Resource Detectives Program in Full Swing • Strategies for Staying Cool

MSAA

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The MOTIVATOR

Bringing Information to People with Multiple Sclerosis

MS RESEARCH UPDATE

The MSAA Motivator

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

Cover Story

By Susan Wells Courtney

Research findings from two large medical conferences are summarized, highlighting 20 approved and experimental drugs for MS.

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Featured MSAA Program

By Peter Damiri

MSAA program recruits volunteer "detectives" to help create a national database.

Departments

By Douglas G. Franklin

MSAA President and CEO Doug Franklin talks about MSAA's Resource Detectives Program, the MS Coalition, and medical conferences. This issue's Board Sidebar (written by Amanda Bednar) features Board member Bob Reichenbach.

By Jack Burks, MD

MSAA's chief medical officer answers questions sent in by readers.

By Amanda Bednar

Among other news, MSAA launches its MSi informational video program series.

The Multiple Sclerosis Association of America's mission is to enrich the quality of life for everyone affected by multiple sclerosis.

By Bruce Makous

MSAA's new Vice President for Development Bruce Makous gives his greetings; President's Circle is launched; and readers establish an MSAA gift annuity.

By Shelley Peterman-Schwarz

A first-hand description of heat sensitivity is given, along with strategies for staying cool.

By Christine Norris

An introduction to MS terminology, symptoms, and trials is provided.

By Judy Heath

A reader of *The Motivator* talks about her hot-air balloon adventure.

Three informative books from MSAA's Lending Library are outlined.

MSAA Multiple Sclerosis Association of America

America's Charities

Health Information

2007 APEX Awards for Publication Excellence

Up Front

By Douglas G. Franklin
MSAA President and CEO

Douglas G. Franklin

Through a generous donation from Novartis Pharmaceuticals Corporation, MSAA now has the seed money needed to launch its Resource Detectives Program in full swing. This program was developed more than two years ago from a wonderful concept, which gives people the opportunity to help others while performing volunteer work from their own home on their own schedule.

The Resource Detectives Program will be recruiting volunteers, particularly individuals with MS, to serve as "detectives," who will play a vital role in educating members of the MS community and creating a massive database. This national resource will ultimately provide an inventory of local MS centers, professionals, agencies, and additional support systems to be accessed by individuals with MS, family members, and care partners.

Independence is just one of the many benefits which the Resource Detectives Program will provide. Members of the MS community will be able to access local resources on their own, without going through a lengthy search process which may or may not yield the best services for their needs. Through this initiative, MSAA continues its efforts to reach more people in more places across the nation. For more information, please refer to the article on Resource Detectives, which begins on page 30.

In other news, the MS Coalition is moving forward with great momentum. For those not familiar with this group, the MS Coalition is an affiliation of several independent MS organizations dedicated to the enhancement of the quality of life of all those affected by MS. Its mission is to increase opportunities for cooperation, and provide greater opportunity to leverage the effective use of resources for the benefit of the MS community.

The MS Coalition is presently seeking 501(c)3 status, which will register the group as a formal charity. Recently, members of the Coalition worked together to establish an MS Caucus in Washington, DC, to advocate for the MS community and to support such vital issues as funding for MS research and legislation to benefit individuals with disabilities.

MSAA also participated as an exhibitor this spring at the American Academy of Neurology's Annual Meeting and the Consortium of Multiple Sclerosis Centers' Annual Meeting. These are always ideal forums in which to meet with other organizations, pharmaceutical companies, and equipment suppliers, to share information and discuss new ideas. Several MSAA staff members attended lectures and workshops to learn about the latest in MS research, treatments, and patient care. For more information, please see our cover story on page 7.

MSAA is expanding its operations across the country and this summer we are as busy as ever. We welcome your input to our efforts and seek your ideas and support. Together we can all make good things happen! u

Doug Franklin joined MSAA as President & CEO in 1999. He has a distinguished career in association leadership and is a former national trainer in strategic planning for the Peter Drucker Foundation. A published international expert in the field of social marketing, he is a graduate of four universities. He currently serves on the National Board of the Key Philanthropic Organizations Committee of the American Society of Association Executives and serves on the Executive Committee of Health First – America's Charities Board in Washington, DC.

Meet MSAA Board Member Robert Reichenbach

Bob Reichenbach initially became involved with MSAA in 2003, when he and his wife, Diane, participated in their first TransMontana snowmobile ride. TransMontana is a charity snowmobile ride organized every January by MSAA Northwest Regional Director Sue Pencoske. The ride takes place in Montana across 500 miles – starting at the Canadian border near Eureka, and continuing down to West Yellowstone.

While taking part in these TransMontana snowmobile rides, Bob came to understand the valuable work that MSAA performs in the multiple sclerosis community. Bob explains, "During these fundraising rides, I met numerous people involved with MSAA, one of whom was MSAA President and CEO Doug Franklin. While on my first ride, Doug took the time to help me fine-tune my snowmobiling skills."

Bob continues, "We had many conversations over the years while taking breaks from riding the mountain trails. Doug would often talk about his work and his goals at MSAA, as well as the mission of the organization; he really painted a true picture of how MSAA helps improve the quality of life for people affected by MS."

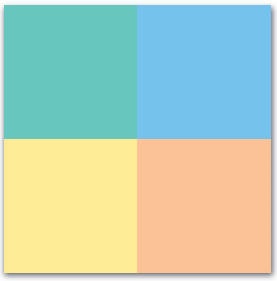
Bob also spent time with Sue (ride organizer and regional director) as well as former MSAA Board Chairman and present member, Joe King. He felt a strong connection to MSAA and the value that it has as an organization.

As a relatively new member of MSAA's Board of Directors, Bob hopes he can help MSAA to further develop and implement its programs. He notes, "One of my goals as a Board member is to assist with MSAA's financial growth. The MS community has a strong need for the services MSAA provides, and I hope to play a role in continuing this vital mission."

Professionally, Bob holds the position of compliance manager with the Bank of New York/Mellon Corporation. With his financial services background, Bob will be serving on the Audit Committee, where he will be involved in MSAA's budget and financial accountability.

Bob resides in North Huntingdon, Pennsylvania with his wife Diane. As one might guess from his active participation in the TransMontana rides, when not at work, Bob enjoys the great outdoors.

— Amanda Bednar



MS Research Update

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

Several medical organizations from around the world hold extensive annual meetings to update medical professionals on the latest information available on disease research and treatments. During the spring of each year, the American Academy of Neurology (AAN) and the Consortium of Multiple Sclerosis Centers (CMSC) are among those organizations holding international meetings dedicated to neurological conditions and multiple sclerosis (MS).

Staff members from MSAA attend these meetings to provide information to members of the medical field, so they may inform their patients of MSAA's vital programs and services. MSAA's staff also attends educational sessions to learn about new treatment approaches and ways to further help members of the MS community.

Through a large survey conducted by MSAA, individuals with MS have expressed a strong desire for the latest news in MS research. In response to this need, MSAA strives to offer this information through its website and publications, particularly in articles such as this one appearing in *The Motivator.*

Numerous trials are currently being conducted to determine the safety and effectiveness of medications for the treatment of MS. Trials not only include experimental drugs and therapies, but also FDA-approved disease-modifying therapies (DMT) for MS, where various drug and dose combinations are studied, and long-term efficacy as well as safety are continually re-evaluated.

On the pages to follow is a listing of the six FDA-approved drugs as well as a number of experimental drugs currently being studied in the treatment of MS. Below each listed medication are several highlights about the drug and related research. This is not a complete list and space does not allow for all studies and their results to be included. Please note that in many instances, initial study results should be considered as preliminary. Additional studies and/or evaluations are needed before these findings may be confirmed.

Many readers of *The Motivator* are well-versed in MS terminology and disease pathology, but anyone wishing to review the basics, or learn about them for the first time, may choose to first read the Health and Wellness column in this issue. Beginning on page 48, this column gives an overview of MS, evaluative procedures, how clinical trials are conducted, and treatments. This information may be helpful in better understanding the research information to follow.

FDA-Approved Medications for the Treatment of MS

Avonex® (interferon beta 1-a)

Parent company: Biogen Idec

Taken via weekly intermuscular injections

Approved for relapsing forms of MS and for individuals with clinically isolated syndrome (CIS), which is the initial symptom a patient reports prior to a diagnosis of MS

May affect the immune system by decreasing damaging cells and increasing cells that suppress inflammation

The ACT trial evaluates Avonex in combination with (1) methotrexate (MTX), (2) intravenous methylprednisolone (IVMP), or (3) both MTX and IVMP; data showed favorable trends in multiple clinical and MRI outcomes; adding MTX and IVMP may be helpful in patients on Avonex with continuing active disease; reported to be safe and well-tolerated

Five-year data for initial treatment with Avonex after CIS show continued positive effects on patients receiving Avonex from beginning versus placebo

Ongoing, Phase III trial for relapsing-remitting MS (RRMS) combines Avonex with Copaxone (COMBI Rx trial), using three arms: Avonex alone, Copaxone alone, and combination of both

Betaseron® (interferon beta 1-b)

Parent company: Bayer HealthCare Pharmaceuticals

Administered via subcutaneous injection every other day

Approved for relapsing forms of MS and individuals with CIS

May affect the immune system by decreasing damaging cells and increasing cells that suppress inflammation

The BENEFIT TRIAL evaluated the impact of Betaseron on patients with CIS; over the three-year period, risk for confirmed progression of permanent disability was reduced by 40 percent, while patients were 41 percent less likely to progress to clinically definite MS

BECOME study, using new MRI techniques, compared Betaseron versus Copaxone in RRMS; enhancing lesions were similar, while black hole data favored Betaseron.

BEYOND study in progress evaluates regular-dose versus double-dose Betaseron, as well as versus Copaxone

Follow-up data after 17 years from Betaseron's pivotal placebo-controlled trial show continued effectiveness and safety

Rebif® (interferon beta 1-a)

Parent companies: EMD Serono, Inc. and Pfizer Inc

Administered through subcutaneous injections three times weekly

Approved for relapsing types of MS

May affect the immune system by decreasing damaging cells and increasing cells that suppress inflammation

One-year data from an ongoing two-year study show that the new formulation of Rebif is better tolerated than the original formulation; compared to an earlier trial (EVIDENCE study), percentage of those positive for neutralizing antibodies (NAbs) at 48 weeks was reduced; also, injection-site reactions were reduced by nearly two-thirds

Studied in combination with atorvastatin (Lipitor®); study found combination resulted in an increase in MRI and clinical disease activity; statins now believed to block the therapeutic effects of interferons, statins not recommended when taking an interferon

Studies being conducted with Rebif's effect on CIS

Data being analyzed for study comparing Rebif to Copaxone

Copaxone® (glatiramer acetate)

Parent company: Teva Neuroscience, Inc.

Given through daily subcutaneous injections

Approved for RRMS

Has anti-inflammatory properties and may have a neuroprotective effect

Study with primary-progressive multiple sclerosis (PPMS) was stopped due to lack of effectiveness; in a subsequent analysis, may be effective for men, but more studies needed

A pilot study with double-dose Copaxone looks encouraging, with a reduction in relapses and lesions as seen on magnetic resonance imaging (MRI)

Study being conducted with a double-dose of Copaxone (FORTE study)

An ongoing trial combines Copaxone with Avonex (COMBI Rx trial)

Another study looks at Copaxone combined with minocycline (an inexpensive, oral antibiotic); the combination reflected consistent pattern of benefit in reduction of new and active lesions; also reported to be safe and well tolerated

Being tested in the treatment of CIS (PreCISe study)

FDA-Approved Medications for the Treatment of MS

Novantrone® (mitoxantrone)

Parent company: EMD Serono, Inc.

Given via intravenous injection once every three months for a maximum of two-to-three years

The doses are limited to avoid the risk of cardiotoxicity (heart damage); risk of developing leukemia is also increased with long-term use, and women may have menstrual irregularities

Novantrone is an immunosuppressant and destroys all rapidly dividing cells, including those in the immune system

Also used to treat cancer

Has been approved for individuals with secondary-progressive MS (SPMS), progressive-relapsing MS (PRMS), and worsening RRMS; not indicated for PPMS

Used by some physicians to treat patients whose disease is rapidly worsening, or who are not responding favorably to the first line of treatment (Avonex, Betaseron, Copaxone, or Rebif)

Previous studies have shown a significant reduction in active lesions and a reduction in disease progression

Tysabri® (natalizumab)

Parent companies: Biogen Idec and Elan Pharmaceuticals, Inc.

