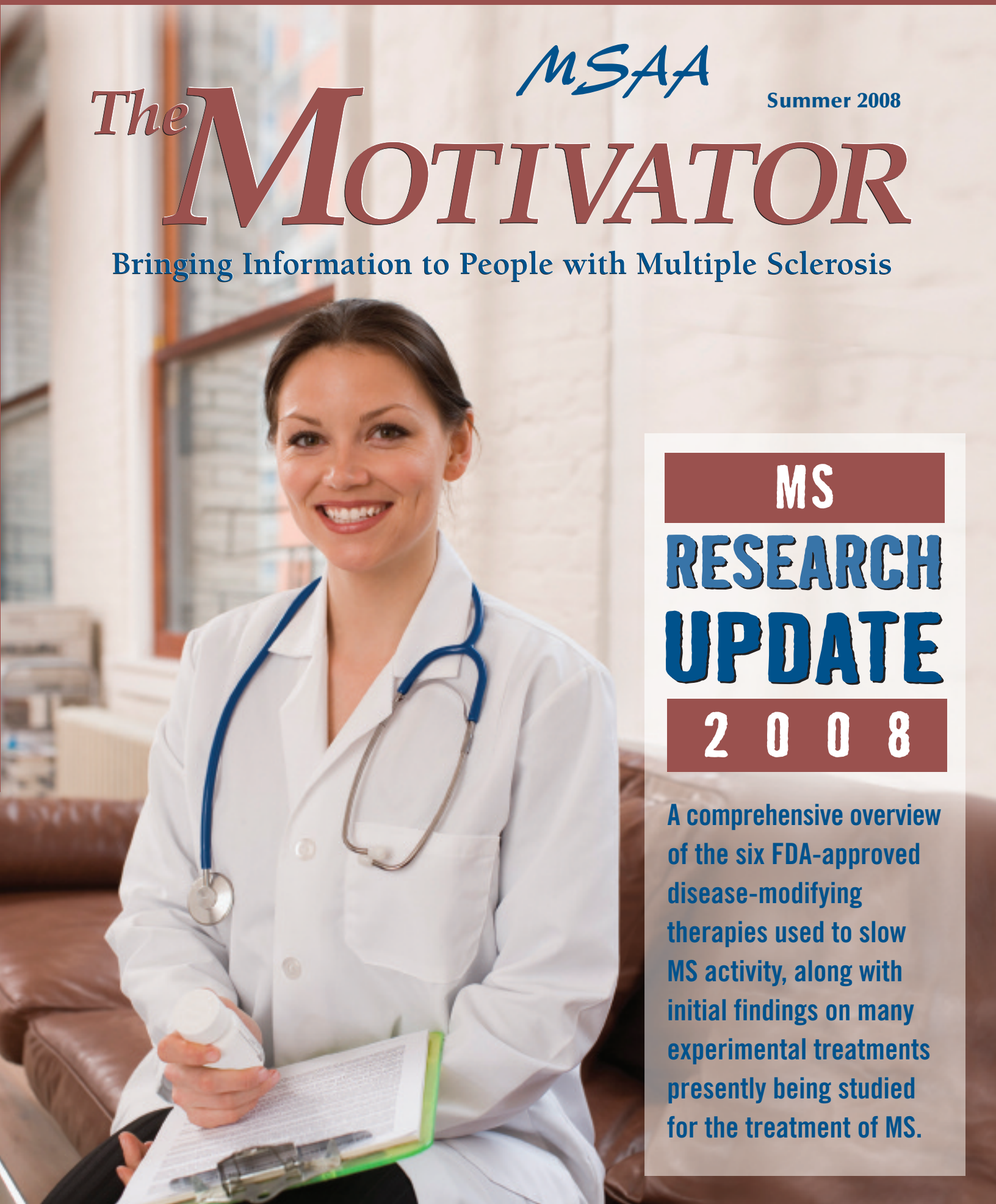
MSAA

# The MOTIVATOR

Summer 2008

Bringing Information to People with Multiple Sclerosis



## MS RESEARCH UPDATE 2008

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.

The MOTIVATOR

**Published by the Multiple Sclerosis Association of America**

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COVER STORY

## *MS Research Update 2008*

*By Diana M. Schneider*
*Reviewed by Jack Burks, MD* ..... *4*

MSAA's annual Research Update presents the latest trial results and research trends in disease-modifying therapies for MS.

DEPARTMENTS



***Due to space limitations, the Sympton Awareness and Stories to Inspire columns could not be included in this issue, but will appear in future issues of The Motivator.***

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.

# Up Front

By Douglas G. Franklin
MSAA President and CEO

*Douglas G. Franklin*

Spring and summer are always busy times at MSAA, and this year is no exception. We are issuing more cooling equipment than ever before and welcome the challenge of expanding our program and service offerings across the country. Additionally, MSAA was a participant and an exhibitor at the American Academy of Neurology (AAN) and Consortium of Multiple Sclerosis Centers (CMSC) conferences. Both provide information on new and current multiple sclerosis (MS) therapies and I encourage you to read our cover story highlighting these updates (beginning on page 4).

At the CMSC conference in Denver, Colorado, MSAA held its annual general meeting with our Board of Directors. This presented an excellent opportunity for MSAA staff and Board members to attend workshop sessions while participating in Board-related activities. MSAA welcomed two new members, Bobby Soileau, who is featured in this issue's Board Spotlight, and Bill Saunders. We also have a new executive committee led by our new Board Chairperson Eric Simons.

As president of the Multiple Sclerosis Coalition (MSC), I am pleased to announce the MSC has received 501(c)3 status from the Internal Revenue Service (IRS), an important milestone. While in Denver, a full business meeting of the MSC took place and considerable progress was made on the organization's planning and outreach. The MSC was also active during the CMSC meeting as several members led a workshop on advocacy and critical public policy issues affecting those with MS. In May, I attended the National Multiple Sclerosis Society's Public Policy conference in Washington, DC, along with MSAA Vice President of Communications & Marketing Andrea Griesé. We spoke with their full assembly about the work of both MSAA and the MSC. Pursuing improved quality of life for everyone affected by MS is everyone's responsibility and we are pleased to be able to lend our support to such efforts on behalf of our MS constituents.

In program news, the Bayer USA Foundation recently awarded a significant contribution to MSAA to pilot a Life Coaching program. Using a certified life coach, this program will teach critical problem-solving strategies and skills to help people with MS find practical solutions in their daily lives. Members of our Healthcare Advisory Council have worked hard to develop guidelines for this program and we will be delighted to launch it next year thanks to this funding.

On a final note, many of you are aware MSAA has an ever-expanding library of online, on-demand educational videos available through **msassociation.org**. Our latest video, *A Closer Look at Clinically Isolated Syndrome and MS* is now available. For individuals without internet access, many of our videos are available on DVD through our free Lending Library (please see page 48). ◆

*Doug Franklin joined MSAA as President & CEO in 1999. He has a distinguished career in association leadership and is a former national trainer in strategic planning for the Peter Drucker Foundation. A published international expert in the field of social marketing, he is a graduate of four universities.*

*He currently serves: on the National Board of the Key Philanthropic Organizations Committee of the American Society of Association Executives; on the Executive Committee of Health First -- America's Charities Board in Washington, DC; and as president of the Multiple Sclerosis Coalition.*

## *Meet MSAA Board Member Bobby Soileau*

Bobby Soileau discovered our organization through MSAA's Northwest Regional office's charity snowmobile ride, known as TransMontana. This annual ride takes snowmobilers across the state of Montana in an effort to raise funds for MSAA. "I have an addiction to high-altitude snowmobiling," confesses Bobby. "I love anything that is above 10,000 feet."

