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The MOTIVATOR

Summer 2009

Bringing Information to People with Multiple Sclerosis

MS Research UPDATE 2009

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MSAA™
Multiple Sclerosis Association of America

The MOTIVATOR

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2008 APEX Awards for Publication Excellence

A portion of this magazine has been printed on recycled paper using soy-based ink.

COVER STORY

DEPARTMENTS

MSAA™ Multiple Sclerosis Association of America

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

MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

Up Front

By Douglas G. Franklin
MSAA President and CEO

Douglas G. Franklin

Despite the challenging economic times, I am pleased to report that supporters of MSAA continue to help us fulfill our mission in so many ways. Our Board members have been very attentive to our needs as we look to keep our vital programs and services strong while maintaining fiscal sustainability.

This spring, two important medical conferences were held: the American Academy of Neurology (AAN) Annual Meeting in Seattle and the Consortium of MS Centers (CMSC) conference in Atlanta. This edition of *The Motivator* highlights updates from these two conferences. We are pleased to provide fair and balanced information for our readers.

While in Atlanta, the Multiple Sclerosis Coalition (MSC) held its annual meeting. At this meeting I was asked to serve another three-year term as MSC President, and we welcomed two new members: the International Organization of Multiple Sclerosis Nurses and the United Spinal Association, bringing the total number of members to nine. Our unified effort is tremendously important to addressing critical issues for the MS population.

"Supporters of MSAA continue to help us fulfill our mission...we look to keep our vital programs and services strong while maintaining fiscal sustainability"

Social media continues to grow with our use of Facebook and YouTube. Please look for MSAA on these sites. While online, please also visit MSAA's blog, "Life Lessons," at **www.msassociation.org**.

In closing, the growth of programs, services, and educational forums throughout our regional offices hit record highs this year. It is a tribute to all of the hard work and dedication of the great team we have here at MSAA. Together, we will continue to serve more people in more places with quality programs and caring support. ◆

Doug Franklin joined MSAA as President & CEO in 1999. He has a distinguished career in nonprofit leadership and is a former national trainer in strategic planning for the Peter Drucker Foundation. A published international expert in social marketing and corporate social investment, 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; on the Executive Committee of Health First – America's Charities Board in Washington, DC; and as President of the Multiple Sclerosis Coalition.

MS Research UPDATE 2009

A comprehensive overview of the six FDA-approved disease-modifying therapies used to slow MS activity, along with initial findings on many experimental treatments presently being studied for the treatment of MS.

Written by Dr. Diana M. Schneider
Reviewed by Dr. Jack Burks
Edited by Susan Wells Courtney

Based on the positive response to the "MS Research Updates" appearing in the Summer 2007 and 2008 issues of *The Motivator*, this article incorporates new information about the six approved disease-modifying therapies (DMTs), as well as experimental drugs currently being studied for the treatment of MS. Highlights and recent research results are provided for each drug. This is not a complete list and not all studies and their results are included. Initial study results should be considered preliminary, as additional studies and/or evaluations may be needed.

This information is based on a wide range of sources, including the extensive journal literature on MS and its management, a review of ongoing clinical trials, and papers presented at major national and international conferences. These include the American Academy of Neurology (AAN), the Consortium of Multiple Sclerosis Centers (CMSC), and the American and European Committees for Treatment and Research in Multiple Sclerosis (ACTRIMS and ECTRIMS).

A brief overview of MS terms and clinical trials has been included on the next page. For additional information, the "Health and Wellness" column from the Summer 2007 issue of *The Motivator* gives an overview of MS terminology, evaluative procedures, clinical trials, and treatments. To request a copy, please call MSAA at **(800) 532-7667** or view it online at **www.msassociation.org/publications/summer07/health.asp**.

Please note that this article does not include medications for managing the symptoms of MS. Treatments for symptom management are the subject of an article in the Winter/Spring 2009 issue of *The Motivator*. To view, download, or print a copy, please go to **www.msassociation.org/publications/winter09/cover.story.asp**.

Editor's note: MSAA does not endorse or recommend any specific products or therapies. Readers are advised to consult their physician before making any changes to their medication, diet, exercise, or other regimen.

An Overview of the MS Process, Terminology, and Clinical Trials

Eighty-five percent of people with multiple sclerosis (MS) begin with relapsing-remitting MS (RRMS), with temporary symptom flare-ups or "relapses." If untreated, 90 percent advance to secondary-progressive MS (SPMS) within 25 years, experiencing a progressive worsening of symptoms. The majority of individuals not initially diagnosed with RRMS are diagnosed with primary-progressive MS (PPMS), which involves a gradual but steady accumulation of neurologic problems, without relapses or remissions. A small percentage of patients have progressive-relapsing MS (PRMS), which is a progressive course from the onset with acute relapses.

MS is a neurologic disorder affecting the nerves of the central nervous system (CNS), consisting of the brain, optic nerves, and spinal cord. Nerve fibers (axons) have a protective, fatty-rich protein covering known as myelin. With MS, the body's immune system malfunctions and sends disease-fighting cells into the CNS to destroy its own myelin.

To reach the nerves within the CNS, the immune system cells and molecules must cross a protective barrier that lines the brain's blood vessels, the blood-brain barrier (BBB). The immune system's white blood cells include lymphocytes. These may be B cells, which produce antibodies to fight against "foreign invaders" (such as bacteria or viruses), or T cells, which help to regulate the immune response. Another type of white blood cell is the macrophage, which ingests and destroys foreign substances.

The attack creates inflammation along the nerves where the myelin and axons are experiencing damage. These areas of disease activity are lesions. With the help of oligodendrocytes (cells that produce and maintain myelin), damaged myelin may be restored through remyelination, particularly early in the disease. Lesions may be viewed by a magnetic resonance imaging (MRI) scan of the brain and/or spine. Inflammation can be better evaluated with gadolinium enhancement – a type of dye given to the patient via injection.

The Kurtzke Expanded Disability Status Scale (EDSS) gives scores from one to 10 to measure disability, largely in terms of mobility. Other assessment scales for MS include Kurtzke's Functional System (FS) and the MS Functional Composite (MSFC).

Clinical trials ensure the safety and efficacy (effectiveness) of potential treatments. Studies conducted in the United States need to be reviewed and approved by the Food and Drug Administration (FDA).

Phase I trials test for safety in humans. They are usually small, and typically involve fewer than 100 "healthy" volunteers. Investigators usually observe how the human body responds to the medication, determining safe doses and related side effects.

Phase II trials typically run up to two years. About 100 to 300 people with the disorder (in this case, MS) are given either the active drug or a placebo to determine a drug's safety and efficacy.

Phase III trials can take several years to complete and involve 1,000 to 3,000 participants at different medical locations. These trials evaluate safety and efficacy, as well as additional benefits and adverse reactions. If the results are favorable, an application for approval is submitted to the FDA.

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

For more information, please refer to the "Health and Wellness" column of the Summer 2007 issue of *The Motivator*. MSAA also offers a monograph titled, *Understanding Clinical Trials*. To view, download, or order free copies online, please visit MSAA's website at www.msassociation.org. To order free copies by phone or to speak with a Helpline consultant, please call MSAA at (800) 532-7667.

Avonex® (interferon beta-1a)

Parent company: *Biogen Idec*

Taken via weekly intramuscular injections; dosage is 30 mcg.

Approved for relapsing forms of MS and for individuals with clinically isolated syndrome (CIS). "CIS" is defined as a single attack (or appearance of one or more symptoms characteristic of MS) with a very high risk of developing MS, when no other diseases are apparent.

Avonex has been shown to reduce the number of relapses and lesions on MRI, as well as slowing the progression of physical disability.

Interferons appear to reduce inflammation by modulating a favorable balance between cells that increase inflammation and cells that decrease it.

An extension of the CHAMPIONS study will continue to evaluate whether immediate initiation of therapy after a first attack continues to delay the development of further attacks and neurologic disability over 10 years.

The ASSURANCE 15-year follow-up study is evaluating the longer-term impact on the development of disability of early versus delayed initiation of therapy in relapsing-remitting MS (RRMS). Of the 172 participants who completed the original study, about half are still using Avonex, and significantly fewer of these individuals have reached a disability status of 6.0 or greater than those who did not continue treatment. Some patients in the study have used Avonex for up to 17 years. The study is attempting to identify factors that predict a positive response, with no significant clinical disease progression with long-term continued use.

A new Phase III trial is now recruiting individuals with RRMS to test BIIB017, a "pegylated" interferon beta-1a. Pegylation is a chemical modification of the interferon beta-1a molecule that will allow it to be given subcutaneously (under the skin) every two or four weeks, in contrast to the current once-a-week intramuscular (deeper) injection. This drug was recently granted "Fast Track" designation by the United States' Food and Drug Administration (FDA). This program allows for faster approval of new drugs which are found to be effective in treating serious conditions.

Combination and Comparative studies: The ongoing three-year, Phase III CombiRx trial for RRMS is comparing three treatment arms: Avonex with Copaxone, Avonex alone, and Copaxone alone.

The ACT trial evaluated Avonex in combination with methotrexate, intravenous methylprednisolone, or both. Methotrexate is an immunosuppressive drug and methylprednisolone is a steroid that decreases inflammation. Data suggested that adding these medications might be helpful in patients on Avonex who have continuing active disease.

A study of individuals with RRMS that combines Avonex with Cellcept® is ongoing. Cellcept is an oral immunosuppressant medication used to prevent transplant rejection.

Betaseron® (interferon beta-1b)

Parent company: *Bayer HealthCare Pharmaceuticals*

Administered by subcutaneous injection every other day; dose is 250 mcg.

Approved for relapsing forms of MS and individuals with CIS.

Betaseron reduces the number and severity of exacerbations (attacks) of MS. It also stabilizes the total lesion area as compared to those without treatment.

Interferons appear to reduce inflammation by modulating a favorable balance between cells that increase inflammation and cells that decrease it.

The BENEFIT trial evaluated the impact of Betaseron on patients with CIS. The risk for developing clinically definite MS (CDMS) was reduced by 41 percent at two years versus placebo-treated patients. The risk for confirmed progression of sustained disability was reduced by 40 percent at three years in those receiving Betaseron from the onset of CIS, versus those people whose treatment was delayed. A positive effect on cognition has also been demonstrated over the five years of the study.

Follow-up data after 16 years from Betaseron's pivotal placebo-controlled trial of RRMS, which led to marketing approval of the drug, show continued effectiveness and safety. The results suggest that early treatment was more effective when given at the first sign of the disease than if treatment is delayed.

A new, thinner-gauge needle and autoinjector provide for greater satisfaction and comfort. These improvements are associated with fewer injection-site reactions, which can enhance compliance and increase comfort.

Combination and Comparative studies: The BRIGHT study of the relative tolerability of Betaseron versus Rebif favored Betaseron. Rebif has been reformulated but this newer formulation is not yet available in the United States; it may become approved in the near future.