Administered via intravenous infusions every four weeks

Humanized monoclonal antibody approved for relapsing forms of MS

Blocks activated immune-system cells from crossing blood-brain barrier (BBB) into central nervous system (CNS)

FDA granted approval based on 66-percent reduction in relapses compared to placebo (AFFIRM trial) and 54-percent reduction in relapses for those taking Tysabri plus Avonex, versus Avonex plus placebo (in Avonex-treated patients with continued disease activity)

Temporarily suspended when two patients taking both Tysabri and Avonex developed Progressive Multifocal Leukoencephalopathy (PML), an often-fatal viral disease occurring in immuno-suppressed patients

Since its re-release, 10 months into safety studies (TOUCH program in United States), no new cases of PML found; participants continue to be monitored

Three-year data show continued effectiveness (reduction in relapses, favorable MRI data, and a reduction in progression of disability)

Experimental Oral Medications for the Treatment of MS

Oral Cladribine

Parent company: EMD Serono, Inc.

Given via oral intermittent administration in treatment cycles

Treatment cycles are four-to-five doses on consecutive days, ranging from once every 28 days to twice yearly, depending on the study regimen

Interferes with the behavior and proliferation of immune-system cells

Designated as a Fast Track product (for relapsing forms of MS) by the FDA for potentially quicker approval; Fast Track programs help to expedite the development of new drugs aimed at treating serious conditions

Enrollment complete for two-year, Phase III, multi-center CLARITY study in progress; will assess the safety and efficacy of oral cladribine (using two dose levels) versus a placebo in RRMS

ONWARD Phase IIb study combines oral cladribine with the new formulation of Rebif; study in progress

Fingolimod (FTY720)

Parent company: Novartis Pharmaceuticals Corporation

Oral medication taken daily

Studied in trials for RRMS

Traps T-cells in lymph nodes, lowering number in blood; reduces permeability of the BBB; may reduce damage to nerves and enhance nerve repair

Reduces the number of active immune-system cells in the brain and other organs; will need to monitor patients to watch for adverse events

Phase II study showed up to 77 percent of patients remained relapse-free for more than two years; low rate of disease activity as observed on MRI

RRMS patients being recruited for FREEDOMS large-scale Phase III study of Fingolimod versus placebo

Ongoing trial compares Fingolimod to Avonex in RRMS

Experimental Oral Medications for the Treatment of MS

BG00012 (fumarate; fumaric acid esther)

Parent company: Biogen Idec

Oral drug taken once daily

In trials for treating psoriasis

This drug works as an Immunomodulator, with anti-inflammatory properties; may potentially have neuroprotective effects

Studied in RRMS

Phase 2b safety-extension study used three dose levels; highest dose resulted in a 69-percent reduction in the formation of new gadolinium-enhanced lesions compared to placebo; a 32-percent reduction in relapse rate was observed; over the 48-week period, BG00012 was reported to be safe and tolerable

Two-year, Phase 3 study to assess efficacy (relapse rate, progression of disability, and formation of active lesions) and safety in RRMS patients; will include two dose levels and compare to placebo and Copaxone; Recruitment of 2000 patients began in early 2007

Laquinimod

Parent companies: Teva Neuroscience, Inc. and Active Biotech

Oral medication taken daily

Studied in relapsing types of MS

This drug works as an immunomodulator, altering certain processes of the immune system

Results from a Phase II trial for individuals with RRMS significantly reduced disease activity by 40 percent (as measured by MRI)

Compared to the placebo-treated group, the study showed trends toward: reducing annual relapse rates; more patients were relapse-free during the trial period; time to first relapse was delayed; and the drug was well tolerated

Initiation of two global Phase III trials for individuals with relapsing MS was announced in June 2007; trials to be conducted in the United States, Europe, and other locations

Teriflunomide

Parent company: Sanofi-aventis

Oral tablet taken daily

Works as an immunomodulator, affecting T-cell synthesis

Related to a type of drug used to treat rheumatoid arthritis

Phase II trial, with both RRMS patients and SPMS patients with relapses, evaluated two dose levels versus placebo

Trial results included significantly fewer enhancing lesions in the treated groups and a lower relapse rate; high-dose group had fewer patients experience an increase in disability (versus the placebo group) and a trend toward more relapse-free patients; treatment was well tolerated

Two, Phase II studies are in progress; one adds Teriflunomide to the treatment regimen of patients taking interferon; the other study adds Teriflunomide to the treatment regimen of patients taking Copaxone

Phase III study is in progress

Estriol

Drug already available in marketplace

Oral pill given daily

Studied in patients with RRMS

Estrogen-like hormone that may have both neuroprotective and anti-inflammatory properties

Studies are based on the fact that individuals with autoimmune disease often experience reduced disease activity during pregnancy; estrogen is thought to suppress the immune system during pregnancy so the fetus is not identified as a foreign body, thereby avoiding an attack from the immune system

Small pilot study with 10 non-pregnant women showed an 80-percent reduction in enhancing lesions; also showed cognitive improvements

Seven universities in the United States are conducting a larger trial, enrolling 150 participants to receive daily Copaxone injections along with a daily estriol pill or a placebo

Experimental Oral Medications for the Treatment of MS

Statins

Atorvastatin (Lipitor®) and simvastatin (Vytorin®, Zorcor®) are among the statins presently being studied as potential treatments for RRMS

Statins are oral medications prescribed to lower cholesterol

Exhibit immunomodulatory effects, with anti-inflammatory properties

Successful in animal studies with MS-like disorder

Open-label clinical trial with simvastatin showed decrease in new MRI lesions

Small trial combining atorvastatin with Rebif in MS patients (whose disease was stable) found that while the combination was well-tolerated, MRI and clinical disease activity increased; this study with Rebif indicates that statins block the positive effects of interferons and is not recommended

Results expected soon from a large study with atorvastatin in patients with CIS

A study is planned for simvastatin to be added on to treatment with Copaxone for individuals with RRMS; also study with simvastatin versus placebo with acute optic neuritis

Experimental Monoclonal Antibody Medications for the Treatment of MS

Campath® (alentuzumab)

Parent companies: Genzyme Corporation and Bayer HealthCare Pharmaceuticals

Administered via once-yearly cycles of intravenous infusions (other dosing and methods of administration have been used)

Used to treat Leukemia; also studied in the treatment of rheumatoid arthritis

Targets certain T-cells, B-cells, and macrophages; results in a depletion of T-cells

CAMMS223 Phase 2 study compared Campath to high-dose Rebif in an open-label study with RRMS patients

Interim analysis from CAMMS223 showed a 75-percent reduction in risk of relapse and a 65-percent reduction in progression to significant disability in those treated with Campath

Dosing was suspended in September 2005 when a few patients developed a serious bleeding condition from decreased platelets in the blood, resulting in one fatality

Patients need to be monitored closely due to risk of significant toxicities

Apparently more effective when given in RRMS versus SPMS

Experimental Monoclonal Antibody Medications for the Treatment of MS

Rituxan® (rituximab)

Parent companies: Genentech and Biogen Idec

Administered via intravenous infusions

Targets certain B-cells that produce antibodies, resulting in less antibody-mediated damage

Used to treat lymphoma, rheumatoid arthritis, and lupus

Preliminary results are positive in RRMS studies; also positive results in neuromyelitis optica (NMO), a condition similar to MS, causing inflammation of the optic nerve and spinal cord

Phase I open-label, multi-center RRMS study shows that after two treatment courses and 48 weeks, frequency of lesions and relapses was reduced; safe and well-tolerated during study

Recently completed phase II trial with RRMS; showed significant reduction in total number of enhancing lesions versus placebo group; also, more patients remained relapse-free in treated group

Phase II/III trials in progress for PPMS

Serious adverse events have been reported in Rituxan-treated patients with other diseases including PML; patients must be closely monitored

Zenapax® (daclizumab)

Parent companies: Biogen Idec, Inc and PDL BioPharma

Administered via intravenous infusions every four weeks; also studied in subcutaneous injections

Used to prevent rejection with organ transplants

Works by targeting receptors on activated T-cells, limiting T-cell expansion, and reducing inflammation

Two small, open-label studies showed positive results

Another study was conducted with RRMS and SPMS patients who continued to experience worsening disease activity despite conventional MS drug therapies; study showed drug was well tolerated; reported to improve or stabilize 60 percent of patients; reduced number of active lesions in both RRMS and SPMS patients

Ongoing CHOICE Phase II trial adds Zenapax (given subcutaneously biweekly) to interferon treatment in 30 patients with active MS; interim data show that the treated group experienced a significant reduction in new or enlarged enhancing lesions

SELECT trial will study Zenapax versus placebo in patients with RRMS

Other Therapies Being Studied for the Treatment of MS

MBP8298

Parent company: BioMS

Administered intravenously every six months

Proposes to make the immune system tolerant to Myelin Basic Protein (target of MS attack), by giving large doses of this synthetic peptide (protein) drug

Phase II trials showed that versus placebo, MBP8298 safely delayed median time to disease progression by five years in progressive (SPMS) patients

MAESTRO-01 is an ongoing study with 611 SPMS patients in Canada and Europe; one-year interim safety analysis recommended to continue study as planned

MINDSET-01 is a phase II trial with RRMS patients in Europe; now fully enrolled with 215 patients

MAESTRO-03 is a phase III trial (with SPMS patients) in the United States, which began enrolling its 510 patients in June 2007

Appears to be more effective in patients with certain genetic types, which includes approximately 75 percent of the MS populations

NeuroVax™

Parent company: Orchestra Therapeutics

T-cell vaccine given by intra-muscular injections

Comprised of three T-cell receptor (TCR) peptides, NeuroVax stimulates T-cells that can suppress a specific T-cell believed to be involved in MS and the attack on myelin

Effective in animal studies with an MS-like disorder

Found to induce strong disease-specific immune response in more than 90-percent of MS patients who received the treatment

According to Orchestra Therapeutics, "Strong immune responses to the peptides are important, since previous clinical data indicate a correlation between the strength of T-cell response to TCR therapy and clinical benefit after one year of TCR therapy."

Currently in Phase II clinical development for a 200-patient, placebo-controlled study

Tovaxin™

Parent company: Opexa Therapeutics

T-cell vaccine given via subcutaneous injections every four weeks

Works similarly to a vaccine for a virus or bacteria; myelin-attacking cells are removed from a small amount of the patient's blood; these cells are inactivated and then injected back into the patient; the immune system is stimulated to potentially recognize and eliminate the inactivated cells and the same attacking cells not removed from the blood

TERMS is a placebo-controlled study being conducted at 40 sites in the United States with CIS and RRMS patients

Recruitment of 150 patients for this phase IIb study expected to be complete by mid-year (2007)

TERMS is one of three ongoing studies using the current vaccine

Patients completing the one-year trial may participate in an open-label, one-year extension study where all patients would receive Tovaxin

Fampridine SR® (long-acting fampridine, 4-aminopyridine)

Parent company: Acorda Therapeutics

Sustained-release tablet of investigational drug fampridine, given orally twice daily

Improves communication between damaged nerves and may result in increased neurological function

Studied for MS symptom management (including walking speed and strength)

A 14-week, Phase III, multi-center trial in patients with MS found that nearly 35 percent of the treated group showed consistent improvement in walking speed, versus just over eight percent of the placebo group; treated group also experienced an increase in strength

Adverse events attributed to fampridine were similar to those in previous studies, including an increased risk of seizures; this risk appears to be dose related, and the sustained-release formula is designed to reduce the risk of seizures

A second phase III study, MS-F204, has begun; 200 patients are anticipated to be enrolled at 35 MS centers in the United States and Canada

Additional Studies

The preceding overview of approved and experimental drugs for MS is only a fraction of the many treatments presently being studied. Some of the other disease-modifying investigational drugs and therapies include familiar ones, such as azathioprine (Imuran®), corticosteroids, cyclophosphamide (Cytoxan®), immunoglobulin; methotrexate, methylprednisolone, plasma exchange, and stem cell therapy, along with lesser-known ones, such as A4I, CDP323, minocycline, mycophenolate mofetil (CellCept®), pioglitazone (Actos®), SB-683699, and Topamax® (topiramate).