*Bobby Soileau (right) with Ross Maclean during this year's TransMontana ride.*

After his first ride in 2004, he was hooked. Bobby explains, "I loved the camaraderie of the event. There was so much caring and compassion among the riders in doing something positive for the MS community. The good feelings were infectious."

In addition to participating in the TransMontana ride, through his carpentry business, Bobby has donated several pieces of woodwork and cabinetry to an auction which is held in conjunction with TransMontana. Bobby's donated items have raised thousands of dollars for MSAA.

Referring to MSAA President and CEO Doug Franklin, and MSAA Board Members and former Chairpersons Joe King and Ross Maclean, Bobby continues, "Over time, I have come to know Doug, Joe, and Ross. During the rides, we have had many conversations about MSAA and its mission. Through those talks it became clear to me that I wanted to be a part of the organization."

During his tenure, Bobby hopes to have a great impact on MSAA and the MS community. "As a Board member, I would like to assist with bringing in new donors, allowing MSAA to provide more services to more people," states Bobby. "The staff is extremely dedicated to the cause. One of my goals is to see the organization fully supported in the years ahead so we can help even more people."

Currently, Bobby resides in Rosemount, Minnesota with his two children, Andy and Maggie.

***— Amanda Bednar***

# MS RESEARCH UPDATE 2008

**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 Update" that appeared in the Summer 2007 issue of *The Motivator*, this article incorporates advances and new information about the six Food and Drug Administration (FDA)-approved disease-modifying therapies (DMTs), as well as experimental drugs currently being studied for the treatment of MS. Below each listed medication are several highlights about the drug and related research. This is not a complete list and not all studies and their results are included. Please note that, in many instances, initial study results should be considered as preliminary, as additional studies and/or evaluations are needed before these findings may be confirmed.

The information provided 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 meetings dedicated to neurologic conditions and multiple sclerosis (MS). 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).

While many readers of *The Motivator* are well-versed in MS terminology and disease pathology, a listing of basic MS terms may be found on page 33. For additional information, readers may refer to the Health and Wellness column from the Summer 2007 issue of *The Motivator.* This column gives an overview of MS terminology, evaluative procedures, clinical trials, and treatments. To request a copy, please contact MSAA by calling **(800) 532-7667**. It may also be viewed online at **www.msassociation.org/publications/summer07/health.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. Additionally, this article does not include medications for managing the symptoms of MS. Treatments for symptom management will be the subject of an article in an upcoming issue of *The Motivator*.

## ***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), a single attack not yet diagnosed as MS.

Avonex has been shown to reduce the number of relapses and slow the progression of physical disability.

Interferons may affect the immune system by decreasing damaging cells, while increasing cells that suppress inflammation. They may also reduce the transport of potentially damaging immune-system cells from entering the brain.

An extension of the CHAMPS study will determine if immediate initiation of therapy after a first attack continues to delay the development of further attacks and the development of neurologic disability over 10 years.

The ASSURANCE 15-year follow-up study will evaluate the longer-term impact on the development of disability of early versus delayed initiation of therapy in relapsing-remitting MS (RRMS). Positive data is now available from eight years of treatment.

The TODAY trial, now recruiting, is studying the side effects of gradually increasing to full dosage from a partial dose, relative to starting at full dose. A pilot study of 27 patients suggests that the combination of initial-dose titration (increasing to a full dose gradually) and analgesic drugs reduces flu-like side effects with Avonex.

### COMBINATION AND COMPARATIVE STUDIES:

The ongoing, Phase III COMBI Rx trial for RRMS uses three treatment arms: Avonex with Copaxone, Avonex alone, and Copaxone alone.

The ACT trial evaluated Avonex in combination with methotrexate (MTX), intravenous methylprednisolone (IVMP), or both; data suggested that adding MTX and IVMP may be helpful in patients on Avonex who have continuing active disease.

A study of individuals with RRMS that combines Avonex with Cellcept® is now recruiting. It will evaluate changes in brain-lesion volume activity in RRMS.

The combination of Avonex with bi-monthly high-dose intravenous methotrexate is being examined, as is a single high dose of methotrexate prior to beginning treatment with Avonex.

## **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 therapy leads to a decreased number of exacerbations (attacks) of MS, increases time between exacerbations, and generally less severe exacerbations as compared to those taking a lower dose or no medications, and stabilization of the total lesion area as compared to those without treatment.

Interferons may affect the immune system by decreasing damaging cells, while increasing cells that suppress inflammation. They may also reduce the transport of potentially damaging immune-system cells from entering the brain.

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

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.

### 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.

The BECOME study is using new MRI techniques to compare Betaseron versus Copaxone in RRMS; enhancing lesions and clinical data were similar, while MRI black-hole data favored Betaseron.

The BEYOND study compared Betaseron versus double-dose Betaseron versus Copaxone. All were well-tolerated, and dramatically and equally reduced relapses (primary outcome). 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.

## ***Rebif®*** *(interferon beta-1a)*

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

Administered by subcutaneous injection three times weekly; dosage is 22 or 44 mcg.

Approved for relapsing types of MS.

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

Interferons may affect the immune system by decreasing damaging cells, while increasing cells that suppress inflammation. They may also reduce the transport of potentially damaging immune-system cells from entering the brain.

A 96-week study of the Rebif new formulation (RNF) demonstrates that it is better tolerated than the original formulation; it results in less injection-site reactions and pain, but flu-like reactions were more common. Fewer neutralizing antibodies (NAbs) were seen with RNF. The ongoing IMPROVE trial is evaluating the efficacy of RNF in RRMS, as measured by the number of active lesions on MRI. This formulation is not yet available in the United States.

An ongoing study is looking at the use of Rebif for CIS to confirm its effectiveness in delaying the conversion to CDMS.

In the COGIMUS study, patients on the 44 mcg dose for two years developed less cognitive impairment than those on the 22 mcg dose.

### COMBINATION AND COMPARATIVE STUDIES:

In one study, 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 pilot-study now recruiting will look at the benefit of combining Rebif with Cellcept early in the disease.

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.

An ongoing three-year Phase II clinical trial is comparing low-dose and high-dose Campath with high-dose Rebif in patients with early, active RRMS. Its primary outcome measure is the time to sustained accumulation of disability and relapse rate.

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 - GA)*

***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 by acting essentially as a decoy. Copaxone also increases anti-inflammatory lymphocytes and brain-derived neurotrophic factor (BDNF), with potential neuroprotective effects.

A pilot study with daily double-dose Copaxone versus single-dose Copaxone suggested it reduced relapses and lesions as seen on MRI. However, the company recently announced that a second study did not confirm a difference.

The 36-month PreCISe study has shown a successful delay in the conversion of clinically isolated syndrome (CIS) to clinically definite MS (CDMS).

RRMS patients receiving long-term Copaxone treatment showed more life satisfaction, better health, and greater satisfaction with therapy than untreated individuals or those receiving only short-term treatment with Copaxone or interferon beta.

### COMBINATION AND COMPARATIVE STUDIES:

The COMBI Rx trial will compare the combination of Avonex plus Copaxone to Copaxone alone and Avonex alone.

Another study looks at Copaxone combined with oral minocycline; the combination reduced the number of new and active lesions; also reported to be safe and well tolerated.

A currently recruiting trial is studying the effect of combining Copaxone and estriol in RRMS on relapse rate. A pilot study using the same combination had encouraging results.

An ongoing study of prednisone in 500 relapsing MS patients treated with Copaxone will measure changes in brain volume after three years as its primary outcome.

## ***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. Careful monitoring both during and after treatment is necessary. Dose varies according to an individual's weight.

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

The drug delays 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.

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.

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

Researchers suggested that the therapy was well-tolerated and may reduce the risk of adverse events seen with higher doses of Novantrone.