In the BECOME study, new MRI techniques compared Betaseron to Copaxone in RRMS. The study found that enhancing lesions and clinical data were similar.

The BEYOND study compared Betaseron versus double-dose Betaseron versus Copaxone. All were well tolerated, while dramatically and equally reducing relapses. The T2-lesion volume MRI data favored Betaseron. As a result of this study, double-dose Betaseron will not be pursued since it was no more effective than the standard dose of Betaseron or Copaxone in clinical outcomes.

Rebif® (interferon beta-1b)

Parent companies: *EMD Serono, Inc. and Pfizer Inc*

Administered by subcutaneous injection three times weekly; dosage is 22 or 44 mcg. The 44 mcg dose appears significantly more effective than 22 mcg.

Approved for relapsing types of MS.

Rebif reduces the frequency of relapses and slows the progression of disability. It also has been shown to reduce MRI lesion area and activity compared to placebo.

Interferons appear to reduce inflammation by modulating a favorable balance between cells that increase inflammation and cells that decrease it.

The Rebif new formulation (RNF) is designed to minimize the development of neutralizing antibodies that may decrease the response to treatment. A 96-week study demonstrated that it is better tolerated than the original formulation; it results in less injection-site reactions and pain. Fewer neutralizing antibodies (NABs) were seen with RNF. The completed IMPROVE trial documented the efficacy of RNF in RRMS, as measured by the number of active lesions on MRI at 16 weeks. This formulation is not yet available in the United States, but it may be approved in the near future. An ongoing study will evaluate the effect of RNF on quality of life, tolerability, treatment satisfaction, and injection-site redness.

A once-weekly dose of Rebif previously demonstrated an effect on delaying CDMS. An ongoing study is looking at the use of Rebif 44 mg four times per week for CIS to confirm its effectiveness in delaying the conversion to CDMS.

A 96-week trial of methylprednisolone as an add-on to Rebif is reported to significantly reduce the relapse rate in participants who showed clinical activity during interferon therapy.

Combination and Comparative studies: In one study, the combination of Rebif with atorvastatin (Lipitor®) increased MRI and clinical disease activity, suggesting that statins may block the therapeutic effects of interferons. However, two other studies did not support this, and more data are needed.

A study now recruiting will combine Rebif with minocycline (an inexpensive antibiotic that has immunomodulatory properties). The primary outcome is time to the first documented relapse.

A comparison of Rebif versus Copaxone showed an equal and robust effectiveness in reducing relapses (primary outcome). Some MRI outcomes were better for the group treated with Rebif.

Copaxone® (glatiramer acetate)

Parent company: *Teva Neuroscience, Inc.*

Given through daily subcutaneous injections; dosage is 20 mg.

Approved for RRMS.

It has been shown to significantly reduce the annual relapse rate in relapsing-remitting individuals.

Copaxone is a synthetic protein that mimics myelin basic protein, a key component of the myelin sheath that is damaged in MS. It appears to block immune system T cells that damage myelin, and may decrease inflammation by shifting the balance among T-cell subtypes, as well as other effects.

Data is now available for 15 years of Copaxone® treatment. Approximately one-third of patients experienced disease progression, but more than 80 percent remain ambulatory without mobility aids. This group will continue to be followed to 20 years.

The Phase III, 36-month PreCISe study has shown a successful delay in the conversion of clinically isolated syndrome (CIS) to clinically definite MS (CDMS), as well as a reduction in MRI activity. Evidence suggests that the mechanism of action may include a neuroprotective component that prevents damage to axons. It also may induce lymphocytes to produce factors that enhance the survival of cells that produce myelin.

An Austrian study indicated that a switch from interferon beta treatment to Copaxone was beneficial for individuals who discontinued interferon treatment because of a lack of effectiveness, whereas those who transferred due to side effects showed no substantial change on Copaxone.

Preliminary evidence suggests that long-term maintenance treatment with glatiramer acetate treatment following immunosuppressive therapy with Novantrone may be effective and well tolerated for individuals with rapidly progressive MS and may stabilize the disease.

Combination and Comparative studies: The COMBI Rx trial is still ongoing, and is comparing the combination of Avonex plus Copaxone to Copaxone alone and Avonex alone.

A Phase II study of Copaxone taken with oral minocycline found that the combination reduced the number of new and active lesions. The two drugs were also reported to be safe and well tolerated when taken concurrently.

A trial to study the effect of combining Copaxone and estriol (a naturally occurring estrogen hormone) in RRMS on relapse rate is currently recruiting. It will evaluate relapse rate, severity of relapses, and changes in the EDSS.

A study of prednisone (a steroid) in 500 relapsing MS patients treated with Copaxone is ongoing. The trial will evaluate changes in brain volume after three years as its primary outcome.

Tysabri® (natalizumab)

Parent companies: *Biogen Idec and Elan Pharmaceuticals, Inc.*

Administered via intravenous infusion every four weeks. Dose is 300 mg.

Approved for individuals with relapsing types of MS. This drug is generally recommended for patients who have not responded adequately, or who cannot tolerate, another treatment for MS.

Tysabri has been shown to reduce the number of relapses and slow disease progression. It also reduces the number of lesions in the brain as seen on repeated MRI scans.

This laboratory-produced monoclonal antibody acts against a molecule involved in the activation and function of lymphocytes and their migration into the central nervous system (CNS). Recent data suggest that it may also enhance myelination and stabilize damage to the myelin sheath. Preliminary results suggest that the drug may actually produce an improvement in function.

Recent studies indicate that the drug increases the cumulative probability of achieving a sustained improvement in disability in RRMS, and substantially reduced clinical and MRI activity after breakthrough disease on other therapies.

Following a suspension of the drug after two patients developed Progressive Multifocal Leukoencephalopathy (PML), an often-fatal viral infection of the brain, Tysabri was re-released. All patients now receive the drug through safety monitoring programs such as the Tysabri Outreach: Unified Commitment to Health (TOUCH™) Prescribing Program and registered infusion centers and pharmacies; and the international Tysabri Global ObseRvation Program In Safety (TYGRIS). Approximately 56,700 patients have been treated with the drug worldwide, with about 35,000 currently taking it; there have been 10 reported cases of PML since the re-release, in addition to the two cases seen in the early trials. Studies are ongoing to see if it is possible to predict which individuals may be at risk for this condition.

Some side effects include liver damage, a three-fold increased incidence of herpes zoster infections, occasional infections of a variety of types, and rare instances of anemia that are easily treatable.

The drug shows continued effectiveness, as measured by a reduction in relapses, favorable MRI data, and a reduction in progression of disability. It also shows promise as a therapy in patients who had a previously poor response to other disease-management agents. It significantly improves patients' perception of health-related quality of life, reduces MS-associated pain, has at least a mild positive effect on fatigue and depression, improves fatigue and cognitive function, and may reduce loss of vision associated with RRMS.

FDA-APPROVED MEDICATIONS

Novantrone® (mitoxantrone)

Parent company: *EMD Serono, Inc.*

Given via intravenous infusion once every three months for a maximum of two-to-three years. The total dose that can be taken is limited to avoid the risk of damage to the heart. Dose varies according to an individual's weight.

Novantrone is approved for use in SPMS, progressive-relapsing MS (PRMS), worsening RRMS, and people who are not responding favorably to standard therapies.

It appears to delay the time to a first-treated relapse, reduces the number of relapses, delays the time to disability progression, and decreases the number of new lesions that can be detected by MRI. It also appears to stabilize disease activity in some individuals with SPMS.

Novantrone is an immunosuppressant that has been used for years to treat cancer. It targets rapidly dividing cells, including those believed to be involved in MS. Side effects may include cardiac disease and leukemia; patients are closely monitored to minimize these risks.

Preliminary evidence suggests that low-dose Novantrone may be used as an add-on rescue therapy in RRMS patients who respond poorly to other DMTs. The anti-inflammatory response was evident after six months.

Combination and Comparative studies: A study to evaluate the use of Novantrone before Copaxone treatment, versus treatment with Copaxone alone, found beneficial results as measured by annual relapse rates in the Novantrone-induced group.

EXPERIMENTAL ORAL MEDICATIONS

Statins

Statins are oral medications most commonly prescribed to lower cholesterol. Their anti-inflammatory properties make them of interest for possible use in MS.

A number of studies are ongoing, primarily in CIS and RRMS. Studies are either alone or in combination with the interferons, Copaxone, or other agents approved for use in MS.

The effects of statins combined with interferons are controversial and mixed, and additional data are needed to evaluate conflicting results.

EXPERIMENTAL ORAL MEDICATIONS

Cladribine

Parent company: *EMD Serono, Inc.*

This drug is given orally once or twice a year, depending on the study regimen. It is currently used in an injectible form to treat leukemia.

Based on studies of injectible cladribine showing an average 90-percent reduction in gadolinium-enhancing lesions and a marked reduction in relapse rate, the orally administered form was designated by the FDA as a Fast Track product for relapsing forms of MS, for potentially quick approval. It may be approved by the FDA within a year.

This drug causes a preferential and sustained depletion of specific classes of T cells in the immune system. It also seems to directly influence the overall T-cell response.

The two-year Phase III CLARITY trial of two levels of cladribine versus placebo met its primary end point, showing 55 to 58-percent reductions in annualized relapse rates. In the ongoing two-year extension study, all participants will receive cladribine.

The ONWARD Phase II study of 200 individuals who have experienced at least one relapse while taking Rebif is now recruiting. This study combines oral cladribine with Rebif.

The Phase III ORACLE MS study will assess the safety and efficacy of two doses of oral cladribine versus placebo in individuals who have had a CIS. The study is currently recruiting participants.

Laquinimod

Parent company: *Teva Neuroscience, Inc. and Active Biotech*

Oral medication taken daily.

Laquinimod is being studied in RRMS. It is an immunomodulator, and may have other mechanisms of action.

A Phase II, 36-week trial showed a 40-percent reduction in disease activity as measured by MRI, a trend toward reduction in annual relapse rates, and a delay in the time to first relapse; the drug was well tolerated. A continuation of this study is ongoing, and is assessing the safety, tolerability, and efficacy of two doses of laquinimod in subjects with RRMS followed by an open label phase of laquinimod 0.6 mg daily. Preliminary data suggest that the drug reduces disease activity on MRI and has good tolerability.

The ongoing BRAVO study is comparing laquinimod to Avonex. Outcome measures are relapse rate, the accumulation of disability, and disease activity on MRI.

The ongoing placebo-controlled ALLEGRO study will determine the efficacy of daily oral treatment with laquinimod in RRMS. Its outcome measures include the number of confirmed relapses, the accumulation of physical disability, and MRI changes during the two-year study period.

EXPERIMENTAL ORAL MEDICATIONS

BG00012 (BG 12; fumarate; fumaric acid esther)

Parent company: *Biogen Idec*

Oral medication taken daily.