Some drugs, such as lamotrigine and riluzole, are specifically in trials for neuroprotection (to keep nerve fibers and the myelin intact). The latter drug, riluzole, is also in a trial to study its effectiveness in patients with chronic cerebellar ataxia.

The preceding overview also listed one drug for symptom management, Famprindine SR (for walking and strength). Once again, several other drugs and therapies are being investigated. For example, Avanir Pharmaceuticals' Zenvia™ (formerly Neurodex), is a drug in development for involuntary emotional expression disorder (IEED) in patients with MS. IEED is characterized by sudden and unpredictable episodes of crying, laughing, or other displays of emotion. In response to safety concerns raised by the FDA, Avanir Pharmaceuticals is planning a confirmatory Phase III study with a new, lower-dose formulation of Zenvia.

Several trials are either planned or in progress for the treatment of other MS symptoms as well. Ritalin, memantine, donepezil (Aricept®), and Provigil® (modafinil) are all being investigated for their effects on cognitive function. In addition to evaluating the effect of sleep on fatigue, treatment trials for fatigue include: 3,4-diaminopyridine, aspirin, Provigil, sublingual tizanidine tablets, and Tysabri (in a study named "ENER-G"). Studies planned or in progress for spasticity include cannibis-based medicine extract (Sativex), IPX056, and sublingual tizanidine tablets.

Neuropathic pain, which is a common and debilitating issue in MS, has a number of potential drug treatments. Studies are in progress or planned for: lidocaine, extended-release oxycodone, Cesamet® (nabilone) alone or with gabapentin; pregabalin, paroxetine, duloxetine, Sativex, and levetiracetam. The latter drug, levetiracetam, is also under investigation for tremor in MS. Trials for the treatment of optic neuritis include simvastatin, as well as erythropoietin in conjunction with methylprednisolone. Botulinum Toxin Type A is being tested for its effectiveness in treating overactive bladder.

Additionally, cranberry is being studied for the prevention of urinary tract infection (UTI). Whole Body Vibration Therapy, and training with APOS (All Phase of Step Cycle) Kit, are each under investigation to improve balance. With Depression, which is traditionally treated through medications and counseling, researchers are looking into the positive effects which may be gained from fish oil.

Occasionally, readers of *The Motivator* have contacted MSAA inquiring about treatment with low-dose Naltrexone (LDN). No scientifically acceptable data are available, however, the University of California in San Francisco is currently sponsoring a Phase III trial of LDN. This study will compare individuals treated with LDN to those receiving a placebo; treatment responses will be determined by quality of life composite scores.

As mentioned earlier, this article does not include all of the potential drugs and therapies under investigation for the treatment of MS and it symptoms, but it does include a good number of those receiving much attention at this time. Anyone interested in additional information about these clinical trials, or anyone interested in participating in a clinical trial, may visit **www.clinicaltrials.gov**. This website is a service of the United States National Institutes of Health, developed by the National Library of Medicine.

The Future of MS Research

Experts from around the world are passionate in their quest to identify the causes of MS and the changes in the body which occur as a result. Scientists look to improve the methods of observing and measuring disease behavior, using the most advanced technology available.

Researchers today are more aware of the cellular makeup of the different types of lesions. A lesion's appearance and its degree of inflammation or injury provide a window into the processes that are occurring. From this vital information, scientists and pharmaceutical companies begin the long road to drug approval, starting in a laboratory and devoting years of study before reaching an MS patient. Future research will continue to look for clues into the mysteries of MS.

Among topics of growing interest is the mounting evidence behind sunshine and vitamin D's potential role in the development of MS. Vitamin D may offer some protective properties, but more studies are needed. A viral component may play an important role as well; individuals infected with the Epstein-Barr virus (EBV) may be at an increased risk of developing MS, with a possibly greater risk for those with a history of mononucleosis (a manifestation of EBV infection). Studies also support the theory that cigarette smoking increases the risk of MS, while smoking has already been tied to a faster transition from a relapsing type of MS to a progressive type (RRMS to SPMS). Additionally, genetic factors have long been known to increase one's chances of developing the disease. More specific genetic associations (genes for interleukin 2 and 7 receptor alpha) appear to be associated with immune dysfunction in MS.

These are just a few of the many areas of study that are providing important insights into the development and behavior of MS. With six FDA-approved disease-modifying therapies already available for the treatment of MS, and many more investigational drugs and therapies in the pipeline, the MS community has much to look forward to in the coming years. u

Ask the Doctor

By Dr. Jack Burks
Chief Medical Officer for MSAA

Dr. Jack Burks

Q: Is plasmapheresis still a procedure being used in the treatment of MS? What are the risks and benefits, and where can I find out more information on this treatment?

A: Plasmapheresis, also known as "plasma exchange," is a procedure which extracts blood from the patient and sends it through a machine. This machine separates the blood cells from the plasma, and then replaces the plasma with a solution before returning the blood to the body. Plasmapheresis works by removing or diluting elements of the plasma in the blood that may contain antibodies, which can increase the damage caused by MS.

Plasmapheresis is used by some doctors in extreme cases, when a serious exacerbation does not respond to intravenous steroids. While this treatment improves the chances of recovery from that specific attack for some patients, the long-term benefits still remain uncertain. However, this temporary improvement may allow time for long-term therapy to be initiated.

The procedure is expensive and may need to be repeated. Numerous risks can occur with any such type of procedure, and your treating physician will need to discuss these risks with you. Usually people tolerate the procedure very well.

The Mayo Clinic has been a leader in the field of plasmapheresis for MS patients. According to the website for the Mayo Clinic (**www.mayoclinic.com**), "Plasma exchange may help restore neurological function in people with sudden severe attacks of MS-related disability who don't respond to high doses of steroid treatment… Replacing your plasma may dilute the activity of the destructive factors in your immune system, including antibodies that attack myelin, and help you to recover. Plasma exchange has no proven benefit beyond three months from the onset of the neurological symptoms."

I recommend that you first talk with your treating physician about the procedure and inquire about the feasibility of visiting an MS-specialty clinic. These clinics may be involved in MS clinical trials for you to consider.

A list of clinics is available through the Consortium of Multiple Sclerosis Centers' (CMSC) website at **www.mscare.org**. If you don't have internet access, MSAA's Helpline consultants are able to assist you with finding an MS center near you. The MSAA's Helpline number is **(800) 532-7667**.

Q: Do you think that participating in an MS trial is a good idea?

A: Without clinical trials, we would have no scientifically valid treatments for multiple sclerosis and no FDA-approved treatments. I personally would like to thank all of the courageous MS patients who have

taken certain risks to participate in such trials. By doing so, they have enabled the scientific community to develop the six FDA-approved medications that have helped so many MS patients over the past 14 years. Additionally, treatments now being studied for MS will offer even more therapies in the near future.

Therefore, from my perspective, I recommend that patients pursue learning about new clinical trials being conducted in their area. Those considering becoming a participant need to weigh the risks versus the benefits, and discuss these with their treating physician.

Additionally, I recommend that patients interested in clinical trials establish communication with specialty MS centers in their areas (see CMSC website listed on page 23) to be informed of future potential opportunities. I also advise that interested MS patients evaluate NARCOMS, which is a project of the CMSC. This program enables patients to participate in important research questions via the internet.

Clinical trials are becoming available for patients with primary-progressive disease (PPMS) and secondary-progressive disease (SPMS). These will provide new opportunities for patients who were not eligible for treatment trials previously.

Also, MS patients who are of African-American descent may respond differently to specific treatments, compared to Caucasians. Future trials may help us to understand the different responses within ethnic populations.

Q: **I have had MS for about 10 years, and although I have had few exacerbations, two recent bouts have startled me – with symptoms of vertigo, headaches, numbness, and blurred or double vision. I had been taking Avonex for one year but have switched to Copaxone for the past four months. I am a 34 year-old African-American woman, and in the small town where I live and work, my situation appears to be very uncommon... I do see a neurologist, but my feeling is that he does not specialize in MS, so I wanted to get your advice.**

A: While I am not your treating physician and do not give specific medical advice, your situation concerns me. The fact that you are an African-American woman with MS increases my concern, because as I noted in the answer to the previous question, African-American patients may respond differently to specific treatments, in comparison to Caucasian patients. You do not mention whether your two recent attacks occurred on Avonex or while on your new treatment with Copaxone.

My advice is to discuss your specific situation with your treating neurologist and ask if he or she would recommend you receive a second opinion from a specialized MS center in your region. I would suspect that if you have had no new attacks while on Copaxone, your neurologist would not recommend a change to your treatment plan. However, you need to be under close observation for the foreseeable future.

Q: My daughter had a terrible MS exacerbation two months ago, and while she is better, things are still not back to normal. Having been diagnosed at age 19, she's now 37 with three toddlers. She has never taken any of the medications for MS as she was doing great. Her MS specialist at a university has suggested participating in a clinical trial with Copaxone, where some participants receive a double dose. Patients are monitored every three months with MRIs, blood tests, etc. Do you have any opinion on this as far as her safety, and are getting several MRIs dangerous? We do have complete confidence in her MS specialist, but feel it never hurts to get another opinion. Thank you.

A: I feel badly that your daughter had a "terrible exacerbation" two months ago. I am pleased that she is getting better. While I do not give specific medical advice, I am strongly supportive of her MS specialist recommending treatment. In my opinion, the clinical trial with Copaxone is an excellent opportunity to evaluate a potential added benefit to an already FDA-approved MS treatment, which has helped so many patients. Your neurologist's recommendation to participate in the trial should be seriously considered.

In the preliminary trial of double-dose Copaxone, the clinical and MRI results were very encouraging. However, your daughter needs to discuss the potential increased side effects that might occur with any medication trial. I am not concerned about safety issues with numerous MRIs, unless she has had problems with the contrast material infused with this test. MRIs are not dangerous. You may also want to get a second opinion from another MS center in your area, although I believe you are receiving excellent advice.

Q: Recently, someone suggested a treatment of 3mg daily Naltrexone for MS (the website is www.LowDoseNaltrexone.org). I appreciate hearing your views about the treatment. I have had SPMS for the last 15 years and I take Copaxone.

A: From my perspective, low-dose Naltrexone has not been adequately tested in multiple sclerosis. Some of my patients who take this medication (against my medical recommendation) have reported feeling better, which may be due to endorphin changes in the brain or a placebo response. Does this treatment really change the course of MS? The data is just not available.

The first thing I recommend is to consult your treating physician and inquire about their impression on the benefits you have received from Copaxone. If your physician is not satisfied with your response to Copaxone, I would discuss other FDA-approved options for MS treatment. The bottom line is that I strongly favor treatments that have good scientific data versus treatments that primarily rely upon anecdotal experiences. Historically, more than 200 MS "treatments" have failed to demonstrate a benefit after being studied scientifically.

Many patients experience improvement even when they are placed on the placebo

arm of a clinical trial, which means they are in the group receiving an inactive drug (trial participants do not know if they are in the group receiving a placebo or receiving the active drug being studied). Referred to as the "placebo effect," this positive response is not specifically related to the inactive drug they are receiving. Unfortunately, many of these patients have a short-lived response, which is unlikely to affect their long-term outcome of their disease. I would also ask your treating physician about clinical trials in secondary-progressive MS (SPMS), which have positive preliminary results. For example, MBP8298 is being tested in SPMS at more than 50 specialty centers in the United States.

