Any unusual responses to the drug are being investigated and reported to the FDA. Three cases of progressive multifocal leukoencephalopathy (PML) have resulted in two deaths so far in patients on Tysabri. PML is an often-fatal brain disorder thought to be caused by the activation of a virus known as the “JC Virus.”

According to a press release from Biogen Idec and Elan, dated August 9, 2005, no new confirmed cases of PML have been discovered. Almost 2,000 MS patients from clinical trials participated in the safety evaluation. With no additional cases of PML among patients exposed to Tysabri, Biogen Idec and Elan are taking preliminary steps to restart clinical trials in MS.

For more information, please see “Recent News” on MSAA’s website at www.msaa.com, or call MSAA at (800) 532-7667.

Interim Results from Campath® Trial

Encouraging results although some adverse events

In September 2005, Genzyme Corporation and Schering AG Germany announced the interim results of a phase II

trial comparing Campath® (alemtuzumab) with Rebif® (interferon beta-1a). These results came from an efficacy (looking at effectiveness) and safety interim analysis, following the completion of one year of treatment in a planned three-year trial with active relapsing-remitting MS patients.

Campath is a humanized monoclonal antibody that binds to a specific target (CD52) on cell surfaces, directing the body to destroy potentially damaging cells within the immune system. For these studies, Campath is administered in annual intravenous (directly into the vein) infusion regimens (a five-day course of doses is given the first year; a three-day course of doses is given during the second year and beyond).

According to the companies’ announcement, the one-year interim analysis showed a 75 percent reduction in relapse rate and a 60 percent reduction in the risk for progression of clinically significant disability for individuals treated with Campath, as compared to those receiving Rebif. Serious adverse events, however, occurred in two participants on Rebif, four participants on the low dose of Campath, and five participants on the high dose of Campath. Three documented cases of idiopathic thrombocytopenic purpura (ITP) occurred in the Campath groups (causing a low platelet count with the potential for abnormal bleeding). One of these three cases resulted in death; the other two individuals affected are responding to treatment. Two participants taking Campath developed Graves’ Disease (a treatable thyroid condition). The companies are not disclosing

details about the adverse events which were experienced by six other study participants, except to say that none of the adverse events were unexpected and that no cases of progressive multifocal leukoencephalopathy (PML) have occurred.

The companies are implementing safety provisions and have consulted with the United States Food and Drug Administration (FDA). The companies have temporarily suspended the dosing of Campath in this study.

MSAA Vice President and Chief Medical Officer Dr. Jack Burks explains, “Campath is not FDA approved at this time for the treatment of MS. While these early results are encouraging, patients needing treatment today should not delay being treated with currently available therapies, if advised by their treating MS neurologist.”

For more information please see “Recent News” on MSAA’s website at www.msaa.com, or call MSAA at (800) 532-7667.

Important Findings Presented
To follow are highlights from some of the educational and poster sessions given at the American Academy of Neurology’s Annual Meeting held earlier this year. This is a continuation of the cover story on the same topic in the Summer 2005 issue of *The Motivator*. As space allows, additional summaries may appear in future issues.

Interferons and Pregnancy...

Over the course of eight studies with 3,361 women and 69 pregnancies, interferon beta-1a administration is still contraindicated

and not recommended for women who are pregnant or are trying to become pregnant. While the majority of pregnancies have the potential to go full-term and deliver a healthy baby, this report showed a higher incidence of lost pregnancies (when receiving interferon within two weeks or less of conception). Until more data is available, patients are “strongly advised” to stop interferon treatment prior to becoming pregnant.

MRI as an indicator of continued disease activity...

Through the OPTIMS multi-center trial, investigators concluded that a single active MRI scan after six months treatment is the best indicator of persistent disease activity in those treated with Betaseron. They found that a patient with an active scan at six months will probably remain active for the entire first year of treatment, and such patients should be considered for a change in treatment, such as an adjustment in dose or drug selected. Increasing the dose of Betaseron by 50 percent led to a dramatic decrease in this MRI activity. (Readers are cautioned not to alter their treatment or dose unless under the guidance of their physician.)

Treatments delay progression of MS...

A French observational study of 1,609 individuals with RRMS suggests that disease-modifying treatments begun prior to reaching any noticeable disability (having an EDSS of three or less) may delay the progression of long-term disability. The mean number of years for follow-up was 13, with some patients being followed for more than 20 years.

Copaxone restores immune function...

A small study in Boston, Massachusetts was conducted to see how glatiramer acetate (Copaxone) affected CD4+ and CD25+ T-cells, which help to regulate the immune system. Researchers hypothesized that individuals with MS may have a loss in terms of frequency and/or function of these cells, which may contribute to a lack of immunoregulation observed in MS patients. Five of the seven MS patients in the study showed impaired function of these cells. Function was largely restored three months after beginning treatment with glatiramer acetate, indicating that this therapy may rapidly improve regulatory CD4+ and CD25+ T-cell function early in the course of treatment.

New treatment for PBA...