This drug may have a distinct dual mechanism of action. It is an immunomodulator with anti-inflammatory properties that appears to suppress macrophage activity (immune cells that stimulate lymphocytes) as part of its anti-inflammatory activity. It also may have neuroprotective effects; this is due to its activation of a substance that is critical for resistance to cellular damage from what is termed "oxidative stress," as well as for normal immune function. It is being studied in RRMS.

Ongoing studies continue to show a reduction in the formation of new gadolinium-enhanced lesions compared to placebo, a significant reduction in relapse rate, and decreased disease activity on MRI

The Phase III DEFINE and CONFIRM studies continue to recruit participants. The DEFINE study is comparing two doses of BG00012 against placebo in 1,011 patients; the CONFIRM study is testing two levels of the drug against Copaxone and placebo in 1,232 patients.

Trials to date indicate that the drug is safe, and that its overall tolerability improves with continued use. A long-term Phase III efficacy and safety study is enrolling approximately 1,700 individuals who participated in earlier trials.

Teriflunomide

Parent company: *Sanofi-aventis*

Oral medication taken daily.

This drug is an immunomodulator that affects the division of T cells.

A Phase II trial of RRMS evaluated two dose levels versus placebo. The treated groups had significantly fewer enhancing lesions and a lower relapse rate; fewer patients in the high-dose group experienced an increase in disability versus placebo, and there was a trend toward more relapse-free patients. Treatment was well tolerated. An extension of this study will document the long-term safety in individuals who participated in this study, and will also document long-term efficacy on disability progression, MRI parameters, and EDSS. Based on the positive results from the Phase II study, a Phase III study with an estimated enrollment of 1,100 is currently recruiting participants. It will evaluate the effect of two doses of teriflunomide on the frequency of relapse; the effect on worsening of disability, fatigue, and safety will also be evaluated.

Phase II combination studies of teriflunomide added to interferon beta and Copaxone are still ongoing. Both will evaluate tolerability and safety, the number of gadolinium-enhancing lesions, and burden of disease on MRI.

A two-year Phase III study is still recruiting participants who have had a first episode (CIS) consistent with MS. Its primary outcome measure is conversion to CDMS. Secondary measures include relapse rate, burden of disease and other MRI variables, and the proportion of patients who remain free of disability.

EXPERIMENTAL ORAL MEDICATIONS

Fingolimod (FTY720)

Parent company: *Novartis Pharmaceuticals Corporation*

Oral medication taken daily.

Fingolimod blocks potentially damaging T cells from leaving lymph nodes, lowering their number in the blood and tissues. It may reduce damage to nerves and enhance nerve repair. Data in the animal model of MS (EAE) suggest that fingolimod may have neuroprotective effects.

Adverse events may include slowed heart rate, increased blood pressure, airway obstructions, and infection.

A 36-month Phase II study showed that 60 percent of RRMS patients remained relapse-free and had a low rate of disease activity as observed on MRI. The FREEDOMS Phase III studies of low-dose and high-dose fingolimod versus placebo are ongoing. An extension study, FREEDOMS II, is evaluating long-term safety, tolerability and efficacy; all participants are receiving fingolimod.

There have been two deaths from Herpes virus infection in the FREEDOMS trials.

The INFORMS study of fingolimod is the only PPMS trial now ongoing. The study will evaluate the effect of fingolimod relative to placebo on delaying the time to sustained disability progression. It will evaluate safety and tolerability, effects on MRI parameters, and patient-reported outcomes over the 36 months of the study.

The TRANSFORMS trial is a 24-month study of the efficacy of fingolimod as compared to Avonex in individuals with RRMS. Individuals on Avonex experienced an average of 0.33 relapses per year (or one relapse every three years), while those on fingolimod had 0.16 – 0.20 relapses per year (or roughly one relapse every five to six years). A higher dosage level of fingolimod was associated with fewer relapses.

EXPERIMENTAL MONOCLONAL ANTIBODY MEDICATIONS

Campath® (alemtuzumab)

Parent companies: *Genzyme Corporation and Bayer HealthCare Pharmaceuticals*

Administered once yearly by intravenous infusion over three-to-five consecutive days. The drug is approved for the treatment of B-cell leukemia and targets T cells, B cells, and macrophages. Side effects include a reduction in blood clotting, thyroid disorders, infusion reactions, and infection. Patients need to be monitored closely due to risk of significant toxicities.

Trials of Campath include the CAMMS223 Phase II study, which compared Campath to high-dose Rebif in RRMS. After three years, Campath was more effective than Rebif at suppressing relapses and preventing disability. It also appeared better at improving self-reported mental and physical well-being. More than 50 percent of the Campath-treated patients actually improved.

EXPERIMENTAL MONOCLONAL ANTIBODY MEDICATIONS

Rituxan® (rituximab)

Parent companies: *Genentech and Biogen Idec*

Administered via intravenous infusion.

Binds to a molecule on the surface of B cells and depletes them from the circulation.

Serious adverse events have been reported in Rituxan-treated patients with other diseases, including PML (as with Tysabri); patients must be closely monitored.

A Phase II trial in RRMS examined the effect of a single course of treatment, two infusions administered two weeks apart. At 24 and 48 weeks, the number of active lesions was reduced by 91 percent and relapses were reduced by 58 percent.

A Phase II/III trial of Rituxan in 435 adults with PPMS did not achieve its primary goal of slowing disease progression.

An ongoing Phase I trial in neuromyelitis optica (NMO), an MS-like disorder, demonstrated a significant reduction in relapses with Rituxan.

The drug has also been tested in 26 people with RRMS who experienced continued clinical activity despite treatment with one of the approved disease managing treatments. Over the 24 weeks of the trial, participants received four doses of Rituxan while continuing to take their same medication. Participants showed statistically significant improvement in their MS Functional Composite Scores.

Zenapax (daclizumab)

Parent companies: *Biogen Idec and PDL BioPharma*

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

Zenapax is a genetically engineered antibody against a substance necessary for the growth of T cells. It results in a sustained but reversible reduction in activated T cells, and reduces inflammation.

A study in RRMS and SPMS patients (who continued to experience worsening disease activity with interferon-beta therapy) showed the drug was well tolerated. The study also reported to improve or stabilize 60 percent of patients and reduced the number of active lesions.

The ongoing CHOICE Phase II trial adds Zenapax to interferons in 30 patients with active MS; the treated group experienced a significant reduction in new or enlarged enhancing lesions. A recent study used the drug alone in those participants in the CHOICE study who had developed neutralizing antibodies to interferon-beta. The results suggest that the effect of Zenapax is not dependent on the presence of functioning interferon-beta, indicating that it may have potential as an independent therapy.

An ongoing study of RRMS will determine the effect of three different doses of Zenapax on brain-lesion activity as measured by MRI. An extension study is also underway that will focus on safety and tolerability.

OTHER THERAPIES BEING STUDIED

Dirucotide (MBP8298)

Parent company: *BioMS*

Administered intravenously every six months.

This synthetic fragment of myelin basic protein (MBP) replicates the site on the MBP molecule that is believed to be a target of attack by cells of the immune system.

Early trials showed that dirucotide was safe and tolerable, and delayed the median time to disease progression by five years in people with SPMS. MAESTRO-01 is a Phase III trial in patients with SPMS, followed up by MAESTRO-02 (an open-label study). MAESTRO-03 is a phase III trial in 510 people with SPMS.

In late July 2009, Eli Lilly and BioMS Medical Corporation announced that dirucotide did not meet the primary endpoint of the MAESTRO-01 study, which was the delay of disease progression in SPMS as measured by EDSS. As a result of these findings, ongoing studies will be discontinued. Lilly and BioMS will continue to evaluate available data and determine how to proceed.

In a small RRMS trial (MINDSET-01), dirucotide did not affect the primary outcome of clinical attacks versus placebo.

Tovaxin™

Parent company: *Opexa Therapeutics*

This is a T-cell vaccine given via subcutaneous injection every four weeks. In this process, T cells are removed from a small amount of the patient's blood, inactivated, and then injected back into the patient. As a result, the immune system is stimulated to recognize and eliminate the inactivated cells as well as active cells.

A Phase II study showed significant improvements in the annualized relapse rate of patients with RRMS or SPMS, and there was a decrease in myelin-reactive T cells in the blood.

TERMS is an ongoing placebo-controlled one-year study in patients with CIS and RRMS to evaluate Tovaxin's efficacy, safety, and tolerability. Participants in the trial also participated in an open-label, one-year extension study. The treatment was found to be safe, but did not achieve statistical significance in the primary endpoint, which was the cumulative number of gadolinium-enhancing lesions. Additional analysis of immunologic and other effects are ongoing, and further clinical trials may be developed.

BHT-3009

Parent company: *Bayhill Therapeutics*

This DNA vaccine to myelin basic protein (MBP) contains the gene for MBP and is administered by intramuscular injection. This therapy is designed to cause immune tolerance, by reprogramming the immune system to modulate the response of the antigen-specific immune cells involved with MS. This would reduce the attack against the MBP in the myelin sheath.

Preliminary studies indicate that the vaccine is safe and well tolerated. More studies may be forthcoming.

OTHER THERAPIES BEING STUDIED

Vitamin D3

An inverse relationship appears to exist between vitamin D3 status and the probability of developing MS. Vitamin D3 supplementation may be a possible therapy in MS.

A Phase I/II trial of high-dose oral vitamin D3 with calcium trial showed that high-dose Vitamin D3 – 10,000 IU/day or higher – is safe and tolerable, with some evidence of clinical improvement. More data are needed.

An Australian study found that people with CIS had less cumulative skin damage caused by the sun than controls, suggesting that they had less sun exposure. In a Canadian study of children who had experienced a single neurologic episode, the 16 percent who went on to develop MS had significantly lower vitamin D levels than those who did not.

Evidence is beginning to accumulate of a complex interaction between genetic susceptibility to MS and the role of vitamin D. The risk of developing MS is three times higher among those who carry a single copy of a specific gene variant and 10 times higher in those carrying two copies of the gene, which appears to be involved in the immune system. Proteins activated by vitamin D bind to and alter the function of a section of the chromosome near this gene, suggesting that vitamin D deficiency during pregnancy might alter the function of fetal genes, predisposing children to MS. The gene contains a "switch" that is activated by one form of vitamin D; it was missing from the variants not associated with MS.

Tetracycline Antibiotics

The tetracycline antibiotics, including minocycline and doxycycline, have immunomodulatory and neuroprotective activities. They appear to decrease the passage of leukocytes across the blood-brain barrier.

In a small trial in patients with RRMS, minocycline decreased gadolinium-enhancing activity by 50 percent over a period of six months. A subsequent 24-month trial showed a significant decrease in lesion activity and clinical status.

A Phase III trial beginning in 2008 is studying the effect of 100 mg of oral minocycline twice daily on the conversion of CIS to a diagnosis of MS at six and 24 months.