An ongoing study of safety and tolerability is collecting data about Novantrone therapy. The 500 patients in the study will be assessed over five years, with the primary outcome measures being the incidence of symptoms of adverse events.

### COMBINATION AND COMPARATIVE STUDIES:

A study to evaluate the use of Novantrone as an induction agent before Copaxone treatment, versus treatment with Copaxone alone, found beneficial results as measured by annual relapse rates in the Novantrone-induced group.

## ***Tysabri®*** *(natalizumab)*

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

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

This laboratory-produced monoclonal antibody acts against a molecule that is involved in the activation and function of lymphocytes and their migration into the central nervous system.

It was approved for the relapsing forms of MS based on a 68-percent reduction in relapses compared to placebo (AFFIRM trial) and a 54-percent reduction in relapses for those taking Tysabri plus Avonex, versus Avonex alone (SENTINEL trial). Disability and MRI lesions were also less with Tysabri.

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 TOUCH Prescribing Program and registered infusion centers and pharmacies, and the international Tysabri Global Observation Program in Safety (TYGRUS). Nearly 31,800 patients are on the drug worldwide, and there have been no new reports of PML in 18 months.

In early 2008, the FDA mandated a label change to include the possibility of serious liver injury associated with the drug's use.

Three-year data show continued effectiveness, as measured by a reduction in relapses, favorable MRI data, and a reduction in progression of disability. In a small initial trial, it also showed promise as a therapy in patients who had a previously poor response to other disease-management agents.

Recent data also shows that the drug 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, and may reduce loss of vision associated with relapsing-remitting MS.

A long-term safety study of 2,500 people with relapsing forms of MS is now enrolling participants.

A Phase I study of alternative routes of administration will test the efficacy and safety of subcutaneous and intramuscular routes of administration.

# EXPERIMENTAL ORAL MEDICATIONS *for the Treatment of MS*

## *Cladribine*

***Parent company:*** *EMD Serono, Inc.*

This drug is given orally for four to five consecutive days, ranging from once every 28 days to twice yearly, depending on the study regimen.

Based on studies of injectable cladribine showing a reduction in gadolinium-enhancing lesions that averaged 90 percent 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. If found to be both safe and effective, it may be approved in 2009.

This drug interferes with the proliferation of a specific class of T cells in the immune system.

The injectable form is generally well tolerated; side effects include fatigue, headache, and infections.

The ongoing two-year, Phase III CLARITY extension study will assess the safety and efficacy of oral cladribine in RRMS, as well as its effect on progression of disability. All participants completed an earlier CLARITY trial that tested two doses of oral cladribine.

The ONWARD Phase II study (of 260 individuals who have experienced at least one relapse while taking Rebif) combines oral cladribine with the new formulation of Rebif, to determine whether the combination is more effective than Rebif alone.

## *Fingolimod (FTY720)*

***Parent company:*** *Novartis*

Oral medication taken daily.

Blocks T cells from leaving lymph nodes, lowering their number in the blood and tissues; may reduce damage to nerves and enhance nerve repair.

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 a low rate of disease activity as observed on MRI. Patients are being recruited for the 24-month FREEDOMS Phase III study of low-dose and high-dose fingolimod versus placebo. Primary outcome measures are safety and tolerability, the proportion of relapse-free patients, and the burden of disease and inflammatory activity as measured by MRI.

The TRANSFORMS trial is now recruiting participants for its third phase. This 24-month study of the efficacy of fingolimod, as compared to Avonex in patients with a documented history of RRMS, has the primary outcome measure of a reduction of relapse rate; secondary measures will include frequency of relapses, inflammatory disease activity as measured on MRI, and time to progression of disability.

## BG00012 (BG 12; fumarate; fumaric acid esther)

***Parent company:*** *Biogen Idec*

Oral medication taken daily.

This drug is an immunomodulator with anti-inflammatory properties; may potentially have neuroprotective effects. This drug is being studied in RRMS.

In a Phase 2b safety-extension study using three dose levels, the highest dose reduced the formation of new gadolinium-enhanced lesions by 69 percent compared to placebo, reduced relapse rate by 58 percent, and decreased disease activity on MRI; over the 48-week period, BG00012 was reported to be safe and tolerable.

The Phase III DEFINE and CONFIRM studies are now recruiting. The DEFINE study will compare two doses of BG00012 against placebo in 1,011 patients. The CONFIRM study will test two levels of the drug against Copaxone and placebo in 1,232 patients.

## Laquinimod

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

Oral medication taken daily.

Laquinimod is being studied in RRMS and is an immunomodulator.

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.

The 24-month BRAVO study is currently recruiting patients with RRMS. It will compare the effect of laquinimod to Avonex. The primary outcome measure is relapse rate; secondary measures are the accumulation of disability and disease activity as measured by MRI.

A trial of safety and efficacy is now recruiting, and will compare laquinimod to placebo in patients with RRMS. The outcome measures are the same as the BRAVO study.

# EXPERIMENTAL ORAL MEDICATIONS *for the Treatment of MS*

## *Teriflunomide*

***Parent company:*** *Sanofi-aventis*

Oral medication taken daily.

This drug is an immunomodulator, affecting the division of T cells.

A Phase II trial of RRMS patients with relapses 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.

Two Phase II combination studies are in progress; one of teriflunomide added to interferon beta; the other adding it to Copaxone. 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 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.

## *Statins*

Statins are oral medications most commonly prescribed to lower cholesterol. Their anti-inflammatory properties make them of interest for possible use in MS. Atorvastatin (Lipitor®) and simvastatin (Vytorin®, Zorcor®) are among the statins presently being studied as potential treatments for RRMS.

An initial pilot trial of simvastatin in an uncontrolled study showed it was safe and reduced MRI activity at six months.

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. In one study, 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.

## *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.

The CAMMS223 Phase 2 study compared Campath to high-dose Rebif in an open-label study with RRMS patients. After two years, there was a 73-percent reduction in risk of relapse and a 71-percent reduction in progression to significant disability in those treated with Campath, a significant benefit over treatment with Rebif. Over 50 percent of the Campath-treated patients actually improved, suggesting a possible neuroprotective action.

The CARE-MS Phase III trial is enrolling 525 patients with previously untreated RRMS to further study Campath vs Rebif. They will be treated with 12 mg IV Campath for five days at month zero and three days at month 12, or to high-dose Rebif (44 mcg). Primary outcome measures are time to sustained accumulation of disability and relapse rate; secondary measures include the proportion of patients who remain relapse-free, a change in baseline Expanded Disability Status Scale (EDSS), the development of disability, and the change in lesion volume.

## *Rituxan®* (rituximab)

***Parent companies:*** *Genentech and Biogen Idec*

Administered via intravenous infusion.

Binds to a molecule (CD20) on the surface of B cells and depletes them from the circulation for an average of nine months. Used in lymphoma, rheumatoid arthritis, and lupus.

Serious adverse events have been reported in Rituxan-treated patients with other diseases such as rheumatoid arthritis and non-Hodgkin's lymphoma, including PML (as with Tysabri); patients must be closely monitored.

A Phase I, 72-week study showed a reduction in the frequency of inflammatory brain lesions and relapses.

A Phase II trial examined the effect of a single course of treatment, two infusions administered two weeks apart. At 24 weeks, there was a 91-percent reduction in the number of active lesions and a 58-percent reduction in relapses. These results continued to 48 weeks.

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

A small trial in neuromyelitis optica (NMO), which is an MS-like disorder, demonstrated a marked reduction in relapses with Rituxan.

# EXPERIMENTAL MONOCLONAL ANTIBODY MEDICATIONS

## *Zenapax®* (daclizumab)

***Parent companies:*** *Biogen Idec, Inc and PDL BioPharma*

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

This drug is used to prevent renal (kidney) transplant rejection. It is a genetically engineered antibody against interleukin-2, a substance necessary for the growth of T cells, limiting their growth and reducing 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; reported to improve or stabilize 60 percent of patients; and reduced the number of active lesions in both RRMS and SPMS patients.