For more information about drugs under development, please refer to this issue's cover story, "MS Research Update," beginning on page 7. Also, you may find information on experimental drugs in the Research News column of MSAA's Fall 2006 issue of *The Motivator*, which can be found by visiting **www.msassociation.org**, clicking on "publications," followed by "*The Motivator*," and then selecting the desired issue. Readers without internet access may call MSAA's Helpline at **(800) 532-7667** for assistance. u

To Submit Questions to Ask the Doctor…

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
c/o Dr. Jack Burks
706 Haddonfield Road
Cherry Hill, New Jersey 08002

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

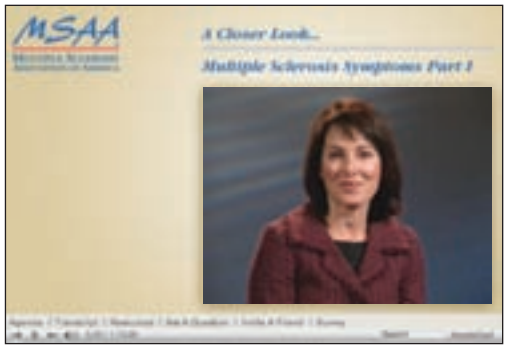
PLEASE NOTE: While several questions in this issue's "Ask the Doctor" column reference Copaxone, this is merely coincidental. MSAA does not endorse any one treatment over another. The policy of MSAA, and the opinion of our Chief Medical Officer Dr. Jack Burks, is that all individuals with MS should consult their treating neurologist or local MS center about FDA-approved, long-term treatment therapies for their MS. While not all individuals with MS are candidates for these treatments, the majority of patients can benefit from one of the six approved medications for MS. Additionally, MSAA receives a large number of questions for the Ask the Doctor column. Unfortunately, we are not able to print all of these questions, but in many cases, similar questions have been answered in previous issues of *The Motivator*. We try to include those questions which are either new to the column, or have not been recently addressed. Readers may refer to previous Ask the Doctor columns by viewing earlier issues of *The Motivator* on MSAA's website (**www.msassociation.org**).

Program Notes

Program Updates…Including MSAA's First MSi Website Video

"A Closer Look" at the Multiple Sclerosis Information (MSi) Program

Multiple Sclerosis Information (MSi) is MSAA's new technology program, launched in June on our website **www.msassociation.org**. MSi features a video program titled *A Closer Look at Multiple Sclerosis Symptoms – Part 1*. This video is divided into four segments and features four MS experts sharing their knowledge on various MS symptoms. Below is a description of the four segments:



Segment 1: "Effective MS Symptom Management," with Jack Burks, MD.
Key points covered: learning about the various MS symptoms, understanding your safety zone, having good communication with your doctor, coping with stress, and the importance of staying active and involved.

Segment 2: "Understanding Depression and MS," with Allison Shadday, LCSW.
Key points covered: distinguishing between sadness and depression, recognizing why depression is a common MS symptom, and learning how to treat depression.

Segment 3: "Learning about Involuntary Emotional Expression Disorder (IEED)," with Daniel Wynn, MD.
Key points covered: defining this lesser known MS symptom, discussing the behaviors of IEED, advice on coping with the condition, and learning about treatment options.

Segment 4: "Managing Spasticity," with Donald Barone, DO.
Key points covered: understanding muscle function and the issues of spasms and contractures, discussing the effects of spasticity on those with MS, plus learning about medical treatments and rehabilitation options.

Viewers can watch the video in its entirety or select specific section(s) of interest. Program features allow viewers to email the video's link to a friend, and the capability to print a transcript of the video.

The development and implementation of MSi is made possible through the funding support of EMD Serono, Inc. and Pfizer Inc, Bayer HealthCare Pharmaceuticals, Avanir Pharmaceuticals, Medtronic Foundation, and The Horizon Foundation for New Jersey.

As the MSi program expands throughout the year, MSAA will continue to produce and release a host of informative half-hour to one-hour web videos, covering such topics as the value of MRIs, the need for early treatment, stress management, and many other real-life issues important to you and your family.

The MSi videos feature (clockwise from upper left) Jack Burks, MD, speaking on the topic of symptom management; Allison Shadday, LCSW, on depression; Daniel Wynn, MD, on Involuntary Emotional Expression Disorder; and Donald Barone, DO, on managing spasticity.

We welcome and encourage you to visit the MSAA website and access these informational videos as they go online throughout 2007.

Cooling Equipment Distribution Program

Hot summer days often lead to hot summer nights. In an effort to relieve some of the symptoms associated with the heat of the evening, MSAA now offers a cooling pillowcase made by Polar Products, Inc. The pillowcase features pouches that contain soft ice packs. The pillow is designed to help individuals get relief for those nights where the temperature is just too hot to get a good night's rest. To request an application for cooling equipment, please visit **www.msassociation.org** or call MSAA at **(800) 532-7667**, extension **130**.

Home Modification Program Update

Due to extraordinarily high demand for the Home Modification Program, MSAA is temporarily suspending this service and is no longer accepting applications for the waiting list. You are welcome to call a Helpline consultant at **(800) 532-7667** for possible resources in your community.

New Video Available in the Lending Library

A video titled *Talking with Your Children about Multiple Sclerosis: A Place to Begin*, is now available to clients through MSAA's Lending Library Program. The video features three families with a parent who has MS. The video also includes an animated explanation of MS, a section with advice from parents who have MS, as well as a section with resources for families coping with MS.

The video is provided by Direct Health Media, which is a nonprofit corporation dedicated to educating patients, their families, and their caregivers, about specific disease information and related topics. *Talking with Your Children about Multiple Sclerosis: A Place to Begin* is also available in Spanish. u

— Amanda Bednar

MSAA's Resource Detectives Program Now in Full Swing

"I was in touch with a wonderful woman at the MS Association who, first and foremost, listened to the situation I was in and began working with me. She took this bull by the horns and was determined to help me. She sent me an information packet which will enable me to order equipment and cooling products from MSAA to make my life easier. Then she researched and put me in touch with an agency that helps people with grants because I need a lift chair, and she let me know about my local Center for Independent Living because I need a ramp… For once I can tell you, all will be well with my MS needs."

This inspirational and appreciative testimonial is from a client who recently received assistance through our Helpline and MSAA's highly effective Resource Detectives Program. As you may know, MSAA's trained Helpline staff works closely with each client who contacts the organization to discuss the many issues, emotions, and challenges that often occur with MS and then works to identify appropriate information, resources, and solutions to resolve each case. By the close of our fiscal year on June 30th, MSAA's Helpline staff responded to and assisted more than 12,000 clients through the agency's toll-free Helpline and email correspondence.

To support the Helpline staff by increasing their efficiency and ability to respond to a rising volume of calls and email, MSAA developed and launched a unique program in 2005 called Resource Detectives. This MSAA program mobilizes a national workforce of trained volunteers who use their skills and ingenuity to research and report to MSAA local agencies and organizations which offer assistance to meet the needs of the MS community.

These "detectives," many of whom have MS, research the internet, place phone calls, attend advocacy meetings, and use other creative methods to seek out the most up-to-date resources for a variety of topics. Examples of topics include financial assistance, transportation, housing/home modifications, legal support, prescription assistance programs, employment resources, and other vital areas of service.

During the past two years, the Resource Detectives Program quickly gained momentum and grew from a few hundred entries

and a handful of volunteers, to a database of several-thousand listings and a true national initiative. To help bolster program outreach and integrate the necessary systems to manage its expansion, MSAA is proud to announce the receipt of a generous grant from Novartis Pharmaceuticals Corporation.

Through this grant, MSAA will be able to develop and disseminate upgraded comprehensive training packages, expand volunteer recruitment initiatives, and institute powerful hardware and software technologies to import, track, and evaluate data collection, all of which will allow us to improve the quality of life for thousands of clients each year. Additionally, future plans are to develop a system where this expansive resource database can be shared and accessed via the internet by the MS community, including MS centers, organizations, physicians, and clients.

MSAA's Resource Detectives research the internet, place phone calls, attend advocacy meetings, and use other creative methods to seek out the most up-to-date resources for a variety of topics.

"MSAA is grateful for the support Novartis Pharmaceuticals Corporation is providing to our innovative Resource Detectives initiative," states Bob Rapp, MSAA's vice president of programs and evaluation. "This program will engage people with MS to identify services of high quality which will directly benefit others with the illness. This concept of utilizing those with the disease in service to others affected by MS provides tangible benefits to both groups."

The core of this program's success is the volunteer, or in this case, the detective. Armed with a telephone, computer, and resilient determination, the Resource Detective works behind the scenes to sleuth and uncover the many hidden resources that help support and serve thousands of MS clients throughout the country.

One such top detective who's been on the case since the program began is Karen Pietrangelo. According to Karen, the Resource Detectives Program is a great way to reach out and help others, while still enjoying all the comforts of home.

Karen explains, "This is an extremely fun project to work on and I can do it from home and fit it around my other commitments. I find it very rewarding to identify resources that actually make a difference in the lives of those with MS. I highly recommend this program and encourage everyone to get involved, especially if they've found a resource that's helped them and want to share it with others. There is no better feeling than to help other people."

With this new program expansion, MSAA needs additional supportive detectives to help continue the exceptional work that began with Karen and the other volunteers.

We need you on the case! To become a Resource Detective or to learn more, please contact Malcolm Friend at **(800) 532-7667, extension 141** or via email at **mfriend@msassociation.org**. Readers may also visit **www.msassociation.org/resource_detectives.htm** for more information.

— Peter Damiri

Thoughts about Giving

Bruce Makous

Greetings from MSAA's New Vice President

I have been on the job nearly seven months, and I find that the work is becoming more and more exciting every day. MSAA is a very inspiring organization, regularly receiving warm appreciation from clients, as well as national recognition for the high quality of our programs.

This culture of excellence creates an outstanding environment for fundraising success. I am delighted to be working to help raise support for this worthy organization.

In my 25 years in the fundraising profession, I have worked at a number of nonprofits – in arts and culture, education, social services, and most recently, with a cancer-research organization. In that time, I have never served in a position that has as much personal resonance for me as MSAA.

This is because I recently celebrated my silver anniversary, 25 years of marriage to my loving wife Bobbie, and Bobbie has MS. I have been helping her through these years with the day-to-day challenges that come with her condition.

I have found that the one thing that has remained the same during all of these years is the constant presence of change. Whether with mobility, career, therapy options, heat management, exercise, gardening, travel, or any of the many facets of Bobbie's life, there are always new challenges to face.

MSAA helps Bobbie and others like her, as well as spouses and care partners like me, overcome challenges. I feel extremely privileged to have this opportunity to help people living with multiple sclerosis lead enriched and fulfilling lives.

The show of thanks we regularly receive at MSAA from appreciative clients is the most meaningful reward for our efforts. I am delighted to work with the entire MS community to support these valued programs and services. u

— Bruce Makous
Vice President of Development

Bobbie Makous has loved to garden since she was very young. Diagnosed with MS thirty-two years ago, she has found working outside to be more and more difficult, especially in the summer heat. Bobbie's cooling hat allows her to spend more time in her garden during the summer, despite the rising temperatures.

MSAA Launches President's Circle Program

In June, MSAA launched the President's Circle program, which gives special appreciation for loyal and generous donors. The first President's Circle reception was held in the Washington, DC area on June 1st. During this important event, MSAA President and CEO Douglas Franklin, along with our Board of Directors, had the opportunity to personally thank MSAA's leading donors.

President's Circle appreciation is provided to donors of $500 or more. More than 300 individuals from across the country currently receive recognition and appreciation as President's Circle donors. u

MSAA President's Circle member Dr. Aida Chohayeb, who contributed $5,000 this past year, receives special appreciation as a Benefactor level donor at MSAA's President's Circle reception on June 1st in Washington, DC. At left is Eric Simons, MSAA Board member and national chairman of the President's Circle. At right is Ross Maclean, chairman of the Board for MSAA.

MSAA's Gift Annuity Program

In April, Herbert and Selma Weisz established a gift annuity with MSAA. The couple will receive income from this gift throughout their lifetime.

"I am delighted to be able to support MSAA through a gift annuity program," said Herbert Weisz. "I had been supporting MSAA through annual contributions, and decided I wanted to establish a legacy gift, too."

A gift annuity is an excellent way for donors to create a legacy fund with MSAA, while also continuing to receive income from that fund. u

Attention: Artists with MS

MSAA is having a contest for artists with MS willing to donate original artwork. Winning artwork will appear on MSAA greeting cards, calendars, and other items distributed by MSAA.

To receive contest guidelines and instructions for submitting your art, please send an email to contest@msassociation.org. Artists without internet access may call MSAA at **(800) 532-7667, extension 149** for more information. u

If you have thoughts about giving, please feel free to contact Bruce Makous at (800) 532-7667, extension 148, or email ***bmakous@msassociation.org****.*

PRESIDENT'S *Circle* LEADERS IN PHILANTHROPY

"I give generously to MSAA in memory of my brother who died of MS complications. MSAA serves a very worthwhile cause in helping people with MS in many ways. It's a good organization."