A study was conducted to assess the safety and efficacy of AVP-923 (Dextromethophan/Quinidine) for the treatment of pseudobulbar affect (PBA) in MS patients. PBA is associated with some neurological disorders and is characterized by uncontrolled episodes of laughing and crying. Study results indicate that AVP-923 is safe, well-tolerated, and highly effective in treating individuals with MS who experience PBA.

Oral MS treatment trial encouraging...

An open-label study was conducted to evaluate the safety and effectiveness of oral fumaric acid in patients with RRMS. This drug is presently used for psoriasis, which may have a similar inflammation process to MS. The drug is thought to suppress inflammation by promoting Th2-type cytokine profile (a chemical produced in the body that works to sup-

press inflammation). According to the researchers of this study, oral fumaric acid significantly reduced the number and volume of gd-enhancing lesions in MS patients during the 70 weeks (approx. one year and four months) of treatment; all patients in the trial remained clinically stable. No adverse events were reported. These findings demonstrate that further studies of oral fumaric acid in the treatment of MS are warranted.

Bone marrow transplants help six patients...

A three-year follow-up of a Canadian phase II trial using bone marrow transplantation showed clinical stabilization or improvements in the six patients who participated. These patients had aggressive MS and each underwent immunoablation (a complete eradication of the immune system to halt ongoing MS immune-mediated damage) followed by autologous (self) stem-cell (bone-marrow derived) transplantation. Those patients who experienced improvement had increased visual and motor capabilities. MRI studies failed to detect any new disease activity in any of the patients.

Ginkgo biloba may improve attention...

In a pilot study, ginkgo biloba was given to individuals with MS experiencing cognitive dysfunction. Participants received either 120 mg of ginkgo biloba twice daily, or a placebo, for 12 weeks. Results suggest that ginkgo biloba may be effective in improving attention for those with cognitive dysfunction as a result of MS. More studies are needed to confirm this finding.

Continued on page 35

Program Notes

Volunteers Make a World of Difference

Each year MSAA strives to serve more MS clients in more places than ever before. Greatly aiding our ability to meet these challenges are the thousands of supportive and dedicated volunteers who have committed their time and resources to help those with MS all across the country.

One of our proudest accomplishments over the past few years has been the continued growth and development of new support groups. These talented and hard-working support group leaders and their active members have helped to build strong connections with fellow MS clients and their families, raise public awareness and understanding, assist with programs and services, coordinate therapy and exercise classes, and conduct vital fund raisers, including the “Sweeten the Season” card candy cane sales program – which is currently underway and in need of volunteers. More recently, numerous support groups have also taken an active role in hurricane relief efforts for those affected by Katrina and Rita.

Four new volunteer programs have also enjoyed great success this past year. Launched in January, Resource Detectives is a group of volunteers who use their skills and ingenuity to research (via the internet and/or telephone directories) local agencies and organizations that provide resources which can assist the MS community. These beneficial resources often

include information on prescription assistance, housing, transportation, and other local services. The information is maintained in a growing national database and passed on to MS clients and families, as requested through our client services department and regional offices. This volunteer program also enables our staff to quickly respond to client requests and handle a larger volume of calls on the toll-free Helpline.

Another new volunteer opportunity is the role of Public Education Ambassadors (PEA). A PEA volunteer represents MSAA at various public events, which include work place giving campaigns, health fairs, and regionally organized public education events. These ambassadors strive to inspire people’s compassion to make a gift to our worthy organization, as well as inform others about the programs and services MSAA provides to individuals with MS and their care partners. As of this fall, we have enlisted volunteer ambassadors in several large cities throughout the United States.

In addition to these new and exciting programs, MSAA is extremely proud of the continuous support offered by our growing network of professional volunteers. These volunteers generated nearly 1,000 hours of support through the summer, assisting with the cooling, equipment, MRI, lending library, and home modification programs, as well as database support and other administrative activities.

Program Notes

MSAA would like to take this opportunity to publicly thank all those who have graciously and so admirably volunteered their time, skills, effort, and support to individuals with multiple sclerosis, their families and care partners, and our organization. If you or anyone you know would like to volunteer or learn more about these opportunities, please contact Malcolm Friend, director of national volunteer services, at **(800) 532-7667**, ext. 8 or www.msaa.com/volunteer.html. ♦

Research News

Continued from page 33

Methotrexate may help progressive MS...

An open-label, 18-month, phase I trial of the intrathecal administration (injection directly into the spinal fluid) of methotrexate (ITMTX) was conducted with 100 patients who had severe MS. Looking at safety and tolerability as the primary objective, and efficacy as a secondary objective, the trial enrolled 74 participants with RRMS or SPMS and 26 with PPMS. Each received a minimum of two pulsed doses via lumbar puncture; most received four doses. Results indicated that the treatment was well tolerated and safe; no one discontinued treatments due to side effects; and 96 percent of the patients stabilized or improved in terms of their EDSS scores. Four patients, all with PPMS, continued to worsen in their EDSS scores. No MRI studies were mentioned. Phase II, double-blind studies are needed to confirm the safety, tolerability, and efficacy of ITMTX. ♦

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Symptom Awareness

Dealing With Depression

Winter is fast approaching, and with its long nights, cold temperatures, and gray scenery, some may find themselves suffering from what many call “the blues.” This issue’s Symptom Awareness column is an overview on depression, taken from the cover story in MSAA’s Winter 2003 issue of *The Motivator*.