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

# OTHER THERAPIES BEING STUDIED *for the Treatment of MS*

## *MBP8298*

***Parent company:*** *BioMS*

Administered intravenously every six months.

This peptide is a synthetic fragment of myelin basic protein (MBP). It replicates the site on the MBP molecule that is believed to be a target of attack by cells of the immune system, in 65 to 75 percent of all people with MS. It is believed to induce or restore immunologic tolerance to attack.

Phase I and II trials showed that, versus placebo, MBP8298 was safe and tolerable, and delayed the median time to disease progression by five years in people with SPMS.

MINDSET-01 is an ongoing Phase II trial with RRMS patients in Europe, comparing MBP8298 versus placebo.

MAESTRO-03 is a phase III trial in 510 people with SPMS who will be followed for two years. Its primary outcome measure is time to progression as measured by EDSS; secondary measures include the degree of change in EDSS and MRI changes.

## Tovaxin™

***Parent company:*** *Opexa Therapeutics*

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

A Phase II dose-escalation study (DES) compared three dose levels for safety and tolerability, changes in EDSS scores, and the frequency of MS relapses. Participants had RRMS (56 percent) or SPMS (44 percent) and were not responsive to approved immunomodulatory therapies. Significant improvements in the annualized relapse rate were seen, and there was a decrease in myelin-reactive T cells in the blood. The middle level dose was selected for future studies.

TERMS is an ongoing placebo-controlled one-year study in patients with CIS and RRMS to evaluate Tovaxin's efficacy, safety, and tolerability. Patients completing the trial may participate in an open-label, one-year OLERMS extension study. Outcome measures will include changes in the number of gadolinium-enhancing lesions on brain MRI, the rate and severity of MS progression, and relapse rate.

## Vitamin D3

There appears to be an inverse relationship between vitamin D3 status and the probability of developing MS, most likely due to its immunoregulatory effects. Vitamin D3 supplementation therefore appears to be a possible therapy in MS.

A Phase I/II trial of high-dose oral vitamin D3 with calcium had as its primary outcome the level of serum calcium; secondary outcome measures included the annualized relapse rate. Treatment appeared to be both safe and tolerable.

A study designed to determine whether peripheral blood regulatory T cells correlate with serum vitamins D and A ratios in people with RRMS demonstrated that the level of these cells were lower than expected in the treated group. The data suggest that the combined effect of vitamins D and A may play a role in suppressing MS disease activity, in part through their effect on these T cells. The required dose to achieve this effect appears to be much higher than that obtained through standard supplementation.

## Tetracycline Antibiotics

The tetracycline antibiotics, including minocycline and doxycycline, have been shown to 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 will study the effect of 100 mg of oral minocycline twice daily on the conversion of CIS to a diagnosis of MS (according to McDonald Criteria) at six and 24 months.

In a study combining minocycline with Copaxone in RRMS, 40 patients showed that the combination was more effective, as measured by gadolinium-enhancing and T2 lesions, as well as relapse rate.

A 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.

## BHT-3009

***Parent company:*** *Bayhill Therapeutics*

This is a DNA vaccine to myelin basic protein (MBP); it 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, and reducing the attack against the MBP in the myelin sheath.

A Phase I/II trial of immunotherapy with BHT-3009 demonstrated that the vaccine was safe and well tolerated, and that it produced an antigen-specific immune tolerance. It also provided favorable trends on brain MRI. This study was conducted with 30 RRMS or SPMS patients, and injections were given at weeks 1, 3, 5, and 9 using three dose levels.

A Phase II study in 267 RRMS patients compared two doses versus placebo. In the lower-dose group, a significant decrease in enhancing lesions was found as measured by MRI in patients with high levels of immune activity at time of enrollment. Injections were given at weeks 0, 2, 4, and every four weeks afterward. The higher dose was found to be ineffective.

A Phase IIb trial for RRMS patients is planned for late 2008.

MS RESEARCH UPDATE 2008

## New Directions in MS Research

Early treatment with one of the approved disease-modifying therapies (DMTs) is now recommended to be considered by all individuals with the relapsing forms of MS. This is a result of the many studies confirming clinical observations that people on 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 magnetic resonance imaging (MRI) scans, and a higher employment rate than individuals who have remained untreated.

There is also strong evidence that 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 outstanding 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.

## Clinical Trials

As the six Food and Drug Administration (FDA)-approved drugs for the treatment of disease progression have now been in use for some time, research and clinical trials are taking several new and exciting directions. These include:

- Studies that expand our understanding of how the existing FDA-approved drugs may be used even more effectively are testing variations in dosage, timing, and other factors.
- An increasing number of studies are comparing the FDA-approved drugs both against each other and in various combinations, to see if therapeutic response can be improved.
  - "Head-to-head" trials compare drugs against each other; ongoing studies include comparisons of Copaxone versus Rebif, Betaseron versus Copaxone, Rebif versus Betaseron versus Copaxone, Rebif versus Avonex, and Rebif new formulation versus Betaseron. Outcome measures include relapse rate, MRI effects, tolerability, and others.
  - Combination trials are designed to see if a combination of agents is better than either alone; ongoing studies include Avonex and Copaxone, Tysabri and Copaxone, and Rebif new formulation with cladribine.
  - Serial trials study the effects of using two drugs sequentially; ongoing studies include Novantrone followed by Copaxone versus Copaxone alone.
- Studies of "add-ons" of new drugs in earlier stages of development and with less available data are evaluating whether the combination of existing approved drugs with newer agents may be more effective than either alone.

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**. This website is a service of the United States National Institutes of Health, developed by the National Library of Medicine. The National Multiple Sclerosis Society also has a downloadable file containing information on clinical trials, which may be accessed at: **www.nationalmssociety.org/research/clinical-trials/index.aspx**.

## Environmental Factors and Genetic Studies

Environmental factors include the long-known statistic that by percentage of population, the frequency of MS increases as one resides farther from the equator, with some exceptions. This trend may possibly relate to factors such as diet and fish oil, reduced exposure to sunshine and vitamin D deficiency, lifestyle, and other environmental issues.

A viral component may play an important role as well. Individuals infected with the Epstein-Barr virus (EBV) may be at an increased risk of developing MS, with a possibly greater risk for those with a history of mononucleosis (a manifestation of EBV infection). EBV is a leading candidate for environmental exposure that increases the risk of MS.

MS also has a significant genetic component, although it has been difficult to assess the nature of MS inheritance because of the relationship with one's environment. Researchers are now able to identify specific DNA sequences that appear to be associated with the risk of MS.

Researchers recently found genetic differences in individuals who respond to interferon-beta treatment and those who do not respond to the drug. In a study of 287 people with relapsing-remitting MS (RRMS), researchers identified 18 genetic variations, some of which were in regions of the genes that code for proteins that might logically be involved in the way that the interferons work. Larger studies are needed, but this is a step toward being able to predict who will respond to specific therapies for MS.

African-Americans tend to have a more aggressive disease progression than Caucasians, and they are more likely to have mobility impairments and symptoms that affect the optic nerves and spinal cord. Recent studies also indicate that African-Americans may be less responsive to interferon-beta treatment, although the potentially differing disease course may be at least partially responsible for this effect.

## 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:** Some drugs, such as several antiepileptic drugs (lamotrigine [Lomictal®], topiramate [Topamax®], and phenytoin [Dilantin®]); riluzole (Rilutek®), a drug used to slow the progression of

MS RESEARCH UPDATE 2008

amyotrophic lateral sclerosis; and brain-derived neurotrophic factor (BDNF) are in trials for neuroprotection, meaning that they may prevent damage to nerve fibers and myelin. Many of the drugs that have neuroprotective activity appear to do so by blocking sodium channels, preventing the entry of calcium into nerve fibers and thus lessening damage, or by decreasing the toxicity of free radicals in the brain.