– Shirley Hatton,
President's Circle donor

THANKS TO OUR MOST LOYAL AND GENEROUS DONORS!!

MSAA's President's Circle recognizes our generous supporters, people whose annual gifts total $500 or more. All gifts to President's Circle support programs that enrich the quality of life for individuals affected by MS. President's Circle members are genuine leaders in philanthropy.

BE A LEADER. BE A PHILANTHROPIST. JOIN THE PRESIDENT'S CIRCLE.

Contact Bruce Makous at **(800) 532-7667**, extension **148**, or email **bmakous@msassociation.org**

MSAA Staff Member Earns America's Charities' Honor

Congratulations to **Director of National Volunteer Services Malcolm Friend**, who received the **2006 National Community Leaders Award** from America's Charities.

This prestigious honor was in recognition of Malcolm's work in building MSAA's **Public Education Ambassador Program** in every state across the country, and using his team to facilitate employee giving for MSAA and for America's Charities.

America's Charities

MSAA is currently recruiting Ambassadors for the busy September-to-December period. For more information, please contact Malcolm Friend at ***(800) 532-7667****, extension* ***143*** *or* ***mfriend@msassociation.org****.*

KEEPING YOUR COOL

By Shelley Peterman-Schwarz

A Warm Reunion

A few years after I was diagnosed with multiple sclerosis (MS), my husband, Dave, and I went back to his childhood home for his 20th high school reunion. The room was packed, the music was deafening, the air was warm, and I was expending great amounts of energy trying to communicate with those around me. I could feel myself wilting by the moment. Not wanting to interfere with my husband's ability to reconnect with his high school pals, I casually wandered off to a table away from the "maddening crowd," where I sat drinking glass after glass of water.

Then I needed to use the facilities. My legs felt like they weighed 1,000 pounds each as I walked to the ladies room – my energy draining out of me like a balloon with a slow leak. Maybe, if I sat in the air-conditioned car for a bit, my strength would return. I asked the wife of one of Dave's friends to join me.

The air outside was like a furnace blast; the heat index was more than 100. Walking through the unpaved parking lot, on heels that were too high given my instability and weakness, was very stressful. I would have fallen three times if my friend hadn't been there to catch me.

The air conditioning in the car was a Godsend. I started to feel better. When dinner was served, I went back into the hall. Thankfully the loud music was replaced by the evening's program, and once the sun went down, the building's air conditioning did a better job of cooling off the room.

Toward the end of the evening, small groups broke off and made plans for after-parties. But I had hit the wall. As much as I wanted to, and I did want to, I couldn't do one more thing. I needed to go home! I felt awful about putting a damper on Dave's plans, so I suggested he take me home and then meet up with his buddies afterward.

By the time we arrived home, I didn't have the strength to walk. Dave had to carry me into the house, undress me, help me in the bathroom, and get me into bed. I was as limp as an overcooked noodle and fighting back a boatload of tears. I was frustrated with my body. I was angry that I wasn't able to keep up – after all, I was still in my 30s! And I was scared; nothing like this had ever happened before.

That was my first experience with what heat can do to a person with MS. Thankfully, I recovered within a few days, and over the more than 20 years that have followed, I have never experienced as severe of a reaction to the heat. I believe

that's because I took the issue of getting overheated, and how it can affect MS, very seriously. Perhaps some of the things I have learned to help me keep my cool will help you too.

Understanding the Effects of Heat

Warning Signs

You may not be aware that the heat is affecting you. Here are some signs to watch for:

- Overall muscle weakness
- Significant loss of energy
- Irritability
- Headache
- Body aches
- Nausea and/or lack of appetite
- Thought processing becomes impaired; you feel as though you can't think or find the right words; you may even have trouble remembering how to do things
- Signs of dehydration include dry, sticky, or cotton mouth; low or no urine output, or concentrated urine appears dark yellow; not producing tears; or feeling lethargic
- Excessive sweating or not sweating at all

Medications and Heat

The medications you are taking can also affect how you respond to heat. Medications may cause dehydration or affect the body's ability to perspire or regulate body temperature.

Consult your prescribing physician or the dispensing pharmacist to learn about any heat-related side effects that your medication may have. (A helpful tip to remember is that the telephone number of the pharmacy is on the prescription bottle's label.)

Being Overheated – What Does It Feel Like?

For me, the warmer I feel, the weaker I feel. It's an overall weakness; I'm unable to move quickly. Expressing myself and processing information becomes a struggle; I feel "mushy-headed."

Every part of me moves in slow motion, especially my thinking. And when you add loud background noises, music, conversation, or frenetic environments with lots of visual activity, you can almost see me melting down like a scoop of ice cream on a hot summer's day.

What about Fever… or Hot Flashes?

Heat-related problems can occur when your core temperature goes up, such as when you have a fever. Your core temperature can also rise when it's hot outside, and even a few minutes in the heat can sap your strength. And when you add in high humidity, even less time is needed before you feel the effects.

My hot flashes were like a wave of warmth that came on slowly, built to a few seconds of intense heat, and then subsided gently and disappeared. For other women, hot flashes can be overwhelming. These too can bring on the temporary effects of overheating.

Will Cooling off Make Everything Fine?

Family members and friends may think that once you are out of the heat and in a cooler environment, you'll perk right up and feel fine. But that hasn't been my experience.

Finding a quiet, peaceful environment where I can escape the sensory overload works best for me. Getting a cool drink and finding a place to close my eyes, while listening to the sounds of silence, is usually the most effective strategy. Sometimes taking a nap can help. After a few hours, I feel like I am back in control.

Tips for Keeping Cool in Warm Weather

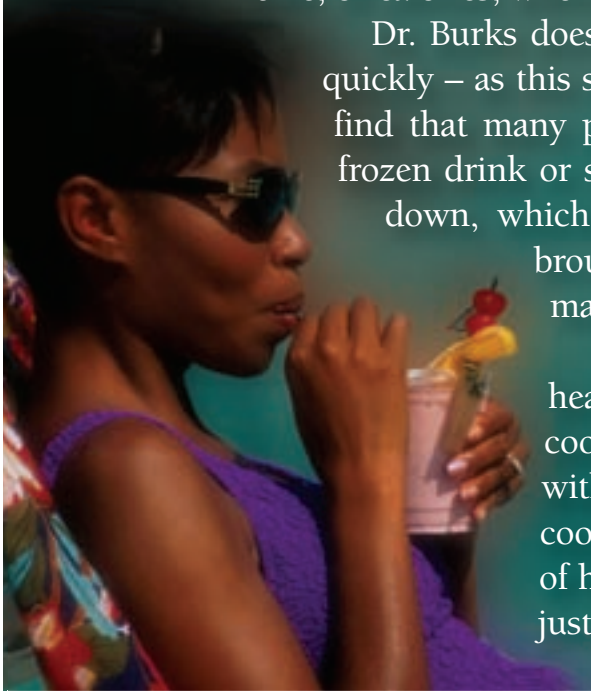
Stay hydrated:

- Sip cool water, not cold, throughout the day. This will allow your body to gradually absorb and use what you drink, rather than having a big drink all at once that may cause you to run to the bathroom.

- Carry water with you everywhere. To ensure that your water is clean, use non-porous polycarbonate (sports bottle) or

Cooling Off With Cold Drinks

MSAA's Chief Medical Officer Jack Burks, MD, notes that many of his patients can get some relief from the heat and related fatigue by sucking on ice chips. Another option that can be beneficial is to sip on a "slushy" type of frozen drink, which can be made in a blender with fruit, juice, and ice cubes. Frozen drinks may also be purchased at a convenience store (often under the brand names of "Slurpee®" or "Icee®"), at a restaurant, or at a fruit-drink stand. He notes, however, that individuals need to be careful not to take in too much sugar, caffeine, or calories, when having these types of drinks.



Dr. Burks does not advise drinking something that is very cold too quickly – as this sometimes causes a momentary headache. But he does find that many patients may get help cooling down by sipping on a frozen drink or sucking on ice cubes and allowing the tongue to cool down, which may affect how quickly one's temperature may be brought back to normal. He points out that the difference may only be about one-degree Fahrenheit.

He also stresses that patients who are feeling overheated do not bounce right back as soon as they have a cool drink or move to a cooler environment. Individuals with MS and their family members need to recognize that cooling down and feeling better happens over the course of hours, and no one should expect to return to normal in just a few minutes.

stainless steel bottles and wash the bottle with soap and hot water every night, paying special attention to the areas at the lip and inside the cap.

- To have cool water with you when you're out and about, fill a water bottle three-quarters full and put it in the freezer. By doing so, the water stays cool long after you take it with you into the warmer temperatures. If your hands are sensitive to the cold or if your hand strength is weak, slide the bottle into a sock, which will absorb the sweat from the bottle as the ice melts. It not only buffers the feel of the ice-cold water, but also helps to prevent the bottle from slipping out of your hands.

- Drinking chilled fruit juice is another option, especially if you are not eating for a long period of time. This helps to keep your blood sugar from going too low, although you need to be careful not to overdo on the amount of juice and other sugars you are taking in, especially if the heat has made you extra thirsty.

- Avoid caffeinated beverages, as these can contribute to dehydration.

Eat cold foods:

- Freeze grapes, blueberries, and other bite-sized fruit for a cold, refreshing, and nutritious treat. Just rinse, drain, spread them on a cookie sheet, and place in the freezer. Once frozen, put the fruit into a plastic bag in the cooler and take along on trips, to the park, or to a ballgame.

Plan your activities around the weather

- Plan ahead and use some type of cooling apparel or accessory to help stay cool, such as a cooling vest, bandanna, wrist bands, cold pack, or cooling pillowcase. Many of these products are described in the following section on cooling products and clothing.

- Stay indoors on really hot days and during the midday when air temperature is hottest. If you don't have air conditioning in your home, try to keep the house as cool as possible by pulling down shades to block direct sunlight, and also use a fan. On dangerously hot days, make sure family and/or friends know you are without air conditioning; you may want to stay with someone until the extreme heat subsides.

- When shopping, if possible, arrange to have someone pick you up and drop you off at the door to avoid walking across a hot parking lot. Also, going to an air-conditioned mall rather than an outdoor strip mall can help you to stay cool. Planning activities in an air-conditioned environment, such as going to the movies, can also be a fun way to avoid the heat.

- Your car can reach high temperatures by just sitting in the sun. Before you begin to drive, if at home and in a safe place, you may want to allow time to put your windows down and leave the door open to let the hot air out and get the air conditioner running. You need to be careful, however, that no children can get into the running car, and to make sure that the car isn't put into gear while the door is open.

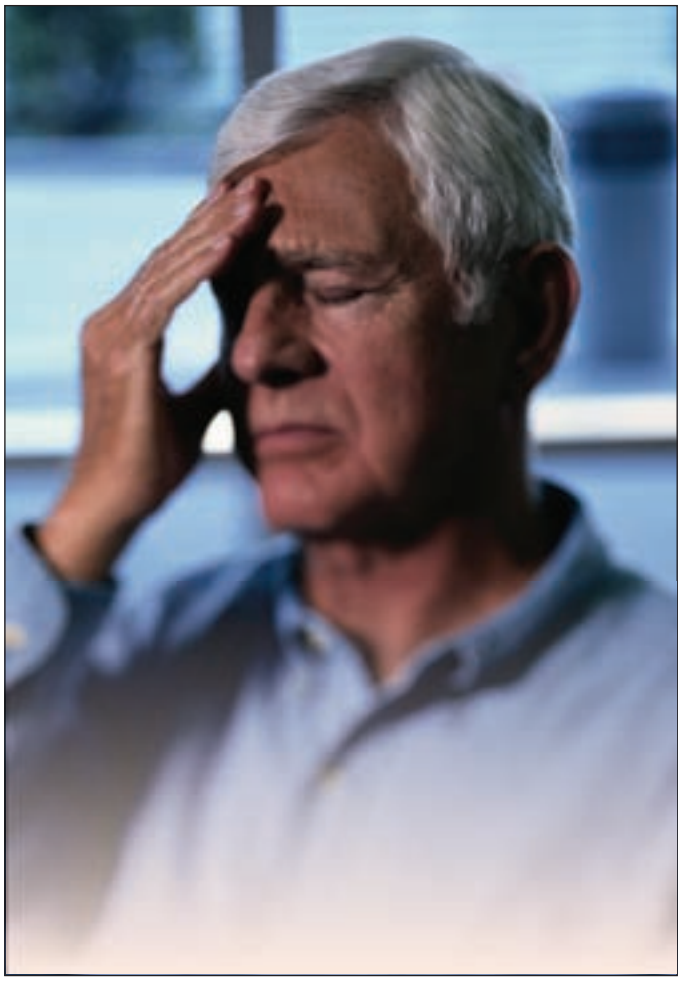
If the kids are playing in the water, join the fun!