A study combining minocycline with Copaxone in RRMS in 40 patients showed that the combination was more effective than Copaxone alone. This was determined by disease activity, as measured by gadolinium-enhancing and T2 lesions, as well as relapse rate.

A small Phase IV study combining doxycycline with Avonex demonstrated a statistically significant reduction of gadolinium-enhancing lesions compared with Avonex alone. A larger trial is needed to confirm these results.

New Directions in MS Research

Early treatment with one of the approved disease-modifying therapies (DMTs) is now recommended for all individuals with the relapsing forms of MS. People taking the "ABCR" drugs – Avonex, Betaseron, Copaxone, and Rebif – have had less disability, a lower annual relapse rate, reductions in the number and size of active lesions in the brain as shown on MRI, and a higher employment rate than untreated individuals. Additionally, early treatment of a single event suggestive of MS can slow progression to clinically defined disease.

Therapies for the progressive forms of MS still lag behind these impressive results for treating relapsing forms of MS, but research is now focused on a number of potential strategies for managing these more difficult, progressive types of the disease, and a few Phase III studies are now ongoing for SPMS and PPMS.

Identifying factors that predict a positive long-term outcome, as indicated by no clinical disease progression with the continued use of specific therapies, could assist in treatment decisions early in the course of RRMS. Conversely, advances are being made in attempts to determine early in therapy which participants may not respond optimally to treatment. This may allow researchers to identify those individuals who should receive alternative or additional therapy.

New drugs are based on new mechanisms, such as selective depletion of specific subtypes of lymphocytes or prevention of cell migration into the CNS. Some seem to act at least in part via a neuroprotective effect. Four monoclonal antibodies (MABs) have now shown efficacy in Phase II or III clinical trials: natalizumab (Tysabri®), rituximab (Rituxan®), daclizumab (Zenapax®), and alemtuzemab (Campath-1). Five oral agents have shown significant positive results in Phase II and/or Phase III trials: FTY-720 (Fingolimod®), BG-12, ABR-215062 (Laquinimod ®), teriflunomide, and leustatin (Cladribine®).

Environmental Factors and Genetic Studies

Genetic differences appear to exist between individuals who respond to interferon-beta treatment and those who do not. Australian researchers have discovered two new locations of genes that are linked to genetic susceptibility for MS. They also indicate a link between genetic susceptibility to MS and other autoimmune diseases, including Type 1 diabetes, rheumatoid arthritis, and Grave's disease (a thyroid disorder), and also the potential involvement of vitamin D metabolism (see previous page).

A study from Ireland found that a slight variation in the DNA (single-nucleotide polymorphism) predicts how early a relapse may occur while on interferon-beta treatment. Potentially, this may help clinicians identify individuals who are less likely to respond to treatment.

Slight genetic variants also may explain why African-Americans tend to have a more aggressive disease progression than Caucasians and may be less responsive to interferon-beta treatment.

New Therapies under Investigation

The preceding overview of approved and experimental drugs is only a fraction of the

many treatments currently being studied. Some of the following are among the most exciting potential therapies under investigation.

Neuroprotective agents: The term "neuroprotection" refers to strategies designed to prevent irreversible damage of a variety of cell types in the CNS, as well as to promoting regeneration after MS-related damage has occurred, with the goal of preventing the development of disability. A variety of neuroprotective strategies are in the early stages of testing. Some of the drugs thought to have neuroprotective activity appear to reduce damage by blocking sodium channels or the release of the neurotransmitter, glutamate. Some of these drugs may decrease the toxicity of free radicals in the brain. A number of research studies are ongoing on a wide variety of agents that may have neuroprotective effects.

Bone marrow-derived stem-cell transplantation: High-dose immunosuppressive therapy followed by transplantation of the patient's own bone-marrow-derived stem cells has been used to prevent transplant rejection for many years. This same type of stem cell has been used in most MS studies, not embryonic or other types of stem cells. The procedure is being tested in MS when very active disease continues while on DMT. Evidence to date suggests that the therapy may be more successful in early stages of the disease.

In a Phase I/II study of 21 individuals with RRMS whose disease had continued to progress despite treatment with interferon-beta, 17 showed improvement of at least one point on the EDSS scale. Five of the 21 relapsed but achieved remission after further immunosuppression. After 37 months, all patients were free from progression, and 16 were free of relapses. Significant improvement was also seen in symptoms such as balance, walking, and weakness, as well as self-reported quality of life.

A Phase 1 safety study is being initiated at the Cleveland Clinic. The treatment being studied involves first removing and storing bone marrow cells, which are returned after the patient is immunosuppressed. This study has approximately 24 participants with relapsing forms of MS (approximately equal numbers with RRMS and SPMS) and evidence of involvement of the visual system. Other studies are ongoing.

Sex hormones: Estriol is an estrogen-like hormone that may have both neuroprotective and anti-inflammatory properties. Its possible use in MS was suggested by the fact that women with MS tend to have fewer relapses during pregnancy, but are often subject to relapses during the postpartum period, when the high levels of female steroids (hormones) present during pregnancy return to normal levels. Seven medical centers in the United States are conducting a two-year trial, enrolling 130 women with RRMS to receive daily Copaxone injections along with a daily estriol pill or a placebo. Preliminary research suggests that estriol and similar steroids act by either preventing oligodendrocytes cell death and/or recruiting undeveloped oligodendrocytes for new myelin formation. Several studies are underway to attempt to uncover the mechanisms through which this effect may occur.

Parasites: There is some evidence that infections such as gut parasites normally help to regulate immune activity, and that the increase in autoimmune diseases in industrialized countries may in part be an unintended consequence of improved hygiene. Ongoing studies selectively expose individuals with autoimmune disease, including MS, to these organisms. Studies are investigating whether controlled infection with helminths (a group of worms that infect the gastrointestinal [GI] tract worldwide) will decrease the number of new gadolinium-enhancing lesions on MRI and increase the number of specific types of T cells; secondary measures will include the percentages of other types of T and B cells. (The parasites will be eradicated after 48 weeks.) A Phase I trial indicated that helminth ova are safe when used in individuals with RRMS.

Other Agents in Early Stages of Testing for Use in MS

Just prior to the printing of this article, the Phase II study of **CDP323** was discontinued due to a lack of significant changes in MRI findings and possibly other clinical measures in the study population. CDP323 is an oral Tysabri-like drug that has a short half-life, meaning that it is removed from the body more rapidly than Tysabri. It was hoped that the drug would have less risk for PML than Tysabri. The cancelled study was evaluating the safety, tolerability, and MRI effects of CDP323 as compared to placebo.

A number of other agents have shown some encouraging immunomodulatory effects, either in animals or humans, and are being tested for possible future use in MS. These include: **RTL1000** (recombinant T-cell receptor ligand), a highly selective protein that binds to and inactivates T cells; **CGP77116**, a small protein similar to myelin basic protein (MBP), designed to modify the immune reaction that destroys myelin; **SB-683699**, thought to reduce the number of active white blood cells entering the brain; **RG2007**, which may block a T-cell pathway involved in MS; **CS-0777**, an oral immunosuppressive drug in Phase I studies; **flupirtin**, a non-opioid analgesic drug that may have a neuroprotective effect; **MK0812**, which targets proteins known as chemokines that attract immune-system cells to areas of inflammation; and **symadex**, which inhibits a pathway involved in macrophage maturation.

Atacicept (ATX-MS-1467) is a "cocktail" of four peptides derived from human myelin basic protein. It appears to block the development of mature B cells and inhibits the survival of antibody-producing cells. The drug is now in Phase II trials to evaluate its safety and tolerability, and to determine whether it reduces CNS inflammation in RRMS on MRI. It is administered via subcutaneous injection.

Anti-Lingo-1 is a monoclonal antibody now being readied for its first human trial. Previous animal studies showed that it promotes spinal cord remyelination and axonal integrity in the animal model of MS (EAE).

A French study with **masitinib**, which targets mast cells, was tested in 35 patients with PPMS and SPMS. Over 18 months of treatment, EDSS scores remained stable in both

treated and placebo groups with PPMS. In the SPMS group, the treated individuals remained stable, while the placebo group averaged an increase of one EDSS point.

MN-166 (ibudilast) is an orally administered small molecule with neuroprotective and anti-inflammatory properties. In the first year of a two-year study in individuals with RRMS, it significantly reduced the percentage of brain volume loss and prolonged time to first relapse by 157 days. It did not, however, significantly reduce cumulative new lesion count, which was the primary outcome measure of the study.

A Phase II study to evaluate the effectiveness of **oral recombinant ovine interferon tau** in RRMS indicated effectiveness over nine months in decreasing the number of new gadolinium-enhancing lesions. It also appeared to be both safe and well-tolerated.

A new clinical trial, now recruiting, will evaluate whether following a specific **low-fat diet** will improve brain damage as seen by MRI. It will also determine whether MS progression is decreased as indicated by clinical evaluation and symptoms.

A Japanese study of a synthetic **vitamin A molecule** seems to prevent early symptoms of MS by blocking the function of a specific type of T cell.

To Learn More about Clinical Trials

Anyone interested in additional information about the clinical trials discussed here, or anyone interested in participating in a clinical trial, may visit **www.clinicaltrials.gov**. The National Multiple Sclerosis Society has a downloadable file containing information on clinical trials, which may be accessed at: **www.nationalmssociety.org/research/clinical-trials/index.aspx.**

Closing Note

In summary, the future of disease-modifying therapies (DMTs) for MS looks bright, both in terms of new information on currently approved DMTs, as well as exciting results for emerging therapies. Because of their complex mechanisms of action and potential side effects, it will be important to weigh the benefits of new treatments against their possible risks.

Research continues into a wide variety of experimental therapies, including those that may be effective for individuals with the progressive types of MS, as well as those with relapsing disease who have not to date responded to any of the presently approved DMTs. Exciting new findings about the processes involved with the development of MS and the mechanisms by which it produces nervous system damage continue to be discovered. The coming years should bring many promising advancements in the treatment of all types of MS.

As always, your personal healthcare professionals will be your best guides to making the right decision for you. The great news is that effective treatments are available. The keys to success are to start therapy early in the disease when it is most effective in preventing the accumulation of nervous system damage, and to stay on therapy once you've begun. ◆

Ask the Doctor

By Dr. Jack Burks
Chief Medical Officer for MSAA

Can MS Lesions Mimic a Stroke?

Dr. Jack Burks

Q: I was diagnosed with MS in 2003. I hadn't had a brain MRI since, until about three weeks ago. I was devastated to learn it had progressed significantly, but I am also worried about something else on the radiologist's report. It said "there was evidence of an old-appearing basal ganglia infarct" on the left side.

I have a new neurologist and he tells me that it is a "small stroke" and I should not worry about it – even though it was not on my MRI in 2003. I believe I know when this happened, but I did not see a doctor at that time, thinking it was a bad flare-up of MS. It took over two months to heal.