If you tend to feel down, you are not alone! Depression can affect anyone, regardless of income, age, gender, nationality, and lifestyle. Nearly 10 percent of the adult American population suffers from a depressive illness during the course of an average year.

Depression is a very treatable illness, and many can enjoy a far greater quality of life just by seeing a professional and getting the help they need. Depression is often best treated through a combination of medication and psychotherapy. In many circumstances, depression may be significantly reduced in a relatively short amount of time.

While anyone is susceptible to depression, individuals with MS experience a much higher incidence. The negative effects of depression on MS are compounded by the fact that depressed individuals may not comply with taking their prescribed medications, and this could cause their condition or other symptoms to worsen. A portion of depressed individuals are at risk of suicide, and this too is greater for individuals with MS.

Symptoms

When diagnosing a major depressive episode, physicians look for five or more of the following nine symptoms to be present during the same two-week period. As noted, a portion of the symptoms listed are also symptoms of MS, which means they may not necessarily indicate depression for someone with MS. These symptoms may be reported by the patient or observed by others, and in general, occur nearly every day.

Symptoms of depression only:

- Depressed mood for most of the day
- Greatly reduced interest or pleasure in all, or almost all, activities most of the day
- Significant weight loss or gain, or change in appetite
- Feelings of worthlessness or excessive guilt
- Recurrent thoughts of death or thoughts/plans/attempts of suicide

Symptoms of depression that are also symptoms of MS:

- Difficulty sleeping or excessive sleeping
- Significant restlessness or slowing down as observed by others
- Fatigue or loss of energy
- Diminished ability to think, concentrate, or make decisions

Treating Depression

The first line of medications in treating depression is a class of drugs known as “selective serotonin reuptake inhibitors” (SSRIs). These include Fluoxetine

(Prozac®), paroxetine (Paxil®), sertraline (Zoloft®), and venlafaxine (Effexor®). Additional antidepressants that are considered to be a “first line of treatment” for depression are bupropion HCL (Wellbutrin®), nefazodone (Serzone®), and trazadone (Desyrel®). Other drugs, such as anticholinergics or tricyclic antidepressants, as well as monoamine oxidase inhibitors (MAOIs), may be options for people who do not respond to the first line of medications already mentioned.

All of these agents may be given alone, or various combinations may be prescribed. Antidepressants do not have an immediate effect, and typically require between four to eight weeks before reaching their maximum level of benefit.

Sometimes individuals want to stop their antidepressant medication as soon as they feel better, thinking they no longer need it. This type of treatment should be continued for at least four to nine months to prevent depression from returning, and medication for more severe conditions may need to be continued indefinitely.

Individuals taking antidepressant medication should never alter their dose, stop taking their medication, or combine it with any other drugs, without first consulting their doctor.

Studies are ongoing to determine if an extract of the herb St. John's wort may have an effect on milder forms of depression. St. John's wort, however, along with other herbal supplements, can have dangerous side effects when taken with other medications. Individuals need to inform their doctor if

they are taking any type of herbal supplement.

Psychological counseling is the second and equally important component for treating depression. Individuals suffering from this condition need to work with a psychiatrist, psychologist, or social worker to discuss their thoughts, behaviors, and outlooks. These medical professionals assist people with their coping skills and help individuals to better adjust to their situations and ultimately feel better.

MSAA's Vice President and Chief Medical Officer Jack Burks, MD, specializes in the treatment of MS and stresses the importance of treating depression. Dr. Burks explains, “What causes depression in MS is not an easy question to answer. Having MS certainly adds stress to one's life, and depression can result from dealing with stress. But depression can also result from medications, and damage to myelin could be involved. Other medical conditions, such as thyroid disease and urinary tract infection, can cause depression as well. An individual can even appear euphoric when actually suffering from depression.

“For these reasons, I always look at the patient's entire picture. After making whatever changes are necessary to existing medications and conditions, using a combination of psychotherapy and medication is the most effective means of treatment.

“Psychotherapy is an integral part of treatment. Examples of therapy options include group, peer, family, couple, and individual counseling. Educating family members is important so they understand

Continued on page 45

Health and Wellness

EMERGENCY PREPAREDNESS

BY ELIZABETH THOMPSON

The path of destruction Hurricane Katrina imposed upon Alabama, Florida, Louisiana, and Mississippi, causes me to wonder how individuals with multiple sclerosis, or any disability, could survive. I have MS, and watching people pushed through filthy water in wheelchairs, places the responsibility squarely on my shoulders to get serious.

My thinking is not fatalistic but realistic. I don't live in a potential hurricane path, but in Washington State we have volcanoes which have erupted, earthquakes, forest fires, and flooding. Other states live with the reality of tornadoes and hail storms, to name a few. We all must consider what resources we rely on regularly and determine how they might be impacted by a disaster.