Swimming in cool water helps to keep your temperature down, but always have other adults with you in case you become affected by the heat.

- Avoid or be extremely cautious when using hot tubs, swimming pools with warm water, saunas, hot baths, and showers. These can raise your body temperature and cause weakness as well as other heat-related symptoms. Always have someone with you when swimming or using a hot tub or sauna.

When you must be out in the heat…

- Find a shady place with a cool breeze.
- If the kids are playing in the water, join the fun or dip your feet in the pool.
- Protect yourself from the sun by wearing white or light-colored clothing that reflects rather than absorbs heat; wearing a hat can also help. For extra cooling, you might try placing a small Zip-lock®-type (re-sealable/watertight) plastic bag, filled with frozen peas or corn, under your hat.
- Use an umbrella to provide shade.
- Pack ice cubes in medium-sized re-sealable (and watertight) plastic bags and place them on top of canned or bottled drinks in your cooler. If you run out of cold drinks, you will have extra water (that is still clean) in the bags after the ice melts.
- Place two small, damp towels in a re-sealable bag and keep it next to the ice in your cooler. When you need a cool cloth, take one of the towels out and use it to cool down. As the towel you are using becomes warm, switch it with the cool towel still in the bag – this way you will always have a cool, damp cloth available.



If you become overheated, you'll need to get out of the heat right away. One option is to find a cool place to relax and have a cool drink, such as water or juice.

If you find yourself overheated…

- Cool your body fast by applying ice, cool compresses, or a water bottle filled with ice cubes and water, to areas of high blood flow – such as the forehead, back of neck, low back, wrists, ankles, or underarms.

- An easy ice pack can come from using a package of frozen vegetables (such as peas or corn kernels) – just remove the package from the freezer, wrap it in a damp cloth, and apply. If using a bag of vegetables as an ice pack, marking it with a permanent marker will let others know that these vegetables should not be used for a meal, since they've been thawed and re-frozen for later use.

- Place your hands and wrists or feet in cool or cold water. For example, a friend of mine often exhibits artwork at outdoor art shows. When the weather is hot, she briefly submerges her feet in a cooler of ice water*. She says it cools her off quickly and the effects last for almost two hours.

  *Please be extremely cautious when using ice or ice water directly against the skin, especially for individuals with numbness. Ice and ice water have the potential to cause ice burns, if left directly against the skin for more than two or three minutes.

- Bathing or showering in cool water is recommended to keep one's body temperature down. Start with warm or tepid water and gradually increase the coolness, giving your body time to adjust.

- Find a cool environment and lie down to rest. This gives your body a chance to recuperate. u

Cooling Resource Directory

The following section provides a list of vendors and products. Please note that other companies not appearing on this list may offer similar cooling products or clothing. Additionally, many of the companies listed offer other cooling items which have not been highlighted in this article. The vendors and products listed are examples of cooling products and clothing available to heat-sensitive individuals. Prices are subject to change and often do not include shipping and handling charges. Prices for larger items have not been included, since product features vary.

Products to Keep You Cool

Chillow® is a cooling pillow that uses water to absorb and dissipate the heat your body emits, leaving a cool sensation. Simply fill the Chillow with water to activate the cooling reaction, press out any extra air, and slip the Chillow into your pillowcase. This cooling product may also ease the pain and discomfort of headaches, back pain, sunburn, and hot flashes – helping users to enjoy a better night's rest.

Chillow is a product of Soothsoft Innovations Worldwide, Inc. and is available at pharmacies. For more information, call (888) 244-5569 or visit **www.chillow.com**. The cost is about $40.

The **Coolband™** body-cooling wristbands include two terry-cloth wristbands and four ergonomically designed, freezer gel packs. Simply freeze the packs, snap them into the specially designed pocket, slip over your wrist, and you will have soothing cool temperatures on your wrists for several hours. Two extra Freeze-N-Go™ gel packs go in the freezer or cooler until the first set is no longer cooling. With its curved design, the Coolband may be worn on your forearm just above the wrist, and will not interfere with wrist activity – including tennis or golf. Wristbands may also be used to "ice" an injury or condition, such as carpal tunnel syndrome.

The product is offered through Cool Therapy, LLC. They may be contacted by phone at **(866) 272-COOL (2665)** or online at **www.coolbandcity.com**. The cost is about $20.

Katabrella® is a flexible umbrella arm which attaches to almost any conventional portable (folding) umbrella, providing hands-free protection from the sun (and rain). Simply wrap the curled Katabrella arm to fit over your shoulder and it supports the umbrella for you.

This product is made by The Peterson Clinic, LLC. For more information, visit **www.katabrella.com**. The cost is about $15.

The **Misty Mate COOL BLAST™ Mister** is a personal air cooler that is an easy and portable way to cool down at work, at home, or when outdoors. Fill the Misty Mate™ canister with tap water, close, and pump to pressurize. It sprays a fine mist on or near your skin, creating a cooling sensation. Several other misting products are available, including a large Mist-N-Shade umbrella that may be setup outdoors and attached to a hose for continuous mist and shade. The product may reduce the immediate air temperature by as much as 25 degrees.

Misty Mate Inc. may be contacted by phone at **(800) 233-6478** or online at **www.mistymate.com**. Sale prices at the time of this article ranged from $15 for the Cool Blast Mister to $40 for the umbrella.

Battery-operated personal fans can tuck into your purse or pack to provide a cooling breeze wherever you go. They are available at most drug or discount stores.

Clothing to Keep You Cool

Akemi, Inc. makes body-cooling vests, neck scarves, bandanas, seat cushions, foot wraps, mitts, and wrist bands designed to cool different parts of your body through evaporation. Each Body Cooler® product is manufactured with special compartments containing non-toxic copolymer crystals. To activate the cooling, you soak the polymers in water for 20 minutes, pat the item dry with a towel, and apply to your skin for fast cooling relief. The crystals absorb up to 400 times their weight and keep cool for a day or two.

Akemi may be contacted by calling **(800) 209-2665**, or through their website at **www.bodycooler.com**.

Heat Relief Depot™ offers a wide variety of cooling products for individuals with MS. One of these is the MiraCool™ fishing hat, a vintage-style reversible bucket hat to keep your head cool. MiraCool Cooling Crystals encased within the top of the 100-percent cotton fabric absorb and hold up to 1000 times their weight in cool refreshing water. The crystals work in combination with the evaporation process, so when worn against the head, cooling sensations are passed to pulse points and carried throughout the body. Just soak in cold water to activate and wear it wet or dry.

The MiraCool fishing hat and other cooling hats are available through Heat Relief Depot, a division of BioChem Corporation, Inc. They may be contacted by calling **(877) 879-1450** or by visitng their website at **www.heatreliefdepot.com**. Product prices for the hats range from $9 to $27.

The **Polar Body Cooling System Kits** help give relief from the heat through a series of cold packs inserted in various pieces of clothing. They are designed to be lightweight and comfortable, while worn under or over your clothes. Each system kit includes: fully adjustable vest with Kool Max® cold packs; two wrist wraps with cold packs; a neck collar with cold packs, and an extra set of cold packs to keep in reserve.

The kits are available from Polar Products, Inc. They may be contacted by phone at **(800) 763-8423** or by visiting their website at **www.polarsoftice.com**. A variety of cooling items may also be purchased separately.

The Cool Shirt® MS Therapeutic Cooling System is an active-cooling system specifically designed to meet the needs of the MS patient. The poncho is easy to put on and comfortable to wear. It includes a specially designed head and neck section that offers fast and effective cooling for the user. The cooling unit has a large handle for easy carrying and a temperature control that allows the user to adjust the temperature to their specific needs. The system comes complete with the poncho, the cooling unit with temperature controls, an eight-foot insulated hose with dry disconnects, and a 110-volt adapter.

This product is offered by Shafer Enterprises, LLC. They may be contacted by phone at **(800) 345-3176** or online at **www.coolshirt.net**.

Silver Eagle Outfitters offers several products made of a unique layering of three super-absorbent fabrics which, when soaked in water, activate a cooling reaction. One product is the "Do-Rag." This has a bandana-like design that keeps your head or neck cool for several hours. Just soak the Do-Rag in water for three to five minutes, wring out, and wear it on your head or neck. The cost is $15.

Another product is the New Generation Classic Cooling Vest. After the cooling reaction is activated, the vest will be noticeably cool to the touch for several hours. This is especially good for people who are in hot environments for extended periods of time. The vest is available in men's and women's sizes, from size small to 4X. Silver Eagle Outfitters may be reached by phone at **(888) 672-6963** or through its website at **www.coolingapparel.com**.

The **StaCool Vest™ Body Core Cooling System** uses high-quality, durable materials, and four easily replaceable ThermoPaks to cool your body core comfortably. Each lightweight "Under Vest" offers up to three hours of cooling per ThermoPak set.

A spare set is also included for a total of eight ThermoPaks per vest. It is available in sizes XS through XXXL. A child's vest and an industrial vest are also available.

The vest is available through StaCool Industries, Inc. For more information, they may be contacted by phone at **(866) 782-2665** or online at **www.stacoolvest.com**.

Steele Inc. offers the **SteeleVest® Body Cooling Comfort System**. This is a vest that contains five special pockets – two in the front and three in back -- which hold starch-based gel ice packs to keep you cool. The cooling gel packs, which can be frozen and refrozen, stay cold for up to four hours. The SteeleVest conforms to your body for a comfortable fit and has open sides that do not restrict your range of motion. The vest weighs five pounds with all five frozen packs in place.

Steele Inc. may be contacted by phone at **(888) 783-3538** or through their website at **www.steelevest.com**. Other cooling items are available.

Special clothing from **Sun Precautions®** protects you from the skin-damaging effects of the sun. Made of Solumbra™ fabric, the clothing features a full line of hats, gloves, shirts, pants, and skirts. These items are lightweight and vented to keep you cool, and the special fabric provides all-day 30+ SPF UVA and UVB sun protection – blocking more than 97-percent of the rays.

Sun Precautions may be contacted by calling **(800) 882-7860** or by visiting **www.sunprecautions.com**. u

– Edited and portions written by John Masino

NOTE: MSAA offers a Cooling Equipment Distribution Program, but certain income and other limits apply. For more information, readers may visit **www.msassociation.org** or call MSAA at **(800) 532-7667**. Callers may dial **extension 130** to request a Cooling Equipment Distribution Program application.

Multiple Sclerosis Coalition to be Honored at Heuga Center Benefit

The Heuga Center for Multiple Sclerosis will honor the Multiple Sclerosis Coalition at The Heuga Center's 22nd Annual Autumn Benefit. The event will be held October 23, 2007, in New York City.

For more information, contact The Heuga Center for Multiple Sclerosis in Edwards, Colorado at **(800) 367-3101** or visit the center's website at **www.heuga.org**.

Readers may also visit the Multiple Sclerosis Coalition's website at **www.multiplesclerosiscoalition.org**, contact MSAA at **(800) 532-7667**, or log on to MSAA's website at **www.msassociation.org**.

RESOURCE DETECTIVES NEEDED

MSAA needs you "on the case" as a **Resource Detective** to help identify valuable resources for the MS community. Through MSAA's Resource Detectives Program, volunteers use skills to research and report to MSAA information about local agencies and organizations that offer assistance for the MS community.

For more information, please contact Malcolm Friend at **(800) 532-7667, extension 141** or visit **www.msassociation.org/resource_detectives.htm.** You may also email Malcolm Friend at **mfriend@msassociation.org.**

MSAA Needs Volunteers!