I am worried; is this common in MS or something else? Should it have been looked into? Will it or something worse happen again?

A: Your questions are very appropriate, but trying to answer them requires considerable speculation on my part. Your brief description and questions raise several more questions. How old are you? Stroke is very uncommon in young adults. Could MS lesions on the MRI be mimicking a "small stroke" in the basal ganglia? (Basal ganglia are structures located deep in the brain, responsible for normal movement.) Do you have risk factors for additional "strokes?" Risk factors include diabetes, heart irregularity, high cholesterol, high triglyceride, hypertension, obesity, and other health conditions. Is your MS getting worse clinically (with more attacks or progressive symptoms), or is the MRI the only thing getting worse? Are you on MS disease-modifying therapies (mentioned earlier)?

What are the next steps? If you have had a stroke, I would recommend you have a stroke prevention and cardiovascular evaluation. As for your MS, new lesions on the MRI in MS patients are worrisome but not unexpected. Brain atrophy or shrinkage is more worrisome, if present.

What can you do to reduce the MS damage? If you are not on an MS disease-modifying therapy, you and your doctor should discuss what options might be appropriate for you. If you are on therapy, discuss the possibility that your therapy may not be optimal. Should this be the case, you may want to consider changing your treatment approach.

Q: I have been diagnosed with primary-progressive MS. There doesn't seem to be very much information on how to treat this form of MS. However, I've read that vitamins C and E may stimulate the immune system. I currently take 500 mg of C and 400 IU of E; if these do stimulate the immune system, should I reduce the amount of C and E that

I take each day? What would be the correct dosage? I take the high dosage of C to fight off colds – which has been effective. Also, I read that fish oil may help with MS. Do you have any opinion on this?

A: No specific treatments for primary-progressive MS (PPMS) are approved by the FDA. However, treatments to help the symptoms of MS are available.

Concerning vitamin supplements, while not FDA-approved for MS, many supplements are taken by MS patients. Vitamins are either water soluble (vitamins B and C) or fat soluble (vitamins A, D, E, and K). Fat-soluble vitamins should be taken in moderation since they can accumulate in the body and have toxic effects. The recommended daily allowance for vitamins is available on nutritional websites, or at your doctor's office. However, some MS patients feel that exceeding the daily recommendation may (as you suggest) help with other MS problems or may reduce the chance of getting a cold. Some vitamins are thought to have anti-oxidant effects which may reduce the MS damage. No evidence is available to support the theory that vitamins may worsen MS by stimulating the immune system. Scientific data in these areas are not rigorous.

Vitamin D (the sunshine vitamin) has been shown to reduce the risk of getting MS. Whether or not taking vitamin D reduces the severity of MS is under investigation. Some MS doctors recommend oral vitamin D supplements, especially for MS patients who are not exposed to much sunshine in the winter. The optimal dose has not been established, but 1 to 2 grams per day is common.

Fish oil may be good for general health, but its specific effects for MS have not been demonstrated conclusively. Taking vitamins and fish oil, under a health care professionals' guidance, is common for MS patients. While the proof of benefit for MS specifically is not proven, they are unlikely to be toxic, except for high doses of fat-soluble vitamins. The specific doses for MS patients have not been determined.

Vitamins and fish oil are different from herbal supplements, such as echinacea. Echinacea and some other supplements may increase immune system activity, which might be a stimulus for more MS damage. For additional information, MSAA's monograph, *Thinking about Complementary and Alternative Medicine?* may be helpful. Written by Thomas M. Stewart, JD, MS, PA-C and Allen C. Bowling, MD, PhD, this publication can assist with finding and evaluating claims

To Submit Questions...

Please submit your questions to:

MSAA
Questions for Ask the Doctor
c/o Dr. Jack Burks
706 Haddonfield Road
Cherry Hill, New Jersey 08002

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

about supplements and other complementary and alternative (CAM) therapies. This free monograph may be viewed, downloaded, or ordered by visiting **msassociation.org** and going to "publications." For individuals without internet access, copies may be ordered by calling MSAA's Helpline at (800) 532-7667.

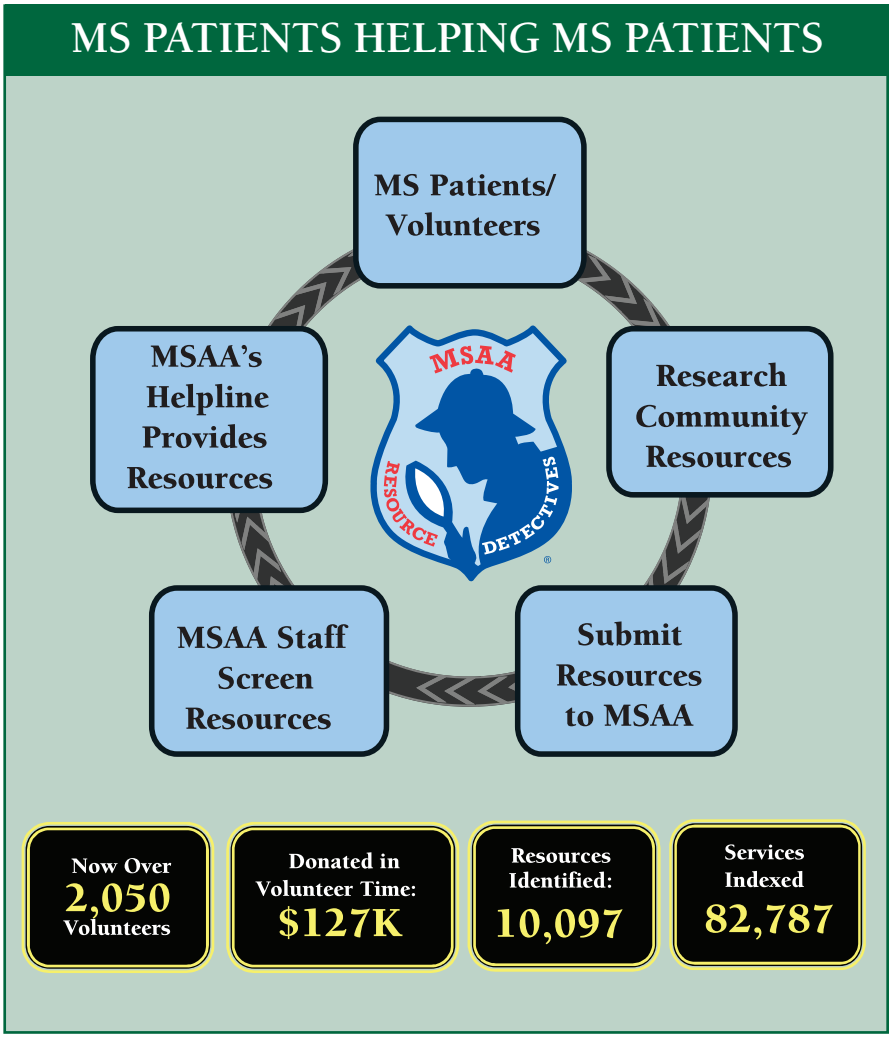
I also recommend Dr. Bowling's book, *Complementary and Alternative Medicine and Multiple Sclerosis*, 2nd edition (Demos Medical Publishing, 2007). This book may be borrowed through MSAA's free Lending Library; please see page 48 for ordering information. In addition, MSAA and the National Multiple Sclerosis Society (NMSS) have recently collaborated on a book for PPMS patients, which is expected to be available this fall. MSAA will also be publishing a booklet on PPMS. Please look for more information on these new publications in our next issue of *The Motivator*. ◆

Jack Burks, MD is the chief medical officer for MSAA. He is a neurologist and the director of program development at the Multiple Sclerosis Comprehensive Care Center, Holy Name Hospital, in Teaneck, New Jersey. Dr. Burks is a member of the Clinical Advisory Board of the NMSS. He has written and edited three MS textbooks, as well as numerous chapters and articles on MS. In recent years, he has lectured and evaluated patients in more than 30 countries.

Empowering MS Patients While Increasing a National Nonprofit's Capacity: MSAA's Resource Detectives Program

By Malcolm Friend, Bonnie Yares, Amanda Montague, and Robert Rapp

The Multiple Sclerosis Association of America (MSAA) receives thousands of calls each year from MS patients across the nation in search of information and resources to meet their varied needs. Many of these requests are directly addressed through MSAA's extensive array of programs and services. Others, however, must be referred to community agencies or resources. The goal of MSAA's Resource Detectives® Program is to establish a comprehensive, up-to-date national resource database to assist those affected by MS.



MSAA's Resource Detectives Program

In 2007, MSAA developed the Resource Detectives virtual volunteer program to meet this challenge in an efficient and cost effective manner by mobilizing volunteer "detectives" (many with MS or relatives and friends of those with MS) to seek out resource information that is beneficial to others with the illness. The Resource Detectives Program relies on a national cadre of virtual volunteers to research and collect information on resources available to MS patients in a wide array of areas. Since the program's inception there are over 2,000 active volunteers who have collected more than 10,000 resources offering more than 82,000 services in the United States.

Engaging MS Patients as Volunteers

The concept of utilizing MS patients in service to others with the disease flows directly from the data collected as part of MSAA's 2005 Client (Patient) Needs Assessment. The demographic and descriptive information generated from the 762 respondents indicated that a significant number of our clients have the required tools, time, and knowledge to become Resource Detectives (80% reported having access to a computer with Internet capabilities, only 30% were working full time, and 70% reported having at least some college education).

Results and Next Steps

By successfully utilizing virtual volunteers, many of whom have MS, to identify resources available to the MS community; the Resource Detectives Program may serve as a model for how nonprofit patient organizations can empower their patient population while also building their own capacity. The resources collected are currently available through MSAA's Helpline, although future plans include partnering with MS centers to enable the information to be disseminated throughout the MS community. The success of the Resource Detectives Program suggests that MS patients can play a powerful role as volunteers in nonprofit organizations. The success of the Resource Detectives Program demonstrates that MS patients can be mobilized to make significant contributions that assist their peers through their voluntary efforts.◆

Thoughts about Giving

By Bruce Makous
Vice President of Development

Meeting the Challenge

Bruce Makous

I am inspired by the continued generosity of MSAA's donors during these challenging economic times. Our supporters realize that, like many other people across the country, people living with MS may be experiencing financial hardship, and MSAA's programs and services are in greater demand than ever right now. Your continued generous support is appreciated by people from every geographical region who receive our free equipment, speak with our Helpline consultants, participate in Life Coaching, and benefit from MSAA's other valuable services.

Similar to the clients we serve, our supporters also reside in every area of the country. In February, MSAA leadership was in Tampa for a Board meeting and we took the opportunity to meet some of our donors in that area of Florida. One of those supporters whom we met, Tamara Gerkin of Port Richey, has a very special way of raising funds for MSAA. She sells her paintings on her website to benefit MSAA!