My heart aches for those affected by Katrina and it awakens my need to prepare. My experience with the Girl Scouts, whose motto is "Be Prepared," and my Red Cross training, along with my limited mobility, should all compel me to plan, yet I have not. If you are like me, are dependent on medications, have children and/or pets... how would you respond if you were told to evacuate?



Moving Past Fear to Take Control

"The act of planning for an emergency or disaster can 'paralyze with fear' even those without unique planning needs," says Elizabeth Davis, managing director of EAD & Associates, LLC in New York City. This company provides expertise in emergency management and special-needs planning, to ensure that people with disabilities are prepared for disasters and their consequences.

"It is assumed to be an uncomfortable process and, therefore, one often avoided. It is our obligation, however, to plan for our own survival to the best of our ability," Davis adds. According to the National Organization on Disability, America's community with disabilities includes 54 million people, so special needs are widespread. The sheer numbers should compel us all to plan, based on our needs.

Davis encourages us by saying, "When

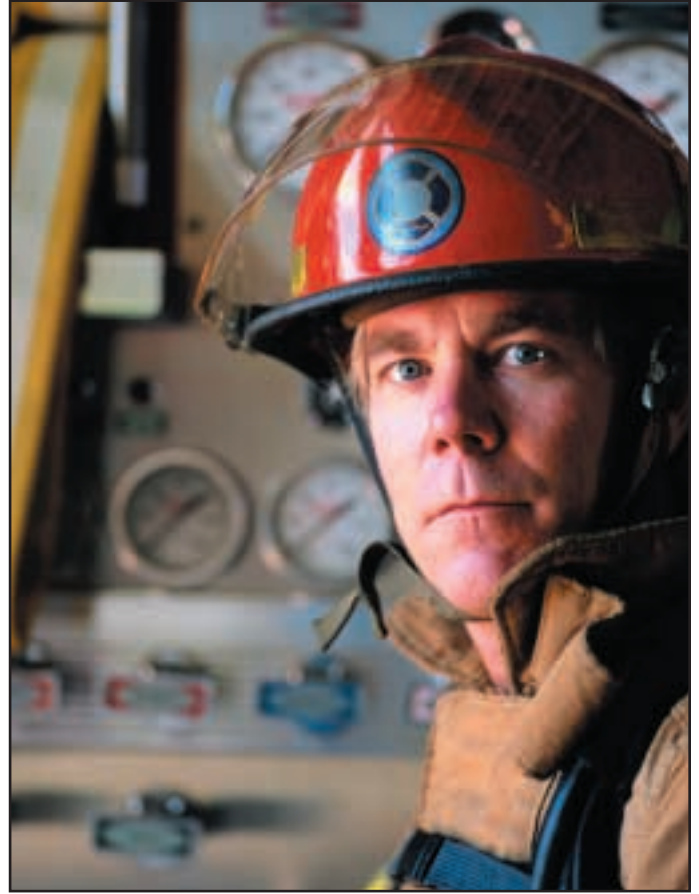
a person with a disability faces certain realities, such as requiring a greater level of reliance during extraordinary times, we also find that we have survival solutions that we use every day, which can be transformed into planning tools. Planning can empower us to get past fear and find ways to take control of our circumstances.” In addition to her professional experience, on a personal level, Davis is well aware of some of the challenges faced by individuals with MS. Davis has a strong bond with a close relative, who has MS and continues in an active career.

Unimaginable Disasters are Signs of the Times

No one expected the tragedy seen on September 11, 2001, as high-jacked planes flew into the Twin Towers, the Pentagon, and a field in Pennsylvania. And amongst other natural disasters within our country, such as earthquakes, hurricanes, tornadoes, floods, and mudslides, the tsunami that hit Indonesia and surrounding countries in December 2004 – killing more than a quarter-million people – was beyond anything we ever imagined. Despite such disasters, many were not prepared, had no way to evacuate, or did not seriously heed warnings when the powerful Hurricane Katrina hit.

Ed, 47, is the battalion chief of a fire station in Florida. Residing in Vero Beach, Florida, Ed has 25 years experience in fire service. He was diagnosed with MS in 1996.

Ed says that he takes care of people at their worst possible time and having MS gives him added sensitivity. “You can live with this disease and contribute to society. I



am very fortunate because MS does not limit what I can do.”

Last year, Ed was on duty during hurricane season. Not being home for two weeks after each storm, along with the stress, takes its toll. “I am asked how I dealt with the stress... I didn’t have time for stress. I was constantly on the go,” Ed recalls. At one point, his crew finally put him to bed after going for three days with no sleep.

Margaret, 59, has MS and has lived in Masaryktown, Florida for 20 years. “Last year there were four hurricanes. When the authorities say to get out of here, I’m out of here,” states Margaret. “I have had my fill of hurricanes. I plan to move to my Indiana hometown within the year.”

Margaret’s advice for others with MS is to register with his or her Emergency

Management Division of the Department of Public Defense and Homeland Security – if this service is available in your area. (For contact information, please refer to the resource section at the end of this article.)

“If you have medical needs, as soon as things are looking bad, someone will come to take you to a place of safety, where doctors, nurses, and medical equipment are available,” Margaret says. “Don’t be a hero. Get out of there and live.”