VOLUNTEERING ASSIGNMENTS INCLUDE:

- Fundraising: Events such as bake sales, trivia nights, and charity dinner parties have all benefited MSAA. Will you organize something similar to benefit MSAA?
- Resource Detectives: Research and report on local resources that help individuals with MS.
- Ambassador Support: Facilitate speaking engagements to community groups and hospitals for our Ambassadors.

For more information about volunteering with MSAA, please contact MSAA's Director of National Volunteer Services Malcolm Friend:
Phone: **(800) 532-7667, extension 8**
Email: **volunteering@msassociation.org**
Web: **www.msassociation.org/volunteer.html**

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

Making Sense of MS Terminology

A guide to understanding medical terms and procedures for individuals with MS

Written by Christine Norris
Co-written and edited by Susan Wells Courtney | Reviewed by Dr. Jack Burks

Whether you've been diagnosed with multiple sclerosis (MS) or if you know someone with this disorder, becoming familiar with its medical terms and procedures is extremely helpful for understanding the symptoms and treatments. While many long-time readers of *The Motivator* have a strong vocabulary of MS-related terms, others – such as family members, friends, or individuals who are newly diagnosed – may benefit from an explanation of common MS terminology.

To follow is a description of terms frequently used when discussing MS. Topics include an overview of MS, an explanation of how the nerves are affected, tools used to evaluate disease activity, a description of the different clinical trial phases, and drugs presently approved for the treatment of MS. Terms are defined within the text and have been bolded for easy reference.

What is MS?

Multiple sclerosis is a neurological disorder affecting the nerves of the **central nervous system** (CNS), which consists of the brain, optic nerves, and spinal cord. Individuals with MS commonly experience their first symptoms as a young adult, and most individuals are diagnosed with the disease at this prime time in their life, when going to school, starting a career, or starting a family. For 80 percent of people with early MS, symptoms may come and go – or "**relapse**" and "**remit**," making the diagnosis difficult. While treatments are available to slow disease activity, researchers have yet to find a cure. MS is not contagious, and in most cases, does not shorten one's expected lifespan.

Symptoms of MS include a wide range of physical, mental, and emotional difficulties. Examples include: visual problems, spasticity (tightening of muscles and spasms), weakness, tremor, numbness, and dizziness; bladder, bowel, and sexual dysfunction; chronic, aching pain; fatigue, depression, and memory problems. Some individuals may experience **L'hermitte's sign**. This is an electrical sensation that runs down the spine to the legs when the neck is flexed forward.

Fortunately, treatments are available for most symptoms. Additionally, at least in early stages of the disease, symptoms may come and go with disease activity. Anyone experiencing these types of symptoms should be referred to a **neurologist**. This is a

physician who specializes in diagnosing and treating disorders of the nervous system, including MS.

What are the types of MS?

On average, 80 percent of people with MS begin with the **relapsing-remitting form of MS (RRMS)**. What distinguishes this type of MS from other types are the temporary symptom flare-ups or "**exacerbations**" (also referred to as relapses, attacks, or bouts), which typically last for one to three months. These are followed by a complete or partial recovery ("**remission**"). Women are two or three times more likely to be diagnosed with RRMS than men.

Between relapses, many people may go into remission for a year or more. During this time, they may remain symptom free, or only experience mild changes with symptoms that did not fully remit following the exacerbation. While symptoms may not appear or worsen between MS attacks, changes do continue within the CNS. Six disease-modifying **treatments** are presently approved by the **Food and Drug Administration (FDA)**, each shown to help slow disease activity. These are described in a later section.

If untreated, more than 90 percent of individuals with RRMS may eventually enter a second phase of RRMS, known as **secondary-progressive MS (SPMS)**, within 25 years. This phase is reached when the patient experiences a progressive worsening of symptoms. SPMS may occur with or without superimposed relapses.

While approximately 80 percent of individuals with MS are initially diagnosed with RRMS, the majority of the other 20 percent are diagnosed with **primary-progressive MS (PPMS)**. This form of MS presents a gradual but steady accumulation of neurological problems from the onset, without the presence of relapses and remissions. Unlike RRMS, PPMS is equally divided between the genders.

Other types of MS exist, but these are not as common. These include **benign MS** (with little or no change after 20 years), **progressive-relapsing MS** (PRMS) (a progressive course from the onset with acute relapses), and **malignant or fulminant MS** (a rapidly progressive disease course).

What causes the symptoms of MS?

In a healthy body, **nerve fibers** (also referred to as "**axons**") have a protective, fatty-rich protein covering known as myelin. This covering insulates the nerve fibers, similar to the insulating rubber covering of an electric wire. Myelin allows for the smooth and uninterrupted flow of **nerve impulses**, which in turn enables the body to send vital instructions from the brain to the different parts of the body.

With MS, the body's own system of defense, known as the **immune system**, malfunctions. It sends disease-fighting cells into the CNS to destroy the body's own myelin. This occurs because the immune system is incorrectly identifying the myelin in the CNS as a foreign body. When the body's own immune system attacks its own tissue, this is referred to as an **autoimmune**

disease. Most researchers believe that MS is an autoimmune disease. Examples of other autoimmune diseases include lupus and rheumatoid arthritis.

Lymphocytes are a type of **white blood cell** and play a strong role in the body's defense system. Lymphocytes can be "**B-cells**," which produce antibodies to fight against "foreign invaders" (such as bacteria or viruses) within the body. They may also be "**T-cells**," which help to regulate the immune response; "**helper**" T-cells can increase an immune response, while "**suppressor**" T-cells can suppress an immune response. Another type of white blood cell is the **macrophage**, and this works to ingest and destroy foreign substances. All of these lymphocytes appear to be involved with the destruction of myelin, with the exception of suppressor T-cells, which aid in stopping the attack.

White blood cells circulate in the blood and are produced when the immune system perceives a foreign body and instructs the cells to eliminate it, thereby "protecting" the body. In order to reach the nerves within the CNS, the immune system cells and molecules must cross a protective barrier that surrounds the blood vessels. Known as the **blood-brain barrier (BBB)**, this layer of cells is designed to prevent damaging cells and other substances in the blood (including those that could cause disease) from entering the brain, optic nerves, and spinal cord of the CNS.

With MS, damaging immune-system cells are able to breakthrough the BBB and enter the CNS, where they begin their attack on the myelin. This break in the BBB is facilitated through **adhesion molecules**, which attach to the lining of the blood vessels and bind to the immune-system cells. The adhesion molecules work like a gate and key, enabling damaging cells to pass through this cell membrane.

Once the damaging cells enter the CNS, macrophages and other lymphocytes begin their attack on the myelin. This creates **inflammation** along the nerves where the myelin is being damaged. Areas of activity are known as **lesions** (or **plaques**). Lesions vary in activity levels, ranging from very active (**acute**), to chronic, to inactive. Often myelin that is damaged may be restored through a process called "**remyelination**," particularly early in the disease. **Oligodendrocytes** are cells which produce and maintain myelin. Over time, however, oligodendrocytes may be lost and fail to repair the damaged myelin.

Areas of damaged myelin become scarred and can no longer fully insulate the nerve – leaving unprotected areas, where

the flow of nerve impulses is interrupted. Additionally, nerves (or axons) eventually experience damage as well, and these damaged nerves are unable to efficiently conduct impulse flow. This interruption in the communication between the brain and other parts of the body results in the symptoms experienced by individuals with MS.

What tools are used to evaluate MS activity?

Lesions may be viewed by a **magnetic resonance imaging (MRI)** scan of the brain and/or spine. The MRI uses a computer, radiofrequency stimulator, and a large electromagnet to provide a picture of the brain. For those with MS, the MRI is used to evaluate the size and location of lesions. Inflammation can be better evaluated with **gadolinium-enhancement** – a type of dye given to the patient via injection prior to the procedure.

Magnetic resonance spectroscopy (MRS) is a procedure used to provide an anatomical picture of lesions. MRS also provides important information about the **biochemistry** of the brain in MS, indicating the types of immune-system cells and other substances found in and around a lesion. Presently, the MRS is primarily used as a research tool.

A **lumbar puncture** (also known as a **spinal tap**) is a procedure where a very thin needle is inserted at the base of the spine and a small amount of **cerebrospinal fluid** (CSF) is collected. CSF is the liquid that surrounds the brain and spinal cord. By collecting a small amount of this fluid, labora-

Magnetic Resonance Imaging (MRI) scanner

tory testing may be performed to evaluate cellular and chemical abnormalities. The neurologist will particularly be looking for **oligoclonal** bands, which are abnormal immune proteins called **immunoglobulins**. These are present in the CSF of roughly 90 percent of individuals with MS, however, they can occur with several other neurological disorders. Since the introduction of the MRI, CSF analysis is used less often, but it can be helpful in supporting an MS diagnosis if the MRI results are normal or inconclusive.

Evoked potential (EP) tests may also be used to help diagnose MS. These tests are especially useful when findings on the MRI scan are normal or inconclusive. Evoked potentials measure the speed of the brain's response to visual, auditory (sound), or sensory (feeling) stimuli, using electrodes taped to the patient's head. Delayed responses can indicate possible damage to the nerve pathways.

In addition to the procedures listed, doctors have several evaluative tools available to help assess a patient's condition. Through these universally accepted systems of measurement, physicians can record their patients' presenting condition and subsequent improvements, relapses, or disease progression. These systems are particularly valuable to clinical trials.

The most widely known scale among the MS community is the Kurtzke **Expanded Disability Status Scale (EDSS)**. Kurtzke, a physician, first introduced this system in 1955 as the Disability Status Scale (DSS). It used whole numbers from one to 10 to measure degree of disability, largely in terms of mobility.

To make the measurements more sensitive, Kurtzke "expanded" the scale by adding half-points between the numbers. The EDSS is used in conjunction with Kurtzke's **Functional System (FS)**. This measures the function of seven major systems in the CNS (plus a section for "other"), each relating to the different areas of functioning that can be affected by MS (such as movement, sensory, bowel and bladder, vision, cognition, etc.). These are

each graded on a scale of zero (normal) to six (severe).

A newer measurement system designed to be even more sensitive is the **MS Functional Composite (MSFC)** scale. This measures lower extremity function with a **Timed 25-Foot Walk**, upper extremity function through the **9-Hole Peg Test (9-HPT)**, and cognitive function, using the **Paced Auditory Serial Additions Test (PASAT)**.

How are drugs and treatments developed?

Clinical trials are conducted to ensure the safety and efficacy of potential treatments for a multitude of diseases and conditions, including MS. Studies conducted in the United States need to be reviewed and approved by the FDA. More drugs to treat MS are being tested than ever before, but prior to their approval, various phases of clinical trials must be successfully completed.

A **Phase I trial** tests for safety in humans and its sampling is small, with typically less than 100 "healthy" volunteers. Investigators may observe how the human body responds to the medication (how the drug is absorbed, metabolized, and excreted). The researchers also will determine safe doses and related side effects. Phase I trials are referred to as "**open label**" and "**unblinded**," because everyone – the patient, medical staff, and investigators, knows the drug and dose that each participant is receiving. Phase I trials can take several months to one year to complete. Sometimes a few individuals who have the disorder (such as MS) will be given the drug to study its effects before going on to the next phase. About 30 percent of medications being studied for MS do not continue beyond Phase I testing.

The next phase of study for experimental drugs is the **Phase II clinical trials**, which typically run for several months to two years. In this phase, approximately 100 to 300 people with the disorder (in this case, MS) are given either the active drug or a **placebo** (a medication that looks the same as the drug being tested but has no active ingredients or physical value of any kind). Phase II studies are often "**double-blinded**." This means that neither the participants nor the medical staff administering or evaluating the new treatment are told who is receiving the drug and who is receiving the placebo. These studies are also "**randomized**," so that participants are assigned to treatment groups (or "**treatment arms**") based on chance. Examples of treatment groups include active drug versus placebo, or high-dose versus low-dose, etc.

Roughly one-third of experimental medications for MS reach the **Phase III clinical trial level**. These trials can take several years to complete and involve 1,000 to 3,000 participants receiving treatment and evaluation at many different medical locations. These studies are randomized, placebo-controlled, and double-blinded. They are designed to provide more information on a potential drug's safety and **efficacy** (effectiveness), as well as additional benefits, side effects, and adverse reactions.