In March, we were in Chicago where President and CEO Doug Franklin and Board Chair Eric Simons hosted an MSAA President's Circle reception. We were so impressed to see the enthusiasm for MSAA among our supporters in the Windy City, including those who have been with us for some time and those who are new to MSAA. We made a personal visit to become acquainted with John Balourdos, a major donor who owns a Chicago real estate firm, and thanked him for his generous support.

Tamara Gerkin poses with one of her lifelike clay sculptures. Tamara contributes the net proceeds from the sale of her work to MSAA to help people living with MS.

Like Tamara Gerkin who donates profits from her artwork, people are finding different ways to continue to give support to MSAA. Another method is through deferred gifts. Many individuals who have been sup-

porting MSAA for several years, have contacted us to learn more about ways to provide funding from a portion of their estates. They want to continue to give after they are gone. This is a way of making a commitment today for a gift tomorrow, when current funds are limited.

It's clear from my many interactions with both donors and clients this past year that the programs and services provided by MSAA are greatly valued from two different perspectives. Those who want to help appreciate the opportunity that MSAA and our programs provide support to those living with MS. Those who are affected by multiple sclerosis greatly appreciate the enrichment MSAA's programs provide every day to their quality of life.

Deferred Giving

Donors frequently ask how they can make a commitment today that will provide funds for MSAA in the future. Here are a few ways to give wisely:

- **A Charitable Bequest:** Your attorney can help you make a provision in your will. Sample language would be:

  I give to the Multiple Sclerosis Association of America, Inc., a nonprofit 501(c)(3) Corporation (IRS ID# 22-1912812), headquartered in Cherry Hill, New Jersey, ____ percent [spelled out] (___%) of my estate to go to MSAA's [Equipment Distribution Program, for example]. This contribution is provided to establish the [e.g., John and Jane Doe Fund for Equipment for People Living with MS].

- **Charitable Gift Annuity:** Make a contribution of $10,000 or more and receive a fixed income each year for life. Income rates vary from 5 percent to 11 percent, and increase with age.
- **Charitable Remainder Trust:** This also provides income for life. Appropriate for contributions of $100,000 or more. You may be able to reduce associated taxes.
- **Gift of Retirement Plan Assets:** Any pension plan, IRA, 401(k), 403(b), or other plan has a provision for designating the beneficiary of the portion of the assets remaining at death. Naming MSAA will create much needed funding that will greatly benefit people living with MS.

- **Gift of Life Insurance:** Donors may make MSAA the beneficiary of all or part of the death proceeds from life insurance. You may also contribute ownership of the entire policy to MSAA. As with other giving plans, life insurance proceeds will create much needed funding that will greatly benefit people living with MS.

Any of these legacy-giving methods may provide funding for a specific program, a permanent endowment, or for general operations. The fund name may be designated to honor the donor or another person.

It is best to discuss your intentions with MSAA staff today to make sure that your fund is established as you wish. A senior staff person will be pleased to talk with you to discuss your goals.

In making your designation, please remember that the Multiple Sclerosis Association of America is a nonprofit 501(c)(3) corporation headquartered in Cherry Hill, New Jersey (IRS tax ID number 22-1912812).

To initiate a deferred gift, please provide the information above to your estate attorney. ◆

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

THE PHILANTHROPY CIRCLE

The following thoughtful corporations and foundations have contributed generously to MSAA to help improve the quality of life for people living with multiple sclerosis. Organizations providing gifts of $10,000 or more are shown in this listing.

CHAMPIONS *($100,000 and up)*

Acorda Therapeutics
Bayer HealthCare Pharmaceuticals
Bayer USA Foundation
EMD Serono, Inc. and Pfizer Inc
Genentech Foundation
Genentech, Inc.
Novartis Pharmaceuticals Corporation
Teva Neuroscience

VISIONARIES *($50,000 to $99,999)*

Eli Lilly and Company

INNOVATORS *($25,000 to $49,999)*

IBM
Medtronic Foundation
The Rhonda Gruber Foundation

ADVOCATES *($10,000 to $24,999)*

Avanir Pharmaceuticals
Biogen Idec
The Chatlos Foundation
Grand Lodge Daughters of Scotia
The Horizon Foundation for New Jersey
The Wal-Mart Foundation

Mobility Independence and Safety

Written by Patricia G. Provance, PT, MSCS

Part III: Wheeled Mobility

Part I of this series focused on ambulation issues and Part II outlined the importance of exercise. These appeared in the Fall 2008 and Winter/Spring 2009 issues of *The Motivator*, respectively. In this third and final segment, we will discuss the many complex considerations related to wheeled mobility.

It is not possible to include all of the options in a short article, so the emphasis here will be on outlining the many factors to be considered, the pros and cons of each type of equipment, and resources to further your education. Individuals with MS who require wheeled mobility most or all of the time should be evaluated by a seating specialist, usually a physical therapist (PT) or occupational therapist (OT) with extensive training in this area. Preferably, this should be done in a "seating clinic," also attended by a family member and/or care partner, along with a rehabilitation technology supplier (RTS) representing a durable medical equipment company. This will help ensure that the most appropriate device is prescribed for each individual situation. It is also important to keep in mind the often progressive nature of MS, and the fact that funding sources usually dictate that a chair last for five to seven years.

Standing wheelchairs provide the physical and psychological benefits of being upright.

Photo courtesy of 21st Century Scientific, Inc.

Factors that need to be considered are:

- *The person with MS* – Individual factors and symptoms include balance, spasticity, weakness, ataxia, sensory problems, pain, fatigue, poor vision, cognitive impairment, transfer independence and safety, history with previous equipment, etc.
- *The device* – Many diverse considerations are needed here, including manual versus power, chair base, support surface, seating, height, width, foot rests and armrests, modifiability, aesthetics, repairs, warranties, etc.
- *One's environment* – Variables include home and work accessibility (indoors, entrances/exits), weight, transportability, and community access

- *One's lifestyle* – Activities the person needs and wants to perform when seated in the device

Manual Wheelchairs

Standard – Lower-end, basic wheelchairs with folding frames, but limited adjustability. Not recommended for a full-time wheelchair user, but can be used as a back-up chair for easier transport in a car or van.

Performance – Lighter weight manual wheelchairs with folding or rigid frames and more adjustability. However, fatigue is still an issue with self-propulsion by MS patients and must be considered.

Positioning – For those dependent for propulsion and repositioning who cannot propel a power mobility device. The manual tilt-in-space is not portable by car and the recliner is not advised for those with "extensor spasticity," which is an increased muscle tone that causes the legs and trunk to straighten and stiffen.

Power Mobility Devices

Folding Power Wheelchairs – Heavy models have some seating options but are difficult to transport. Lighter models give less support.

Power-Assist and Conversion Units – These are devices that can be added on to manual wheelchairs to augment a person's ability to propel the chair. Portable by car, but expensive and do not have power seating options.

Power Scooters – Appropriate for those who do not need significant postural support and do not anticipate a significant decline in function. Range in size, cost and features from a compact "travel scooter" to a large, stable "power operated vehicle" (POV) adequate for full-time use. Four-wheeled models are more stable but have very limited leg room.

Non-folding Power Wheelchairs – Suitable for people with MS who have significant mobility impairment because they can be

MANUAL WHEELCHAIRS

Advantages

- Relatively inexpensive
- Relatively light weight
- Relatively easy to transport
- Relatively easy to maintain and repair

Disadvantages

- May not provide an individual with independent mobility in all environments
- May increase fatigue
- Tilt and recline features cannot be operated independently

Manual Wheelchair

customized for a variety of needs. The seating clinic evaluation will include assessment and recommendation of many features, including chair seat and back (pressure relief and positioning), arm/leg/head rests, electronics and drive controls, and other power options (tilt, recline, elevating leg rests, and seat elevator). It is important that the power base chosen will accommodate modifications that may be needed over time. Due to size and weight (200-300 pounds), they require a van with ramp or lift for transport. A trial with the proposed equipment is important before a prescription is made. These chairs are classified by the position of their drive wheels:

- Rear-wheel drive – have good front stability, turn slowly, track straighter, and are intuitive to drive, but have the largest turning radius so they are less ideal for indoor use.
- Front-wheel drive – the least prescribed because maneuvering is less intuitive, and speed is limited due to fishtailing, though they handle well outdoors.
- Center-wheel drive – maneuvers well both indoors and outdoors, has a small turning radius and newer models have two smaller wheels in both front and rear for additional stability. Even for those who have used a scooter or rear-wheeled drive chair in the past, training may be needed to become accustomed to center-wheel drive.

Standing Wheelchairs – Provides the psychological benefit of being upright. Allows weight bearing through the legs, pressure relief,

and muscle stretch, while building endurance. Also improves circulation, digestion, elimination, and respiratory function. However, these are very expensive and funding is difficult.

Rear-wheel drive power wheelchair

Photo courtesy of 21st Century Scientific, Inc.

Environment and Lifestyle

Although we expect that the need for wheelchairs will diminish in the coming years since the introduction of disease-modifying therapies, historically, it has been estimated that 25 percent of people with MS will eventually need to use a wheelchair (usually power) full time for mobility, while 60 percent will be part-time users of wheelchairs (usually manual) or scooters for travel, shopping, and outdoor activities.

Proper planning is essential to avoid a poor match, so it's important to resist the temptation of easy access via television and internet offers – some sounding "too good to be true!"

SCOOTERS

Advantages

- Generally less expensive than a power chair
- Most users feel they do not look as "disabled"
- Many models are lighter than power wheelchairs
- Some can be disassembled for transport in a vehicle (check weight of heaviest component)
- Swivel seats allow easier transfers

Three-Wheeled Scooter

Disadvantages

- Requires greater strength and dexterity to operate
- No options for alternative driving controls
- Limited options for seating and positioning
- Often not as maneuverable as power wheelchairs (large turning radius)
- Batteries are often smaller and require more frequent recharging
- Generally cannot be modified over time

Take the time to consider:

When and where the device will be used – Space (doorway width, turning radius), access (kitchen, bathroom, garage, home entry) and transport (personal vehicle or public transport). A home accessibility assessment (usually by an OT) is often advisable.

Social Support – Will this increase or decrease family burdens? A positive outcome is improved independence and freedom. However, a wheeled mobility device may increase physical and/or financial demands (transport, transfers, home modifications).

Insurance issues – Know what options are covered under one's durable medical equipment (DME) policy.

Professional Support – In addition to the seating team, having access to the DME dealer for assembly, set-up and training, warranty, maintenance, home visits, repairs, and future adjustments or modifications is essential – especially for power wheelchairs.

Summary

Wheeled mobility, whether full or part time, can broaden horizons and provide a huge boost to functional independence and quality of life. Hopefully this overview will be helpful in the important planning process that is essential for a positive outcome. Resources on the next page should help provide additional references, but should not take the place of an evaluation by a seating specialist. A world on wheels is indeed a bigger world! ◆

ADDITIONAL RESOURCES

Please note that MSAA does not endorse or recommend any specific product or brand mentioned in our articles or advertising.