**Stem-cell transplantation:** High-dose immunosuppressive therapy followed by transplantation of the patient's own stem cells may induce sustained remission in autoimmune disease, and is being tested as a rescue therapy for MS, when very active disease continues while on DMT. Six-year follow-up data in a group of 26 patients with secondary-progressive MS (SPMS) or primary-progressive MS (PPMS) treated with high-dose immunosuppressive therapy followed by stem-cell transplantation shows that most patients remain stable. The therapy may be more successful in early stages of the disease. A recent Phase II study in patients with RRMS suggest some neurologic improvement. Similar results have been obtained in a Brazilian study, in which the Expanded Disability Status Scale (EDSS) was stabilized or reduced in most patients and the number of new MRI lesions was reduced.

**Antidepressants:** A small study of fluoxetine (Prozac®) showed immunomodulating and neuroprotective effects that included a decrease of inflammation and blockage of sodium channels. Small early studies also showed a decrease in new lesions. A Phase II completed study of rolipram, an antidepressant with immunomodulatory activity, focused on tolerability, safety, and MRI changes.

**Sex hormones:** Estriol is an estrogen-like hormone that may have both neuroprotective and anti-inflammatory properties. A small pilot study with 10 non-pregnant women showed a significant reduction in inflammatory lesions as well as cognitive improvement. Based on these results, 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. Additionally, a recent report of four women, whose MS symptoms remitted during infertility therapy, adds weight to the concept that sex hormones may be a viable anti-inflammatory therapy.

**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.)

## Other Agents in Early Stages of Testing for Use in MS

Mycophenolate mofetil (CellCept®) is an oral immunosuppressant medication used to

prevent transplant rejection. In a study of 86 patients, there was a mild but statistically significant improvement in EDSS scores, although the timed 25-foot walk continued to worsen slowly during the study. The mild improvement that was observed suggests that the drug may have potential for the treatment of progressive forms of MS.

A small two-year study of cyclophosphamide (Cytoxan®) in nine patients with aggressive RRMS demonstrated that the drug was safe and well tolerated. There was a statistically significant reduction in disability as measured by EDSS and in the number of gadolinium-enhancing lesions. Several of the patients continued to experience these benefits throughout the study; others experienced clinical and/or MRI exacerbations. The researchers note that this regimen is worthy of further study and may be an alternative to bone-marrow transplantation.

A Phase II study of CDP323, an oral Tysabri-like drug, is currently recruiting participants. This oral medication has a shorter half-life than Tysabri, which means that the drug is removed from the body more rapidly (half-life refers to the amount of time needed for the body to eliminate half of an administered dose). This study will evaluate 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 now being tested for possible future use in MS. These include: the plant hormone beta-sitosterol; the plant-derived antioxidant quercetin; 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; atacicept, a drug that blocks the development of mature B cells and inhibits the survival of antibody-producing cells; and symadex, which inhibits a pathway involved in macrophage maturation.

In conclusion, the MS community continues to have much to look forward to in the coming years. The currently approved MS medications work well, and most have proven to be safe and well tolerated over the course of several years. Emerging immunomodulating therapies currently in trials may offer advantages such as more convenience, less frequent dosing, fewer side effects, and greater effectiveness. However, safety concerns must be addressed. Experimental drugs aimed at providing neuro-protection, may one day prevent the loss of function due to MS progression; while remyelinating agents, designed to repair damaged nerves, may one day offer a return of function to individuals with progressive forms of the disease. Everyone in the MS community looks forward to the time when these potential treatments and cures may become a reality. ◆

# Ask the Doctor

By Dr. Jack Burks
Chief Medical Officer for MSAA

*Dr. Jack Burks*

**Q: I was diagnosed in 1991 with MS, although I have had symptoms since 1986. I worked as a registered nurse on a busy medical-surgery floor until 2002. I have had periods of vision loss at times, but when I go to bed, I sometimes can't sleep because I hear a "whirring noise" in my ears – almost like the sound of a fan running near my ear. Have you heard of anyone having this symptom, and what do you think it may be?**

A: Noises in the ears, called tinnitus, can occur in MS patients as well as in people without MS, especially those subjected to loud noises from the environment (including loud music). Usually, the noise has a ringing quality but other noises can occur. In MS patients, it may be accompanied by balance problems and/or decreased hearing. However, MS patients can also have other (non-MS related) problems that must be considered, such as Meniere's disease. I recommend that you see an audiologist or otolaryngologist (an ear, nose, and throat specialist), who specializes in tinnitus. New treatments are being researched but no "standard" treatment is available. Noise-masking devices, electromagnetic stimulation therapy, and implanted electrodes are potential treatments being evaluated. General information about tinnitus may be found on **www.webmd.com**. An expert on tinnitus in your area can review your treatment options in detail.

**Q: In addition to startling, I have also experienced some other symptoms which my neurologist says are not typical of MS. They include: fainting, vomiting, nausea, shortness of breath after short energy bursts (i.e., while vacuuming), and typical symptoms of having a heart attack (tightness on left side of chest, sore jaw, tingling down left arm, etc.). I've been to many different specialists this past year trying to chase these symptoms down. The cardiologist and pulmonologist say that my heart and lungs are in very good shape. My family practitioner suggested that my MS may be affecting my T-1, T-2, and T-3 (areas of spinal vertebrae). Have you heard of such symptoms and do you agree with my doctor's suggestion?**

A: First, I cannot specifically comment on your family doctor's suggestion about an MS lesion in the thoracic spinal cord that may cause your symptoms. He or she knows you best. In my experience, I cannot recall such a variety of symptoms from a specific thoracic spinal cord MS lesion. You could get a spinal cord MRI to further investigate the possibility of spinal cord damage. I agree with your neurologist that many of your symptoms are not typical of MS. Therefore, I am pleased that your heart and pulmonary (lung) systems checked out okay.

If you cannot find a specific cause and treatment for your symptoms, relaxation techniques may help you to better deal with your symptoms, as they must be very frustrating to you. Biofeedback, self hypnosis, guided imagery, yoga, tai chi, and other techniques have helped many of my patients, even when I have been puzzled by their symptoms.

Q: **I was diagnosed in 1999 with relapsing-remitting MS (RRMS) at the age of 39. My initial attack was quite severe. I was given steroids for a brief period and started on Avonex immediately. I have been on Avonex ever since, and as yet, have had no other relapses. Over the past nine years, I have had three MRIs, and these have shown no changes. The only symptom I experience is numbness in my hands. If I continue to be free of relapses in two years, when I turn 50, my doctor says he will recommend that I stop taking the Avonex (provided an MRI at that time shows no changes). What is your opinion in regards to stopping medication after years of no disease activity?**

A: I am pleased that you have had no relapses since your initial episode. There are three ways to look at your good fortune. First, if you only had one attack, you might not have MS. For example, an entity called ADEM (acute disseminated encephalomyelitis) is similar to MS but does not usually recur. Second, your MS may be benign and you may not need treatment. However, I am concerned about this possibility because your initial attack was "quite severe" and "benign" may not stay "benign," even after several years. Third, you have MS and Avonex is working well, in which case you should not stop the drug. Ask your doctor about these and other possibilities in deciding on your future treatments.