More than two-thirds of the drugs that enter Phase III studies successfully complete

this phase. Upon completion, a **data analysis** is performed to determine the overall effectiveness and safety of the drug or therapy. If the results are favorable, an **application for approval** of the drug is submitted to the FDA, whose panel reviews the results and recommends approval if it finds the treatment to be beneficial and safe.

Phase IV clinical trials are conducted after a drug has been approved. Participants are enrolled to further monitor safety and side effects, while evaluating long-term efficacy.

What drugs are presently approved for the long-term treatment of MS?

Six FDA-approved, long-term treatments for MS are available. Many experts now recommend treatment as early as possible with one of these approved, disease-modifying agents. Research has shown that treating after the first attack can significantly delay the amount of time to the second attack. Early treatment is also thought to possibly limit axonal (nerve) injury, which may be irreversible, and later lead to a progressive form of MS.

The FDA-approved long-terms treatments for MS are: **Avonex**® (interferon beta-1a); **Betaseron**® (interferon beta-1b), **Copaxone**® (glatiramer acetate); **Rebif**® (interferon beta-1a); **Novantrone**® (mitoxantrone), and **Tysabri**® (natalizumab). All but Novantrone have been approved to treat RRMS (relapsing-remitting MS).

Novantrone is the first drug approved to treat worsening RRMS, PRMS, and SPMS (secondary-progressive MS). Patients may only be given one of these drugs during any one time period, although trials with combinations of these drugs are being conducted.

Results from several large clinical trials have found that all of these drugs reduce the number and severity of relapses, as well as the development of new areas of inflammation as seen on MRI. These studies also showed some evidence of delaying disease progression on a short-term basis.

Avonex, Betaseron, Copaxone, and Rebif are all long-term treatments that may be given via **self-injections** at home – ranging from weekly to daily doses. These four drugs have long-term data supporting safety as well as efficacy, and are usually the first-line of treatment prescribed by the treating

physician.

Novantrone and Tysabri are administered via **intravenous infusions** (injected directly into the blood stream) at hospitals or infusion centers. Novantrone is given once every three months for a maximum of two-to-three years (to avoid damage to the heart). Tysabri is given once every four weeks, and as the newest drug approved, it does not have a set time limit or maximum number of doses. Either of these drugs may provide stronger results, but they also carry bigger risks. Physicians typically reserve these stronger treatments for patients who do not respond to any of the first four medications mentioned.

For more information

Readers may refer to the cover story in this issue titled, "MS Research Update." This provides updates on study findings, approved medications, and experimental treatments for MS. The terminology given in this Health and Wellness article should be helpful while reading the more in-depth cover story.

For additional information about MSA and to learn about MSAA's programs and services, please visit MSAA's website at **www.msassociation.org**, or call MSAA's Helpline at **(800) 532-7667**. MSAA also has many related publications available on MS and its treatments, including articles appearing in past issues of *The Motivator*; brochures; and specifically, a monograph titled, Understanding Clinical Trials. These are all available through the website and phone number listed above. u

Original photo by Kris Cox

Up, Up and Away!

Written by Judy Heath

I had always dreamed of taking a hot-air balloon ride… someday. With the diagnosis of multiple sclerosis (MS) several years ago, I was forced to either change how I achieved my dreams, or stop dreaming. I chose the former. And since hot-air ballooning has always been romantically appealing to me, it was a dream I planned to keep.

Sometimes, people ask if I feel limited as a wheelchair user. Absolutely… not! Thanks to a sense of adventure and daring ideas, this wheelchair user challenges the norm. As a person with MS, take it from someone who has continued to live an active lifestyle with sometimes creative and perhaps unconventional adaptations. I feel challenged to try to keep my active lifestyle, but it does require some minor changes to the how, when, and where I can do things. A simple matter of preparedness and a little double-checking can make the difference between fun and frustration.

Despite any limitations, I learned on Mother's Day that my dream might soon become a reality. Upon opening a Mother's Day card, I had a surprise I could never have expected: a gift certificate informing me of an appointment for the launch of a lifetime. My adult children surprised me with the trip of my dreams – a ride in a hot-air balloon!

My hot-air balloon adventure was set to begin early one morning in summer. While it was still dark outside, I received a wake-up call from a friend, and I was soon ready to embark on a new adventure. By the time we arrived at the launch site, daylight was increasing and the winds and weather seemed perfect. My ballooning adventure began with meeting the pilot and crew.

Shivering in anticipation, I watched my dream take shape as the crew began inflating the immense balloon. I observed intently as the assembling was systematically carried out. Soon the balloon was ready for the flight. It was almost surreal in the dusky quietness of the morning with only the sounds of propane burners in the air. About six other balloons were being prepared for flight that morning too.

As the heated air filled the balloon, it slowly lifted from the ground. Soon all was ready for liftoff; I just needed to get into the gondola (basket). With my arms around the shoulders of the assistants, I was lifted up, over, and into the basket. Now my anticipation knew no limits. As the balloon struggled to take flight, the ropes were untied and suddenly we were headed skyward!

What an awesome sensation it was to feel myself being lifted away from the ground in a silent whisper. I had no real

"I felt completely secure as I leaned against the wicker basket, watching the earth fall away."

A Mother's Day gift for Judy Heath began her hot-air balloon adventure. In this photo, Judy is pictured with her four children (from left to right) Tamara Meckel, Peter Craig, Aaron Craig, and Lance Craig.

sense of motion; just the visual changes in the landscape told me we were airborne. It was such a gentle liftoff. I don't know what I was expecting. I felt completely secure, as I leaned against the wicker basket, watching the earth fall away.

As we were traveling with the wind, I felt no rush of air, in spite of the coolness of the morning. Once up and away, we floated silently over farmland. I heard the slam of the porch door as the farmer headed out to his morning chores. I also heard the morning sounds of barking dogs and voices of people talking as they carried on their conversations, unaware of the balloon and its passengers overhead.

I felt no movement as I drifted with the wind. All was silent except for the occasional noise of the burner. How small everything appears from your vantage point up among the clouds! Miniature roadways carry tiny cars. The different hues of green and gold show you waterways and wetlands. The balloon sailed quietly off in the direction of a farm I had passed earlier that morning on my pre-flight drive to the launching area.

Silently we floated over the lush spring-green fields of Oregon's Willamette Valley. I was breathless as the morning sunrise glowed into the new day. It was all so spectacular… the balloon ride, the sunrise, and the opportunity to fulfill my life-long dream. Gently we glided over the roads, now busy with traffic.

I had a very definite sense of the uniqueness of this experience. This was a feeling I would treasure and hold tight in my heart, especially on the tougher days when the world isn't so bright and beautiful. Reluctantly, I watched as the landing site came into view. My adventure was quickly ending, but I knew the experiences I had on this trip would be with me forever.

As the air was slowly let out of the balloon, the basket gently bumped to the ground. Suddenly, eager helping hands were guiding the balloon to its resting stop while my heart was still soaring above the treetops. Following the touchdown and the stowing of the balloon, we celebrated in the traditional way – including a toast with sparking cider and a delicious picnic lunch.

Dreams do come true. This well-planned adventure has been one of the most memorable challenges I have ever accomplished! u

Original photos by Kris Cox

About Hot Air Ballooning

The first hot-air balloon flight took place in Paris more than 200 years ago. The craft was made of paper and silk, with two noblemen from the court of Louis XVI and Marie Antoinette piloting the balloon on its 22-minute flight. The pilots were offered champagne to celebrate their first flight, and this tradition is carried on to this day.

If you are interested in hot-air ballooning and you have a disability, first check with your physician to make sure that taking a ride would not pose any health issues. With your doctor's approval, contact the individuals who manage or own a hot-air balloon business in your area, to discuss your special needs. Be honest with yourself regarding your limitations and be sure to request assistance wherever needed. In my adventure, I discovered that people are always willing to help if you are willing to ask. Once on a flight, provided you are having no problems, assuring others that you are okay will help your companions to relax and enjoy themselves as well. u

THE PHILANTHROPY CIRCLE

MSAA gratefully thanks foundations and corporations for their generosity and commitment to people affected by MS.

FOUNDATIONS ($10,000 or more)

The Chatlos Foundation
The Horizon Foundation for New Jersey
Medtronic Foundation

CORPORATIONS ($10,000 or more)

Avanir Pharmaceuticals
Bayer HealthCare Pharmaceuticals
EMD Serono, Inc. and Pfizer Inc
Novartis Pharmaceuticals Corporation
Teva Neuroscience

¿Habla Usted Español?

MSAA's Bilingual Helpline Offers Assistance for the Spanish-Speaking MS Community

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 enrich the quality of life for everyone affected by 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.

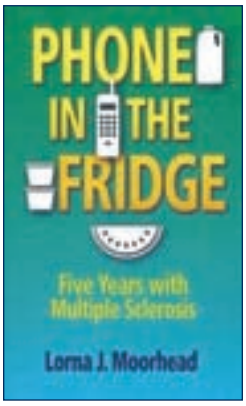
This service has been made possible through the support of The Medtronic Foundation.

Spread the Word

There is Room at the Inn

Written by Candy B. Harrington
Published by Demos Medical Publishing
MSAA Book #274

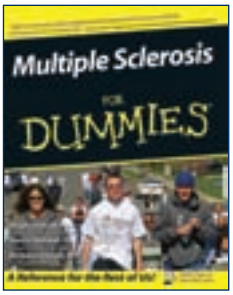
Individuals with mobility issues who plan to visit an inn or bed & breakfast (B&B) will surely want to consult this excellent reference on accessible places to stay. In addition to providing detailed reviews of 117 properties in 40 states, this book also includes photos of many of the inns and rooms, as well as suggestions for accessible sightseeing in the surrounding areas. Featured lodging choices range from quaint B&Bs to mountain retreats, a dude ranch, and even two safari parks.



Phone in the Fridge

Written by
Lorna J. Moorhead
Published by Pathfinder Publishing Inc.
MSAA Book #44

Subtitled *Five Years with Multiple Sclerosis,* Lorna Moorhead writes about her experiences since her diagnosis – using a humorous, honest, and optimistic approach. The author talks about many of the issues involved with MS, such as the struggle for a diagnosis, dealing with symptoms, taking medications, trying alternative treatments, and her often-amusing interactions with friends and family.



Multiple Sclerosis for Dummies

Written by Rosalind Kalb, PhD, Nancy Holland, EdD, RN, and Barbaba Giesser, MD
Published by Wiley Publishing, Inc.
MSAA Book #127

This huge reference is part of the "For Dummies" book series, which gears information for "beginners." *Multiple Sclerosis for Dummies* presents a wealth of MS facts and advice in an easy-to-read format, often using bullets, checkmarks, and icons. It covers a host of topics, from diagnosis and symptom management, to staying healthy and planning for a future with MS.

MSAA Lending Library

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

MSAA Lending Library
Attn: Woody Dyer
706 Haddonfield Road
Cherry Hill, NJ 08002

(Please reference book number)

MSAA has recently published a book to help young children understand MS:

Mommy's Story

An introduction for younger children to learn about a parent's MS

This publication was written to encourage parents with multiple sclerosis to begin the conversation about the diagnosis and ongoing implications of MS with young children. This book is suitable for children ages three to seven.

You may request a copy of **Mommy's Story** by contacting MSAA at **(800) 532-7667**, **extension 129**. You may also visit MSAA's website at **www.msassociation.org**, select "Publications," and complete the order form. In addition, MSAA publications can be viewed and downloaded from **www.msassociation.org**.

N O W A V A I L A B L E :

Thinking about Complementary and Alternative Medicine?

An Introduction for People with MS on How to Find and Evaluate Claims about Complementary and Alternative Medicine

Written by Thomas M. Stewart, JD, MS, PA-C and Allen C. Bowling, MD, PhD.
Both authors are from the Rocky Mountain MS Center in Englewood, Colorado.

This monograph has been created in honor of MSAA's Chief Medical Officer Jack Burks, MD, in recognition of his personal dedication to the MS community, as well as his long-standing commitment to MSAA.

You may request a copy of Thinking about Complementary and Alternative Medicine by contacting MSAA at (800) 532-7667, extension 129, or visit MSAA's website at www.msassociation.org.

This monograph has been made possible through a grant from Berlex.