21st Century Scientific, Inc.
www.wheelchairs.com
(800) 448-3680

Abbey Home Elevator
www.abbeyaccess.com
(800) 842-2239

Able to Travel
www.abletotravel.org
(888) 211-3635

Accessible Design and Consulting
www.accessibleconstruction.com
(866) 902-9800

American Ramp Systems
www.americanramp.com
(888) 715-7598

AmeriGlide
www.ameriglide.com
(800) 790-1635

Bruno Independent Living Aids, Inc
www.bruno.com
Individuals without internet access may check their local listings for a dealer in their area.

Frank Mobility Systems
www.frankmobility.com
(888) 426-8581

Handi-Ramp
www.handiramp.com
(800) 876-RAMP (7267)

Invacare
www.invacare.com
(800) 333-6900

LifeStand (A Permobil Inc. Company)
www.lifestandusa.com
(800) 736-0925

Permobil
www.permobilusa.com
(800) 736-0925

Pride Mobility Products Corp.
www.pridemobility.com
(800) 800-8586

Redman Power Chair
www.redmanpowerchair.com
(800) 727-6684

Rehabilitation Engineering and Assistive Technology Society of North America
Click "Projects" and "Alternative Financing"
www.resna.org
(703) 524-6686

Sunrise Medical
www.sunrisemedical.com
(800) 333-4000

The Home Wheelchair Ramp Project
www.wheelchairramp.org
This program is only for individuals in Minnesota; however, information on the website may be useful for finding other resources and accessibility ideas.

United States Access Board
www.access-board.gov
(800) 872-2253

Wheelchair Getaways (Accessible Van Rentals)
www.wheelchairgetaways.com
(800) 642-2042

Reference:
International Journal of MS Care
(available online at **www.mscare.org**)
Autumn 2005, Special Issue:
"Wheeled Mobility – Evidence and Expertise"

This article is one of a series of three that have been written and generously provided to MSAA by Patricia G. Provance, PT, MSCS. Pat is an esteemed member of MSAA's Healthcare Advisory Council. Pat has 37 years of experience in physical rehabilitation, having been in clinical practice since 1971. In 1982, she started the first MS Rehabilitation Program in Maryland at The Union Memorial Hospital, in addition to her orthopedic caseload. In 2000, Pat joined the University of Maryland Medical System at Kernan Hospital to dedicate her practice to MS, and continued as a clinical consultant with the Maryland Center for MS until her semi-retirement in December 2006. She became an MS Certified Specialist in 2005 and continues as a clinical consultant with the National Multiple Sclerosis Society. Pat is also an active member of The Consortium of Multiple Sclerosis Centers. She currently is teaching and consulting on MS care to patients and professionals throughout the country. Publications include the clinical bulletin, "Physical Therapy in Multiple Sclerosis Rehabilitation," and co-authorship of the textbook, Muscles, Testing and Function with Posture and Pain, 4th and 5th editions.

MSAA expresses sincere appreciation to Pat for her many contributions of her time and expertise to our organization and the individuals we serve, including this valuable series of articles on mobility independence and safety.

Gratitude is also extended to 21st Century Scientific, Inc. for providing some of the photographs used in this article.

Affordable and Fun Things to Do

By Shelley Peterman Schwarz

I live in Madison, Wisconsin, which is often referred to as one of the best places in the country to live, find a job, or raise a family. I know it's true because I've lived here for 40 years. I also know that it is easy for me to become a "homebody" and miss a lot of what my hometown has to offer, especially since I have been living with MS for many years. Sometimes it's just easier to stay home where I can control my surroundings. I have all my creature comforts, things are where I need them, and generally, there are no surprises. And, during this tough economy, I have another excuse for staying home – saving money.

But who wants to stay in the house all summer, or for that matter, any time? When the weather does permit, I really do try and get out, at least for an hour or two. It's good for my mental health and it's especially fun to take advantage of the free and inexpensive activities that surround Madison and the small towns close by. Your community probably offers the same type of activities – concerts in the park, county fairs, farm tours, school and community recreational programs, fishing for people with special needs, water-skiing shows, free boat rides, semi-professional ballgames, and more.

Lots of times I find out "what's happening" from my friends and neighbors who are out and about more than I am. Public libraries and the Bookmobile are also a great source of information because they have bulletin boards where local groups and organizations are also able to post community gatherings and public meetings, as well as activities and programs.

When looking for things to do, I contact my Chamber of Commerce for a calendar of events or to obtain a copy of community magazines to learn about additional free and low-cost activities. Daily newspapers and free publications available at grocery and drug stores often contain ads and announcements for garage sales, flea markets, arts and crafts fairs, garden club plant sales, farmer's markets, and book fairs.

Another idea is to stop by a local hotel to collect brochures and free magazines advertising sights of interest. Often these publications have reduced entrance-fee coupons inside.

When looking for other ways to locate outdoor activities, the internet can provide you with quick information. You can search for local activities, specific attractions, parks, botanical gardens, zoos, even shopping centers to find out about special events they may be hosting.

Attending community festivals, taking part in a historic walking tour, hiking a trail with a guide, or visiting a wildlife preserve are ways to enjoy family time when the

weather permits. Before you go however, be sure to check on accessibility. Ask about the availability of handicapped parking, where to find the accessible restrooms, the location of rest areas, and the type and condition of a walking path. These details are especially important for people with mobility limitations or for those using manual wheelchairs.

Sometimes the weather or other factor prevents you from taking part in outdoor activities, so here are a few ideas for "getting out" while staying in:

Attend an inexpensive or free class at stores like Whole Foods, Williams-Sonoma, and Sur La Table. Sometimes restaurants, gourmet food stores, and hospital/clinic wellness centers also offer classes for "cooking light" or the "how to's" of ethnic cuisine.

Take a class based on a special interest – scrapbooking, knitting, or sewing. Learn a craft; start a hobby; or master some computer software. Make an appointment or just drop in to a specialty store to ask for instruction or to work on a project. Sales people are glad to help you with your project when time permits.

Take a guided tour inside a historical building. To go at you own pace, rent the headphones that narrate the presentation.

Attend a travelogue, a poetry reading, or a guest-author event at a bookstore.

Every year, I learn about new opportunities that make it possible for me to enjoy our wonderful country even more. Here are some of my favorite free and low-cost ideas:

The Federal government offers an *America the Beautiful – The National Parks* and Federal Lands Pass which gives the bearer FREE entrance to all national parks, forests, historical places, and other federal lands and properties operated by the National Park Service, United States Department of Agriculture – Forest Service, Fish and Wildlife Service, Bureau of Land Management, and Bureau of Reclamation. Normally an $80 annual fee, this pass is FREE for a lifetime for a person with a disability. To obtain a free pass, just visit any national park or federal land office and provide proof of disability (your disabled parking pass, your SSDI award letter, or letter from your doctor). The pass provides free entry to you and the occupants in your vehicle to federal lands, or at places such as the Jefferson National Expansion Memorial ("Gateway Arch") in St. Louis. When visiting sights such as this memorial, where an individual entrance fee is normally charged, the pass allows the bearer and three adult companions to be admitted at no charge (children 16 and under are free). It may also entitle the holder to 50-percent off other fees (such as those for camping, docking, parking, tours, etc.). Senior citizens, who are age 62 and older but are without a disability, may obtain the same lifetime pass for $10.

Some states, including Florida and Texas, offer discounted entrance or user fees to seniors and/or people with disabilities. Qualifications (age, in-state/out-of-state, etc.) vary, so ask about discounts for people with disabilities (and senior citizens) when you enter.

In Wisconsin, many of the state parks have fully accessible cabins complete with accessible picnic tables and grills that give

By staying active and doing the things you enjoy, you are making an important contribution to your own physical health and emotional wellbeing.

people, even with severe disabilities, the opportunity to enjoy camping. Paradise Springs, located in the Kettle Moraine State Forest has trails and fishing areas designed for people with mobility issues. Whitefish Dunes State Park in Door County has an accessible beach and beach wheelchairs that allow persons with disabilities to enjoy the water. And Devil's Lake State Park near Baraboo rents an accessible kayak.

More and more communities are making outdoor activities accessible. There are accessible trails and fishing piers in many county and local parks. To find out what is available in your area, contact your city, county, and state parks and recreation departments.

People who enjoy outdoor adventure may look for a local Wilderness Inquiry program. Wilderness Inquiry's mission is to make adventure travel accessible to everyone, regardless of your age, background, or ability. They conduct community events where people of all abilities can learn about water safety and try canoeing, kayaking, or paddling one of their Voyageur canoes. (Voyageur canoes are specially crafted for comfort and ease of use.) In my area they have partnered with a local water sports shop to provide an accessible "Paddle Fest" and brought their Voyageur canoes to events from Milwaukee's waterfront to our great state parks. Wilderness Inquiry adventures, scheduled for all areas of the country and the world, include hiking, canoeing, rafting, rock climbing, horseback riding, and more. Experienced with people of all abilities, they will customize your trip with your specific needs in mind. Visit **www.wildernessinquiry.org** to learn more.

Staying Safe and Cool While You Are Out

When it is summertime and you live with MS, the sun, heat, and humidity can wilt you like overcooked spaghetti, even when you're hydrated. But with the proper planning, you can enjoy a day at the beach, take in an art fair, or try camping or paddling.

Start with a good sunscreen, applied liberally one-half hour before you go out and every two hours throughout the day. Make sure that you use enough – a two-ounce shot glass worth for the average adult – and that the sunscreen is new. If not purchased this season, it may not give you adequate protection.

Invest in a good, comfortable hat and shirt with SPF protection of at least 30. Visit **www.spfstore.com** for a full array of cloth-

ing, swimwear, and sunglasses for men, women, and children.

Stay cool with bandanas, with water-absorbing beads or gel inside. Get them wet, tie them around your forehead, neck, or wrists, and you will feel cooler instantly. Bring twice as many as you would wear, so you always have a cool replacement available. You might find battery-operated personal fans to be helpful. Some can be worn around your neck or clipped to a hat brim. Misters are another good option. These continuously spray a very fine mist of water.

For serious cooling power, there are also cooling hats, vests, and other apparel available. MSAA offers a Cooling Equipment Distribution Program that provides cooling apparel to individuals who qualify. For more information, visit **www.msassociation.org** or call MSAA's Helpline at **(800) 532-7667**.

Last but not least, staying hydrated is very important when in a hot environment. Drinking an adequate amount of water is helpful, and crushed ice or "slushy-type" drinks may help you to feel cooler. Avoid drinks with alcohol, caffeine, or too much sugar, as they can reduce or in some cases eliminate the hydrating effect of the liquid you consume.

Staying Connected Without Leaving the House

When the temperatures are hovering near 90 degrees (or higher) and the humidity is palpable, getting out is just not practical. The same is true when ice and snow or other weather factors interfere with one's mobility. At those times it is important to stay connected by reaching out to others. Here are a few of my favorite ways to enjoy friends, family, and the whole world, when I'm forced to stay at home.