Residents should check with their local community government to see where a designated shelter is in the event of an emergency. Should a nearby shelter not be available, residents may become part of the solution by working with local officials to ensure that a program is in place.

All Agree: Evacuate When Advised

When Ed visited special-needs shelters after the storms, many said they would never stay for another storm. “Anyone who has MS needs to prepare and hope such preparation is never needed. Listen to the experts and leave. Make sure you take all your meds,” Ed urgently advises.

Will, 54, of Jackson, Mississippi, agrees with Ed and Margaret, stating, “When civil authorities say, ‘take refuge,’ you should take refuge. We know that some people who have MS have limited resources, but most of us have a card list

to use when we need help.” Will is referring to a holiday card list that many of us have and could access for our personal support system of friends, neighbors, and relatives.

The center of Hurricane Katrina came within 60 miles of Will’s home before changing course. “We were hit with the sidewall of the storm,” Will explains. “We saw the worst of a category one’s 65-90 mph winds for six-to-eight hours.”

Will’s family was without electricity for four days. Will lost his ability to walk as a result of heat and stress. His decision to stay home surprised him since he was formerly the regional director of health and safety for a communications company. “The idea to ‘wait and see’ is not always the way to do it,” Will concludes.

Knowledge is Power

The Center for Disability Issues and the Health Professions’ 44-page guide for people with disabilities, *Emergency Evacuation Preparedness: Taking*

Responsibility for Your Safety, can be found at the following link: www.cdihp.org/products.html#eeguide and selecting one of the four versions to download and view or print. Individuals without internet access may contact MSAA’s Helpline at **(800) 532-7667** for more information. This guide is extremely thorough and addresses virtually every aspect of emergency planning for



individuals with disabilities and other activity limitations. Through questions, explanations, and true stories of individuals with disabilities who needed to evacuate, this guide specifically instructs readers about the importance of preparation; how to evaluate their own needs; and exactly what they need to do to prepare. It also includes evacuation options, references, and resources, as well as directions for establishing a personal support network and compiling one's complete emergency health information.

The Federal Emergency Management Agency (FEMA) offers free, online, independent-study courses. According to Davis, a course devoted to special-needs planning will be available soon. (For contact information, please refer to the resource section at the end of this article.)

According to Web MD, a disaster kit should include the following:

- A battery-powered radio
- Flashlights with extra batteries
- Three-days worth of non-perishable food and water for each household member, plus a manual can opener
- One change of clothing and footwear for each household member
- Blankets or sleeping bags
- Sanitary supplies, such as toilet paper, soap, disinfectant, bleach, personal hygiene items, and garbage bags
- Plastic sheeting and tape
- Personal identification, cash (including coins), traveler's checks, and/or a credit card

- Emergency contact information and family documents in waterproof containers

The American Red Cross offers the following tips for individuals who use mobility aids:

- Store emergency supplies in a backpack attached to your walker, wheelchair, or scooter.
- Store mobility aids close to you.
- Keep heavy gloves in your supply kit for wheeling or making your way over glass and debris.
- For a motorized wheelchair or scooter, have an extra battery. Check with your vendor to learn if you can charge your battery by either connecting jumper cables to a vehicle battery or connecting batteries to a converter that plugs into a vehicle's cigarette lighter. Caution: Charge only one battery at a time.
- Keep a patch kit to repair flat tires and/or keep an extra supply of inner tubes.
- Store a lightweight, manual wheelchair if available.
- If you spend time above the first floor of a building, plan and practice using alternate methods of evacuation.
- Wheelchairs may need to be left behind during an evacuation. If you cannot use stairs, familiarize yourself with lifting and carrying techniques that work for you. Be prepared to give brief instructions on how others can move you.
- Create a list of your personal support network of friends, neighbors, relatives, and disability contacts/services; store this information in a safe place (and

keep a copy in your “disaster kit,” mentioned previously).

Other helpful tips:

- Particularly for individuals who may have communication or cognitive problems, wearing a medical ID bracelet or necklace can be crucial should they become separated from family or friends. For more information, readers may visit www.americanmedical-id.com/home/?usersession or call **(800) 363-5985**.
- Laminate a card listing your full name, medications, allergies, special needs, a contact person, and physician names and numbers; keep this in a place where friends, family, or emergency personnel could easily spot it in an emergency.
- Keep extra sets of important documents, i.e., insurance papers, birth certificates, financial information, etc., and possibly copies of a few irreplaceable photographs, in a fireproof box at home, as well as in a different, secured location (such as a safety-deposit box at the bank).
- Arrange for a contact person who lives at a different location for family members to call if separated during an emergency.
- Make arrangements for your pets (see accompanying story on page 50).

Resources

- For a state-by-state listing of links with the Department of Public Defense and Homeland Security, Emergency Management Division, visit

www.dhs.gov/dhspublic/display?theme=14&content=3283 or call **(202) 282-8000**.