Q: **I'm 44 years old and last year I was given a diagnosis of "probable MS." Additionally, I was diagnosed with systemic lupus and arthritis in 1991; fibromyalgia in 2000; and hypothyroidism as well as diabetes in 2005. From my research, these are all autoimmune disorders. I had a spinal tap and a brain MRI; both were negative. My neurologist said that I do not have MS given the results of these tests. I've read extensively about autoimmune disorders and I've got to say that I still feel as though I may have MS. I don't have insurance and I haven't been able to work since April 2006, so I have no income other than my parents' ability to help with monthly expenses and medical care.**

**Over the past year, I have continued to experience sharp stabbing pain to my face, tingling and numbness of my lips and tongue, blurry vision and pain in my left eye, headaches, tremors, problems with my bladder (urgency, incontinence, and hesitation), extreme fatigue, excessive sweating, general pain, and cognitive problems. These symptoms cycle at different times over months.**

**Is it possible to have systemic lupus and MS? If so, what would be the best route of treatment? Thank you for your time and for caring.**

**A:** Lupus and MS symptoms can overlap and the two illnesses may occur together, but this is very unusual. Also, as your neurologist pointed out, it is unlikely to have MS with a normal spinal tap and MRI. The first step to treatment is making a definite diagnosis. An MS specialist working with a rheumatologist is a reasonable next step. You did not mention any treatments for your lupus or fibromyalgia. Lyrica® (pregabalin), a drug recently approved by the FDA for fibromyalgia, is something to discuss with your doctor. As for a potential MS connection, specific testing that evaluates your vision, bladder symptoms, and cognitive problems may help put your symptoms into better perspective. Your neurologist may want to repeat your brain MRI at some time in the future, if he or she has any further suspicions of MS.

**Q: I was diagnosed with MS in 2004. Two years ago my neurologist sent me in for an MRI, and then a second MRI four months later. Six new spots were found (I had been on Copaxone), so I switched to Novantrone. The Novantrone is working for the disease, as I am having no new symptoms, but my existing symptoms seem to be getting worse. Can you tell me why this might be happening, and is this normal? I asked my doctor but he couldn't give me a definitive answer.**

**A:** I am pleased you are having no new MS symptoms. However, worsening of existing symptoms may indicate that your disease is progressing. A repeat MRI might be helpful. Novantrone is only given for two to three years because of potential toxicity. What then? The other FDA-approved treatment options for MS (aside from Copaxone, which you tried earlier) are interferons and Tysabri. Your neurologist can review these treatments with you, relative to your specific situation. Also, there may be an MS center in your area that is doing a clinical trial on new drugs for MS, if you are interested. However, the first step is to have your neurologist determine if you are progressing. He or she may evaluate your MS according to your history, your examination, and possibly with an MRI. The next step will be to explore other treatment options.

## 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.

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*Jack Burks, MD, is a neurologist, chief medical officer for MSAA, clinical professor of neurology at the University of Nevada in Reno, Nevada, and member of the Clinical Advisory Committee of the NMSS. He has edited two MS textbooks. Previously, Dr. Burks established the Rocky Mountain MS Center and has served on several Boards of Directors, including the American Society of Neurorehabilitation (past president), the Colorado Neurological Institute, the American Academy of Neurology, and the Consortium of MS Centers. In recent years, he has lectured in more than 30 countries.*

# Research News

## MSAA Presentations at the 2008 CMSC Annual Meeting

Each year the Consortium of Multiple Sclerosis Centers (CMSC) holds a meeting to present the latest findings in research, treatments, and care for individuals with MS. The 2008 annual meeting was held in Denver in May. Prior to the meeting, MS specialists, research centers, and organizations submitted summaries of their work for possible platform, poster, "Works in Progress," or "Whitaker Research Track" presentations.

MSAA submitted three presentations, and each was approved by a committee of MS experts for the 2008 CMSC meeting. The first, which was accepted for a platform presentation, introduces exaggerated startle response as an under-recognized but potentially treatable symptom of MS. The second submission was accepted as a poster presentation and provides specific details on the impact of magnetic resonance imaging (MRI) testing on treatment, adherence, and healthcare. The third submission was accepted for the "Works in Progress" category, giving the results of a study, which showed that relaxation through guided imagery can be effective in lowering injection anxiety. To follow are excerpts from these three presentations.

### EXAGGERATED STARTLE RESPONSE (HYPEREKPLEXIA) IN MULTIPLE SCLEROSIS: REVIEW OF 30 PATIENT-REPORTED CASES

Exaggerated startle response or hyperekplexia (also known as hyperexplexia) is not recognized to be associated with multiple sclerosis (MS). The purpose of this report is to increase the awareness of this symptom in MS. Thirty-seven patients self-reported "startle response" after an inquiry in MSAA's "Ask the Doctor" column in *The Motivator*. Most cases of hyperekplexia in the medical literature are related to hereditary neonatal hyperekplexia and post-traumatic stress disorder (PTSD). Hyperekplexia involves an overactive autonomic arousal, which creates difficulty discriminating and interpreting stimuli. The primary treatment reported in the literature has been clonazepam. No MS patients [responding to the survey] received clonazepam. Thirty of the 37 respondents completed the survey. Startle was usually precipitated by auditory (82 percent), visual (17 percent), tactile (six percent), or a combination of stimuli. The average age of onset of MS symptoms was 26 and the onset of startle was 35. Less than 20 percent of MS patients had startle before their MS, which suggests previous trauma (PTSD) is not related. Other data include: 67 percent have the relapsing-remitting form of MS; 93 percent reported multiple episodes per day; 90 percent have an exaggerated startle response at least once a week and half of these experience startling at least daily. Hyperekplexia was variously described as frightening, embarrassing, painful, dangerous (falling), and

disruptive to personal and professional relationships. A total of 73 percent had not had discussions with any healthcare professional, and 17 percent reported that their doctors stated that startle might be related to MS, but had no therapeutic suggestions. In conclusion, hyperekplexia is an under-recognized but potentially treatable symptom of multiple sclerosis. Increased recognition and understanding will promote treatment options.

*— Jack Burks, MD, Miriam Franco, MSW, PsyD, Andrea L. Griesé; Susan Wells Courtney; John J. Masino*

## THE IMPACT OF MRI TESTING ON MS PATIENTS' TREATMENT DECISIONS, ADHERENCE TO MEDICATION AND IN THE MANAGEMENT OF THEIR OVERALL HEALTHCARE

Magnetic resonance imaging (MRI) is an important tool in diagnosing multiple sclerosis and tracking its progression. While MRI exams enable physicians to better understand and manage the treatment of their MS patients, uninsured and underinsured MS patients are often unable to afford an MRI. Through the MRI Institute, MSAA provides financial assistance to MS patients in obtaining an MRI. A survey was sent to MS patients who had used the MRI Institute within the previous year, of whom 220 patients

completed and returned the survey. While 51 percent of patients reported that their doctor suggested having an MRI at least once a year, 93 percent of respondents needed the MRI Institute to either cover the full cost of an MRI (63 percent) or to pay their insurance deductible (30 percent). 91 percent of patients discussed the results of their MRI with their physician, and 29 percent reported that the MRI had shown that their condition had worsened. 75 percent of respondents currently use an FDA-approved medication in the treatment of their MS. After receiving the results of their MRI, 29 percent of respondents reported that they had resumed taking their prescribed medication after having stopped for some time, switched from one approved MS treatment medication to another, or used one of the MS treatment medications for the first time. 78 percent of patients reported making one or more positive lifestyle changes. Specifically, 39 percent reported making changes in their lifestyle (i.e., diet, exercise, rest); 32 percent began receiving treatment for an MS symptom; 33 percent visited or scheduled a visit to an MS clinic or specialist; and 35 percent became more active in monitoring their MS and/or seeking out more information about MS. The research suggests that MRI results have a positive impact on decisions that MS patients make in regards to their treatment options, adherence to a prescribed medication, and in managing their overall healthcare.