Use computer software like Skype to bring not only their voice but live video of your loved ones into your home, no matter where they are in the world. This service is free to download. If you want video capability, you and the person you call will need inexpensive cameras if your computers don't have them. For more information, please visit **skype.com**.

The internet is a great way to connect socially. For instance, you can reach out to friends via email. MSAA offers a Networking Program which connects individuals with MS through email, as well as care partners who want to share email with other care partners. For more information, please visit MSAA's website at **www.msassociation.org**.

Professionally monitored chat rooms and blogs are another good option.

For real-life socializing, you can invite friends over for a pot luck, to watch a ball-game or movie (delivered to you by Netflix or the library), play cards or board games, work on a puzzle (such as a jigsaw, crossword, or Sudoku), or share hobbies. You might even start a book club.

Whatever you choose to do, make it easy; let others come to you and share in bringing the food and other refreshments. Don't feel you need to do everything; friends are happy to help with even set up and clean up. The idea is to stay connected and have fun, in whatever way is energizing and doable for you.

I hope you'll join me in staying active and getting out as much as possible to see new things and participate in fun and affordable activities. When going out just isn't possible, I encourage you to invite people in. "Building community" means enjoying the people, places, and things that are around us. And by staying active and doing the things you enjoy, you are making an important contribution to your own physical health and emotional wellbeing. ◆

Submit Your Best Work!

2009 MSAA Art Contest

2008 Finalist: *Peach Memories* by Lissa Hale

*The theme of the **2009 MSAA Art Contest** is **Transformation**. Please submit work that reflects on the positive impact of change in life. Artists are encouraged to interpret this theme as broadly and creatively as they wish.*

Artwork will only be accepted from individuals who have MS. Work created using watercolors, acrylics, oil, pencils, pastels, ink and other two dimensional media are acceptable. Artwork will be judged by a committee chosen by MSAA, and the winner will be announced in March 2010.

Submissions will be accepted between October 1 and November 15, 2009.

For complete contest rules and submission guidelines, visit support.msassociation.org/artcontest

Art contest paint tube image by Rachel Slepekis

For further information, contact:

Linda Price, Development Coordinator
MSAA
706 Haddonfield Road
Cherry Hill, NJ 08002
Email: lprice@msassociation.org
Phone: (800) 532-7667, extension 146

Multiple Sclerosis, Model Aircraft, and Making Connections

By Alexandra Howson

My dad developed symptoms of MS in 1968 and was eventually diagnosed four years later. During that time he lost his job, family, and sense of self as an avid aviator. After a career in the Air Force, he worked as a payload dispatcher for commercial airlines. But he found that even if he couldn't work or fly planes, he could at least make them. So he retrofitted his home to accommodate not only his disabilities, but also his passion for making model aircraft.

After multiple sclerosis left John Howson unable to work, he devoted much of his time to building model aircraft. The hobby kept his hands nimble, his mind sharp, and helped him connect with others.

Multiple Sclerosis, Occupational Therapy, and Individual Experience

The effectiveness of occupational therapy (OT) can sometimes be difficult to measure in a study setting. However, in the lives of people with multiple sclerosis, OT interventions are frequently reported to improve outcomes in functional ability, social participation, and health-related quality of life. Individual experiences tell the story of how occupational therapy makes a difference to those with multiple sclerosis.

The Long Sharp Pain of MS

In 1968, multiple sclerosis laid its claim on my father – a young, ambitious man from a blue collar 'holler' in Ohio. At that time, he was working as a transportation agent for the now defunct TWA. On one particular Saturday, he developed a headache that didn't improve with medication and became more intense over the next few days.

Difficulty in writing and walking followed, accompanied by fuzziness in his left ear – like the sound of many cicadas – which never really left him. By Monday, he felt so fatigued that he could barely work and he also had severe pain above his left ear. By Tuesday, his headache had increased and he fell twice at work. That night he drove home and never

returned to the job he loved.

Four years after the initial onset of these symptoms, my dad was finally diagnosed with MS. Over this time he lost his job; his wife and daughter no longer lived with him; and the contours of anything resembling the life he had made for himself were gone. He experienced depression and loneliness, while he struggled financially. What saved him, aside from his faith in God, was aviation.

Alexandra Howson with her father John, and some of the model aircraft he built following his diagnosis of MS.

Aircraft Model Making

Ever since he was little, my dad had dreamed of working with airplanes. He joined the Air Force, and following discharge, worked for the major airlines of the 1960s – Pan Am, Northwest, and finally, TWA. He was a disciplined student and a diligent worker with an encyclopedic knowledge of aviation history, aerodynamics, and aircraft design. His colleagues knew him as someone who could work any aircraft from any runway in the world, under any conditions. And he drew creatively on this knowledge as a person with MS. If he couldn't work planes, then he'd make them.

In the late 1970s, my father moved to Kentucky and remodeled a house to accommodate, as he put it, "handicapped living." He lowered countertops; installed cabinets with pullout shelving, a rollout cook top, and ovens with side-opening doors; fitted a Chevrolet van with a Braun automatic lift; acquired an Amigo scooter; and built a wheelchair-accessible addition to the house.

He converted one of his rooms into a craft space where he could spend time making model aircraft. The drawers were filled with supplies: paints, glue, knives, and putty. The closet was stacked with boxes of models he bought in bulk from a mail-order company. He especially liked United States and British planes: Boeing B47 Stratojets, Whirlwinds, Tempests and Spitfires, Westland Lysanders, Sopwith Camels, McDonnell Douglas, Lockheed, Hawker, and even Spruce Goose. His favorite was the Boeing 707, the first United States commercial airplane.

Making model aircraft helped my dad keep his hands nimble. His left hand did not function well; on bad days, it dragged alongside his Amigo. But the process of modeling helped him retain a degree of mobility and dexterity. It demanded that he tear apart or cut the small plastic spars that attached model parts to the frame, paint each individual part, and affix these to each other to create a whole. One airplane could take him weeks to complete; he would work on it in short bursts throughout the day (which typically also

included a careful exercise regime, naps, television viewing, and copying sermon tapes as a service for his church's outreach ministry). As occupational therapy, assembling models certainly enhanced his functional ability and helped him stay sharp.

Making Models, Making Connections

Yet it was also more than this. Making models helped him connect with people, especially when his speech was distorted. At times he suffered from paroxysmal facial pain, but he seldom allowed this to prevent him going to church, even though he could barely talk. At such times it was difficult for people to understand him. But they understood what he was saying when he gave them a plane. He was telling them he cared about them. He was telling them that though he could not speak, he could still participate in the life of the church and contribute to the wellbeing of others.

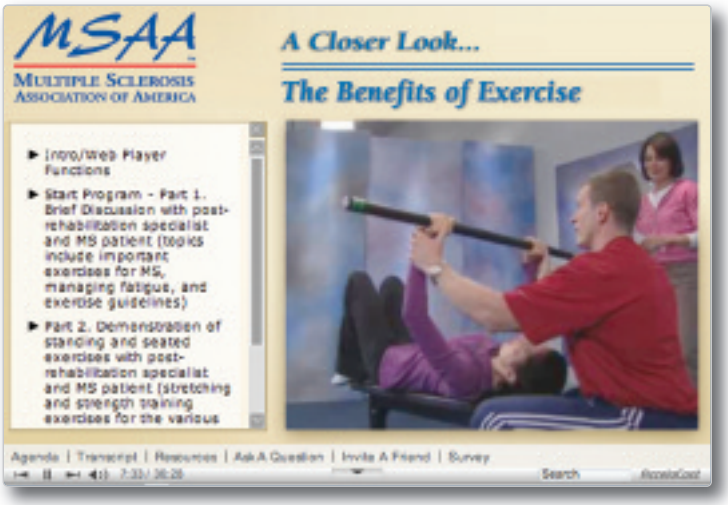
People still remember the airplanes my dad made for them. Following his death in 1999, six weeks after the birth of his second granddaughter, friends and family recalled that they felt grateful they were included in his gift giving. For me, there's no doubt about the value of occupational therapy: through his painting and gluing, my father crafted not just model airplanes, but a life and legacy. ◆

As well as being the daughter of someone with MS, the author of this article is a medical writer who has written books and articles for peer review, newspaper, and trade publications.

MSi On-Demand Educational Videos

MSAA is pleased to offer an extensive library of on-demand video programming which brings knowledge and empowerment right into the privacy and comfort of your home. Some of the most recent MSi videos posted include:

- **MS Research: 2009 and Beyond**
  Updates on current MS treatments, latest news on oral medications, & more
- **The Benefits of Exercise**
  Two-part video featuring demonstrations
- **Making Your Home Work For You**
  Conserve energy, use adaptive devices, and incorporate home modifications with design
- **Art of Symptom Management Series**
  Recorded live doctor-to-patient programs covering common MS symptoms



To view any of the 20+ MSAA educational videos, please visit www.msassociation.org

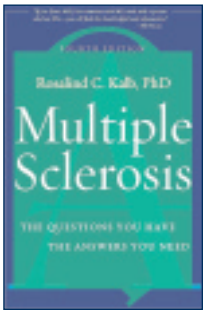
Spread the Word

Health Insurance Resources: A Guide for People with Chronic Disease and Disability, 2nd Edition
Written by Dorothy E. Northrop, MSW, ACSW, Stephen Cooper, Kimberly Calder, MPS
Published by Demos Medical Publishing
MSAA Book #283

This updated reference is designed to help both individuals with disabilities as well as medical professionals in learning about the healthcare system in the United States. Covering such topics as Social Security Disability Insurance, Medicare Prescription Drug Coverage, HIPAA, COBRA, and pharmacy assistance programs, this resource is aimed at enabling individuals to maximize their healthcare benefits.

Barrier-Free Travel: A Nuts And Bolts Guide For Wheelers And Slow Walkers, 3rd Edition
Written by Candy B. Harrington
Published by Demos Medical Publishing
MSAA Book # 18

Anyone planning a trip who is concerned with mobility limitations will want to consult this valuable reference, now in its third edition and highlighted by more than 100 photos. Topics include air-travel logistics, accessible places to stay, cruises with accessible shore excursions, and much more, along with travel rules and regulations affecting travel outside of the United States.



Multiple Sclerosis: The Questions You Have, The Answers You Need, 4th Edition
Written by Rosalind C. Kalb, PhD
Published by Demos Medical Publishing
MSAA Book # 51

Author Rosalind Kalb has once again provided the MS community with a vital guide to the many factors involved with living with MS. Each section features questions answered by medical, legal, and business professionals, to give the most up-to-date information available on everything from diagnosis and treatments, to insurance, employment, family planning, emotional impact, and much more.

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
706 Haddonfield Road
Cherry Hill, NJ 08002

(Please reference book number)