- For the National Organization on Disability’s links and information about disaster information and people with disabilities, visit www.nod.org/emergency or call **(202) 293-5960**; TTY users may call (202) 293-5968.
- The Department of Homeland Security’s emergency preparedness information website may be found at www.ready.gov or by calling **(800) 237-3239 (800-BE-READY)**; TTY users may call (800) 464-6161.
- To find your local Red Cross chapter, go to www.redcross.org. For animal safety, visit www.redcross.org/services/disaster/beprepared/animalsafety.html.
- The International Committee of the Red Cross’ family links website helps to connect those separated by conflict or disaster to find information about their loved ones in order to restore contact. To reach this committee, visit www.familylinks.icrc.org/home.nsf/home/webfamilylinks or call **(877) 568-3317 (877-LOVED-1S)**.
- For information about planning for your service animal, visit www.hsus.org/hsus_field/hsus_disaster_center or call **(202) 452-1100**.

- For information regarding telecommunications for the deaf, readers may go to www.tdi-online.org, or call **(301) 589-3786** for voice service; TTY users may call (301) 589-3006.
- The American Foundation for the Blind may be found at www.afb.org or by calling **(800) 232-5463 (800-AFB-LINE)**.
- For Easter Seals' s.a.f.e.t.y. first program, please visit www.easterseals.com/site/PageServer?pagename=ntl_safety_first or call **(866) 237-2335 (866-BE-SAFE-5)**.
- For the ADA Guide for Local Governments' document titled, *Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities*, readers may visit www.usdoj.gov/crt/ada/emergencyprep.htm or call **(800) 514-0301**; TTY users may call (800) 514-0383.
- FEMA may be reached by visiting www.fema.gov. To apply for assistance during a crisis, call **(800) 621-3362** (FEMA); TTY users may call (800) 462-7585.
- The website for EAD & Associates, LLC may be found by visiting www.eadassociates.com or by calling **(718) 330-0034** (both voice and TTY).

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)

Davis adds, "We are in the best position to know our own abilities and limitations. This is why we must take responsibility and plan. But this also means planning with a strong support network both in and out of our region. Review the plan regularly, including any time it has to be activated and if any condition changes. With practice, we increase our ability to survive exponentially. And a plan is only as good as the last time it was practiced." ♦

Elizabeth Thompson is a freelance writer and a volunteer staff member on msworld.org. She was diagnosed with MS in December 1987 after being symptomatic since 1970. A resident of Monroe, Washington, she can be reached at writeop@msworld.org.

Continued from page 37

MS and can provide support to the affected family member. Stress management techniques such as bio-feedback, visualization, and self hypnosis, are other viable options.

“The big hurdle for many people is to get over the stigma associated with counseling. Individuals need to know that they are not ‘crazy.’ Depression is an illness that needs to be treated. Counseling helps individuals learn how to cope and adjust to one’s changing situation. We all experience “dips” from time-to-time and we need to smooth these out.

“Regardless of which medications and forms of therapy best suit an individual diagnosed with depression, the important

thing is to get help. Depression greatly affects an individual’s quality of life; it can cause additional symptoms, and can even direct a few individuals toward thoughts of suicide. Depression is a serious disorder, and no one should go without treatment.”

For more information or to obtain a copy of the original article on depression, readers may call MSAA’s Helpline at **(800) 532-7667** or log onto MSAA’s website at **www.msaa.com**, click on “publications,” select *The Motivator*, and scroll down to the Winter 2003 issue of *The Motivator*. Included in the article are various strategies on how to feel happier. ♦

— Susan Wells Courtney

¿Habla Usted Español? [Do You Speak Spanish?]

Helping Spanish-speaking MS clients find access to health care, information, and community resources are just a few examples of the support offered through the MSAA bilingual Helpline. Helpline Consultant Richard Palacio reports that calls from Spanish-speaking MS clients and a growing network of social workers are steadily increasing as awareness of service expands throughout the United States and Puerto Rico. MSAA is offering this service in an effort to assist individuals in the Spanish-speaking community receive information, referrals, and reassurance in the fight against this disease.

Individuals requiring assistance may contact MSAA’s Helpline at (800) 532-7667,

extension 108. This Helpline service is another way MSAA strives to enhance the quality of life for individuals with multiple sclerosis.

Call the Helpline for:

- MS Information
- Disability/Insurance Issues
- Reassurance and Support
- Connect to Other MS Resources

La comunidad hispano-hablante puede contactar la línea de ayuda (Helpline) de la MSAA marcando el (800) 532-7667, extensión 108.

This service has been made possible through the support of the Medtronic Foundation.

**EMERGENCY
PREPAREDNESS:**

Don't Forget The Pets!



Our pets are part of the family. The best way to protect your family from the effects of a disaster is to have a plan. Service animals assisting people with disabilities are the only animals allowed in Red Cross shelters.

The Humane Society of the United States, in cooperation with the American Red Cross, has the following suggestions for the safety of your pets:

- Do not leave pets behind.
- Call in advance to confirm emergency shelter arrangements for you and your pets.
- Be sure your pet's "disaster supplies" (listed later) are ready.
- Bring all pets into the house in case you must leave in a hurry.
- Make sure all pets are wearing identification. Attach the phone number and address of your temporary shelter, or of a friend or relative outside the disaster area. You can buy temporary tags or put adhesive tape on the back of your pet's ID tag, adding information with an indelible pen.