***— Amanda Montague, EdM; Robert Rapp, MAPA; Manuela Bechtel; Ronald Ringer; Jack Burks, MD***

## PATIENT EDUCATION: USING RELAXATION AND GUIDED IMAGERY FOR MS: LOWERING ANXIETY ASSOCIATED WITH MS & MS INJECTIONS

**Background:** Stress and anxiety, especially surrounding disease-modifying drug injections (DMT), are major stumbling blocks to adherence. Missed injections due to anxiety are frequent and are a major factor in reduced efficacy. Guided imagery (GI) techniques reduce anxiety that accompany chronic illnesses and painful medical procedures. **Objective:** This study evaluates the efficacy of GI among relapsing-remitting MS (RRMS) patients who experience anxiety, including injection anxiety. **Methodology:** RRMS patients were taught GI at six sites following an initial assessment of anxiety and diagnostic MS information. Relaxation training preceded an MS-specific GI script aimed at lowering anxiety, injection anxiety and the perception of DMTs as a healing ally. The scripted GI CD was given to patients to practice daily for two weeks. The anonymous workshop evaluations and follow-up questionnaires were analyzed. **Results:** To date, 76 percent of participants returned workshop evaluations. Of those, 100 percent indicated they became deeply relaxed, 92 percent found GI to be a helpful technique, and 75 percent reported lowered anxiety. To date, 32 percent returned the follow-up questionnaires. 100 percent reported a lowering of anxiety. Of those, 55 percent specifically reported reduced injection anxiety and 45 percent reported reduced general anxiety as evidenced by improved sleep, confidence, reduced muscle tension, pain and

stress, and renewed energy. 94 percent found the workshop to be of value. **Conclusion:** Guided imagery was found to be effective in lowering general anxiety and injection anxiety in most RRMS patients.

**Supported in part through a Bayer Healthcare Pharmaceuticals Educational Grant.**

*— Miriam Franco, MSW, PsyD, MSCS; Donald Barone, DO; Kathy Barone, RN; Frederick Foley, PhD; Dorothea Cassidy Pfohl, RN, BS, MSCN; Jay Rosenberg, MD; Robin Tillett, RN, MSCN; Katherine Treadaway, LCSW*

**For a full listing of all the abstracts from the CMSC annual meeting, please visit www.mscare.org, scroll down and select "2008 Annual Meeting Highlights," and then scroll down to select "Abstracts."** ◆

**EDITOR'S NOTE:** In the Research News column of the Spring 2008 issue of *The Motivator* (page 28), we noted that a risk for possible liver injury was added to Tysabri's label. We also mentioned that two cases of melanoma (skin cancer) were reported in two individuals taking Tysabri, but a link between Tysabri and melanoma has not been established. Since the two items were mentioned together, we wanted to differentiate these two issues to avoid any confusion.

## Basic MS Terms

**MYELIN:** This is a protective, fatty-rich protein covering of the nerve fibers (axons). Axons work like wires to carry electrical impulses (messages) between the brain, spinal cord, and other parts of the body. The myelin insulates the axons, enabling these messages to travel along the nerves quickly. In MS, myelin is damaged by the immune system, interrupting the flow of nerve impulses.

**RELAPSE:** Also referred to as an attack or exacerbation, a relapse is a temporary flare-up of MS symptoms. Lasting between 48 hours and up to several months, relapses are followed by a complete or partial recovery (remission). These flare-ups occur in relapsing forms of MS, while progressive forms of MS are defined by a steadier worsening.

**LYMPHOCYTE:** These types of white blood cells include B cells and T cells, which help to regulate the immune response. In MS, these can become misdirected and result in damage to the myelin, axons, and neurons (nerve cells).

**LESION:** Also known as plaque, a lesion is an area where inflammation and damage to myelin (demyelination) is occurring or has occurred. Particularly in early disease, the body may repair portions of myelin (remyelination).

**MAGNETIC RESONANCE IMAGING (MRI):** This scanner provides a picture of the brain and/or spine to help evaluate MS activity. Areas of acute inflammation can be better viewed through gadolinium-enhancement, by giving the patient an injection of dye prior to the MRI scan.

# Program Notes

## Informational Needs Survey Results

The Board and staff of MSAA strongly believe that a successful organization must be in constant communication with those we endeavor to serve. This is especially important when assisting those affected by the ever changing course of MS. Being attuned to the needs of our constituents is one reason we believe MSAA receives such positive feedback from our clients for its programs and services.

In 2006, MSAA completed a comprehensive needs assessment that was responded to by more than 700 individuals affected by MS. That survey yielded important data and insights which helped shape our newest program offerings, including MSi (Multiple Sclerosis information), Resource Detectives, and the content for many of our educational programs.

MSAA's most recent survey focused on assessing the informational needs of our clients. The data received from more than 350 respondents confirmed much of what we knew from previous evaluations, but also added important new information. According to survey results, clients continue to place the highest value on receiving information about: MS research, medications and treatments (4.57 average score on a five-point scale, with "5" being the highest level of importance); MS symptom management (4.50); and exercise, nutrition, and physical therapies (4.21).

Printed publications continue to be the most "preferred" method of receiving information for our clients (33 percent of responses). Attending in-person educational programs and support groups are also reported to be popular ways of learning (23 percent combined). And not surprisingly, the number of people who prefer to get their information via electronic means continues to grow.

MSAA will use these survey data, as we have in the past, to design the very best programs and services. We thank all of you who responded to this survey. We also hope you will help us continue to "enrich the quality of life for everyone affected by MS" by participating in future MSAA surveys and evaluations. ◆

*– Robert Rapp*

## Happy Birthday to the Resource Detectives Program

It's hard to believe that a year has elapsed since the start of the Resource Detectives Program, a virtual volunteering experience. We have over 1,000 volunteers registered and more than 5,000 resources reported, providing more than 40,000 services to the MS community. These resources are used by MSAA's Helpline staff to assist clients who call our toll-free number or send email correspondence requesting assistance with their MS-related issues.

Our goal for the upcoming year is to upgrade the system used by the Resource Detectives database. This will enable us to share the data more efficiently in-house and also allow for a pilot

program with select MS centers throughout the country.

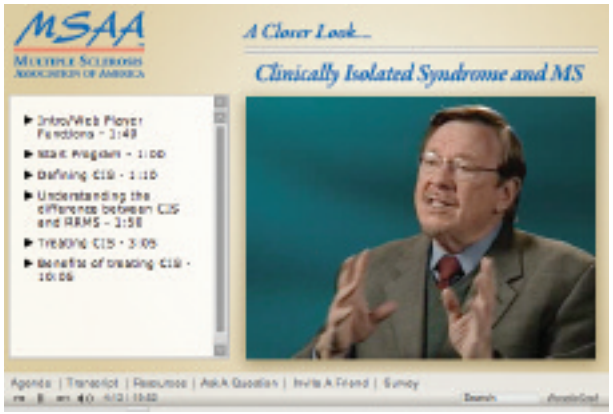
We need volunteers to continue to sign up as Resource Detectives. Their job is to report new resources, ensuring that the latest and the best information for the MS community is listed in the Resource Detectives database. Everyone is welcome to sign up; we would like to see an increase of people with MS volunteering to help – as they know best what the MS community needs. For more information, please contact Bonnie Yares, Resource Detectives manager, at **(800) 532-7667, extension 132**, or via email at **byares@msassociation.org**.

We also welcome you to visit our website at **support.msassociation.org/detectives**.

For more information about the Resource Detectives program, please see the feature article of the Summer 2007 issue of *The Motivator*. This may be viewed and downloaded by going to **www.msassociation.org/publications/summer07**, or readers may call MSAA at **(800) 532-7667** to request a copy. ◆

***– Bonnie Yares***

## New MS Video on Clinically Isolated Syndrome




As part of our continuing effort to use technology to reach more clients in more places than ever before, MSAA recently posted its seventh educational web video, titled: *A Closer Look at Clinically Isolated Syndrome and MS*. This 20-minute video features an in-depth interview with MSAA Chief Medical Officer Dr. Jack Burks on the importance of understanding clinically isolated syndrome (CIS), how it differs from relapsing-remitting and other forms of MS, and the benefits of early treatment.