- Have carriers for each pet, even "pocket animals," birds, etc.
- Prepare a list of boarding facilities and veterinarians who shelter animals in an emergency; include 24-hour phone numbers.
- Ask friends, relatives, or others outside of the affected area if they could shelter your animals. Try to house them together but be prepared to separate them.
- Ask local animal shelters if they provide emergency shelter or foster care for pets in a disaster.

No matter how long the disaster will last, you'll need supplies. Keep items in an accessible place, stored in sturdy containers that can be carried easily (duffle bags, covered trash containers, etc.). Your pet's "disaster supplies kit" should include:

- Medications and records (stored in a waterproof container) and a first-aid kit.
- Sturdy leashes, harnesses, and/or carriers to transport pets safely and ensure

that your animals can't escape.

- Food, potable (drinkable) water, bowls, cat litter/pan, and can opener; keep names and records all in one place with the pet.
- Current photos of your pets in case they get lost.
- Information on feeding schedules, medical conditions, behavioral problems, and the name and number of your veterinarian in case you have to foster or board your pets.
- Pet beds and toys, if easily transportable.



For more information about pets, readers may contact The Humane Society of the United States by visiting www.hsus.org or calling (800) 486-2631 (800-HUMANE-1).

Readers may also contact The American Veterinary Medical Association at www.avma.org/disaster or call (847) 925-8070 ♦



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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:

- Tuesday, November 29th, Educational Workshop on “Intimacy & Relationships,” Promises to Keep Restaurant, Derry, New Hampshire, 6:00 pm to 9:00 pm; speaker Christine St. Laurent, RN, Sturdy Memorial Hospital MS Center
- November 2005, Educational Workshop “Ask the Doctor,” sponsored by Serono, Toms River, New Jersey (date and time to be determined); please visit www.msaa.com for further details
- Wednesday, December 14th, Holiday Luncheon, Hilton at Cherry Hill, Cherry Hill, New Jersey; please visit www.msaa.com for further details

Newly Formed Support Groups:

- Columbia Falls, Maine; contact Dale Smith at (207) 483-4646
- Olean, New York; contact Debbie Heysham at (716) 373-6752

- Westminster, Maryland; contact Dawn White at (410) 756-1033

Support Groups Coming Soon:

- Antes Fort, Pennsylvania
- Brookline, New Hampshire
- Levittown, Pennsylvania
- Syracuse, New York
- Tamaqua, Pennsylvania

New Therapeutic Group

- Tai Chi Class, Dunmore, Pennsylvania
Thursdays, 11:30 am to 12:30 pm
Classes began Thursday, September 8th

MSAA Northeast Regional Office:

Helene Hoffman,
Client Services Coordinator
706 Haddonfield Road
Cherry Hill, New Jersey 08002
(856) 488-4500, ext. 149
(800) 532-7667, ext. 149
Email: hhoffman@msaa.com

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:

- January, “Children & Family Issues in MS Interactive Workshop,” Tampa,

Florida, (date and time to be determined); please visit www.msaa.com for further details

- November through January, “Sweeten the Season” fundraiser; to participate, please call the Southeast Regional Office or visit www.msaa.com for more details

Newly Formed Support Groups:

- Central Palm Beach, Florida; contact Walt Larson at (561) 686-8018
- Decatur, Georgia; contact Kim Schofield at (404) 381-6731
- Greenville, South Carolina; contact Octavius Arnold at (864) 220-2592
- Salem, Virginia; contact Danny Huff at (540) 798-4109

Support Groups Coming Soon:

- Brandon, Florida
- Charlotte, North Carolina
- Mobile, Alabama
- Montgomery, Alabama

Please note: MSAA’s Southeast Regional Office would like to welcome Brenda Preston to its staff as a client services coordinator. Brenda will be working out of the Southeast Regional Office and can be reached at (800) 532-7667, ext. 154 or via email at bpreston@msaa.com.

MSAA Southeast Regional Office:

Linda Chaney, Director
PO Box 66565
St. Petersburg, Florida 33736
(800) 532-7667, ext. 154
Email: southeast@msaa.com

Midwest Region

Upcoming Events:

- Contact the MSAA Midwest Regional Office or visit www.msaa.com for information on upcoming public education programs in your area.
- Readers may call their nearest MSAA support group or contact the regional office for information about upcoming “Holiday Socials”

Newly Formed Support Groups:

- Belpre, Kentucky; contact Susan Courtney at (304) 235-8674

MSAA Midwest Regional Office:

Renée Williams, Director
13938A Cedar Road, #243
University Heights, Ohio 44118
(216) 320-1838
(800) 532-7667, ext. 140
Email: midwest@msaa.com

South-Central Region

Upcoming Events:

- November and December, “MS: Behind the Scenes,” Richard G. Pellegrino, MD, PhD; Dallas, Houston, and San Antonio, Texas; Baton Rouge, Louisiana; Kansas City and St. Louis, Missouri; Tulsa and Oklahoma City, Oklahoma; and Denver, Colorado; (dates and times to be determined); please visit www.msaa.com for further details
- Saturday, December 3rd, “Mind, Body, Spirit: A Woman’s Journey through MS,” Dallas, Texas, (location and time to be determined); please visit www.msaa.com for further details

Newly Formed Support Groups:

- El Dorado, Arkansas; contact Eve Bradford, BS, MPA, at (312) 296-3916 or (870) 862-7093

Support Groups Coming Soon:

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

MSAA South-Central Regional Office:
(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:

- Saturday, December 3rd, “Holiday Luncheon,” Grant Creek Inn, Missoula, Montana, 11:00 am to 2:00 pm
- Friday, December 16th, “Volunteer Holiday Party,” MSAA Northwest Regional Office, Great Falls, Montana, 1:00 pm to 4:00 pm
- Sunday, January 15th through Friday, January 20th, “TransMontana Snowmobile Charity Ride;” starts at the Canadian border near Eureka, Montana and ends at Reynolds Pass on the Idaho-Montana border near West Yellowstone,

Montana

- Saturday, February 4th through Tuesday, February 7th, “Wyoming/Yellowstone Snowmobile Charity Ride;” starts in Alpine, Wyoming and ends in West Yellowstone, Montana

Newly Formed Support Group

- Bozeman, Montana; contact Linda Crowley at (406) 856-3416

Support Groups Coming Soon:

- Hettinger, North Dakota
- Jamestown, 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
Email: northwest@msaa.com

Western Region

Support Groups Coming Soon:

The Western Regional Office is starting support groups 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 one elsewhere may contact the Western Regional Office.

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

MRI Program Expanded

The MSAA MRI Institute has expanded its coverage to include C-Spine scans in addition to scans of the cranium. For more information, please contact MSAA at **(800) 532-7667, ext. 120**; you may also send an email to mriinstitute@msaa.com.

Travel Scholarship

In our last issue of *The Motivator* (Summer 2005), we included an article on travel. On p.34 was a sidebar about the late Kate Christie Zee, MD, PhD, who wrote a book about her travels and created a scholarship fund from the sales of her books to provide travel opportunities for individuals with disabilities. Unfortunately, what proceeds were available have already been used to help individuals with disabilities pay for a small portion of their trip.

Accessible Journeys specializes in accessible travel and oversees the scholarship and book sales. Anyone interested in purchasing a book or getting more information about accessible travel may go to www.disabilitytravel.com/windmills.htm or they may call **(800) 846-4537**.

Please do not contact Accessible Journeys for free travel. The scholarship has no funds available at this time.

Attention: Federal Employees

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- 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

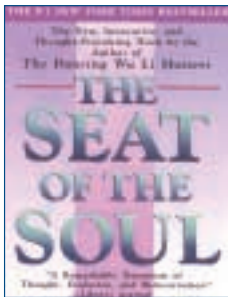
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When completing your CFC form, please remember **#9509** for MSAA



Multiple Sclerosis Association of America
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1-800-532-7667 www.msaa.com

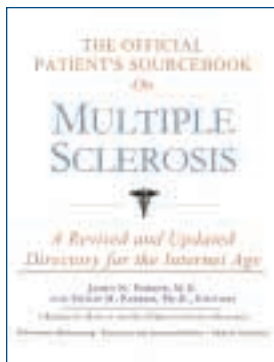
Spread the Word



The Seat of the Soul
Written by Gary Zukav
Published by
Simon & Schuster
MSAA Book #166

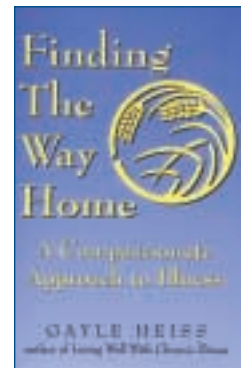
Author Gary Zukav is a graduate of Harvard University and previously won an American Book Award for his written work in science. In this more recent book, Zukav explores the human spirit, providing thought-provoking concepts on topics such as creation and evolution, responsibility and relationships, as well as psychology and inner power. (Please note that this book may contain religious or spiritual ideas that may not be shared by everyone; while MSAA offers this book to anyone interested, MSAA has no involvement with the material presented.)

The Official Patient's Sourcebook on Multiple Sclerosis
Edited by J.N. Parker, MD
and P.M. Parker, PhD
Published by ICON Group
International, Inc.
MSAA Book #226



Published in 2002, this massive reference provides information and additional resources on many topics relating to MS. These topics range from general information on MS and finding a doctor, to drug research, alternative medicine, and nutrition.

Finding the Way Home
Written by Gayle Heiss
Published by QED Press
MSAA Book #162



Living with a chronic illness since 1984, author Gayle Heiss has been facilitating weekly support groups since 1988 while working as a hospice volunteer and companion to people with AIDS. Through her experience and accounts of support groups, Heiss helps individuals living with illness find their strengths and forge their own path to a more fulfilling life.

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:

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Cherry Hill, NJ 08002
(Please reference book number)***