During the interview, Dr. Burks was asked: "How often does CIS evolve into relapsing-remitting MS?" His response, in part, was: "Well, by definition, CIS is a high-risk for getting relapsing-remitting MS. There's one recent study that shows that 85 percent of the patients who are diagnosed with CIS initially will go on to relapsing-remitting MS in just two years." Dr. Burks goes on to point out the importance of this information for early treatment with a disease-modifying therapy, which has been shown to delay the onset of MS.

To view this latest video as well as the other *A Closer Look* programs, please visit **www.msassociation.org**. For readers without internet access, some videos are available on DVD through MSAA's free Lending Library. Please see page 48 for ordering information. ◆

***– Peter Damiri***

# Thoughts about Giving

## Because You Asked

*Bruce Makous*

Few are aware that we have hundreds of thousands of current contributors nationwide, and that our support comes from people living in just about every corner of the nation. MSAA's President and CEO Doug Franklin, as well as MSAA Board and staff members, have spent the past year visiting many of our donors in their home communities at MSAA President's Circle receptions.

We have traveled to meet contributors in Washington, New York, Dallas, and Denver, and we also visited with those in the Philadelphia area where MSAA is headquartered. During our travels, we have learned many things about you, our donors and volunteers.

First of all, you obviously share a common cause – you want to help to enrich the quality of life for people living with multiple sclerosis, which is the core mission of all of us involved with MSAA. Secondly, most of you have someone close to you who has multiple sclerosis, which heightens your reasons for involvement. Thirdly, all of you are generous in contributing your time or treasure or both.

Recently, after a friend increased her giving significantly, I asked her why she had decided to contribute more. "Because you asked me to," she said. I thought about how wonderfully simple her statement was. Being asked to give by someone you know is indeed a strong motivator, and this is a fourth characteristic that all of you share. You help because you are asked.

My friend went on to explain that she had appreciated meeting MSAA's president and Board members at a President's Circle event in her area, and being asked to become involved. Many donors have increased giving levels significantly for this very reason. They have been invited to meet MSAA's leadership and become more involved.

Another way in which we are showing our appreciation to our supporters is making sure that you are invited to our MS public education events in your area. These programs provide valuable information on topics of interest to people living with MS, including progress in research, and issues related to managing MS, such as diet, exercise, mental health, and other important matters.

In the coming year, we will present public education events in dozens of communities nationwide. We also plan to hold President's Circle receptions in Houston, Boston, San Francisco, Tampa, and Philadelphia. Please keep an eye out for your special invitations to these activities so that we can meet you and help you learn more about how your support helps people with MS.

Thank you for responding so generously and for helping people with multiple sclerosis. Your support is very much appreciated.

*— Bruce Makous*
*Vice President of Development*


*Denver MSAA supporter Bill Riedell receives recognition for his generous gifts at the May President's Circle Reception in Colorado. Presenting the award are, from left, MSAA's Development Chair Joe King, Board Chair Ross Maclean and President's Circle Chair Eric Simons.*

## Leaving a Legacy with MSAA

Donors frequently ask how they should go about remembering MSAA in their wills or estate plans. The simplest method is to place a codicil in a will indicating the amount that will be contributed to MSAA, and its purpose. The following sample bequest wording should be submitted to your estate attorney:

*Percentage amount for unrestricted needs:*
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 the most urgent needs of MSAA, as determined by MSAA's president.

*Specific dollar amount for unrestricted needs:*
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, ____ dollars [spelled out] ($___.00) to go to the most urgent needs of MSAA, as determined by MSAA's president.

*Percentage amount for specific program support:*
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 the _____ program of MSAA.

The bequest may also provide funding for a permanent endowment for either general operations or program support, and a fund name may be designated to honor the donor or another person. When choosing to provide program support or endowment funding, it is best to discuss this with MSAA staff to make sure your fund is established exactly as you intend.

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

# NUTRITIONAL TIPS
## FOR INDIVIDUALS WITH MS

*by Maryann B. Hunsberger*

I wanted my family to eat more healthfully when my son was born, but I had no idea where to start. It began one day at a friend's house. She offered me some sugar-free, caffeine-free soda. "If there's no sugar or caffeine in it, what is in it?" I asked. Puzzled, she said that she had no idea. The next morning, I opened my cabinet to prepare breakfast and saw an assortment of cereals. I wondered whether eating cereal was a good way to start my day. Looking at lists full of ingredients that I couldn't decipher didn't help matters.

I wasn't alone in my confusion. People know it's better to eat broccoli than a candy bar, but what about all those gray areas in between the two? It's even more complicated when a person has MS. Which foods are best to eat for optimal health?

*Editor's note: Readers are strongly advised to consult their physician before making any changes to their diet. A doctor can also help determine the exact types of foods and number of daily calories that are specifically appropriate for an individual.*

### What to Eat

According to Nancy Davis, a noted spokesperson on multiple sclerosis and the author of *Lean on Me*, a diet low in saturated fats and high in fiber is the foundation for a healthy eating plan. A good way to follow this plan is to eat fiber-packed fruit and vegetables. Fresh and frozen are best, but sodium-free canned vegetables and sugar-free canned fruit are also good. If canned produce without sodium and sugar isn't available, rinsing canned produce in water is helpful. Whole fruit contains more fiber, less sugar, and fewer calories than fruit juice, so whole fruit is the better option.

Gillian Goodfriend is a registered dietician at the University of Illinois at Chicago (UIC)'s Department of Disability and Human Development. To begin a healthy diet, Goodfriend advises adding one or two more servings per day of fruit and vegetables. "Slowly work your way up to five to six servings each day. A large banana is two servings. Two cups of salad is two servings. Big Red Delicious apples count as two servings. Reaching your goal is more achievable when you think of it that way."

Beans, nuts and seeds are good sources of fiber and protein. Low sodium or salt-free varieties of nuts and seeds are best. One-quarter cup of nuts per day – or two tablespoons of peanut butter – should be a limit for people with weight problems, but others can choose to eat more. Adding one-half cup of canned beans to a salad or soup each day provides plenty of fiber. Having a cup of split pea, lentil, or bean soup with a meal; topping whole-grain toast with fat-free refried beans and salsa; or eating a soy burger are easy ways to incorporate beans.

What about the much-maligned carbohydrates? The carbs that affect health negatively are the simple ones, such as sugar, white flour, white rice, and white potatoes. "If something is white or sugary, the manufacturing process has done part of the digesting for you. The sugar goes into the bloodstream more quickly, so you get hungrier and it raises your blood sugar," Goodfriend explains. Davis recommends avoiding refined sugars altogether, since these simple carbohydrates slow down, rather than speed up, the recovery process in people with MS.

Complex carbs, on the other hand, are nutritious. Whole grains, such as brown rice, barley, 100-percent whole-wheat bread, and old-fashioned oatmeal, digest more slowly, don't cause blood sugar surges, and have more vitamins and fiber. What if someone just can't give up the occasional treat? "I'm not saying to never eat a cookie or a bagel. Just include whole-grain foods as much as you can," says Goodfriend. At least three whole-grain servings each day provide ample fiber and nutrients.

Three servings per day of fat-free or low-fat dairy products provide bone-strengthening calcium, whether an individual has a weight problem or not. Recommending low-fat cheese for thin people might seem odd, but even underweight individuals shouldn't consume too much cholesterol-raising saturated fat from meats and full-fat dairy. "Saturated fat should not be the main source of your fat. It can lead to heart disease," states Goodfriend.

In his book, *The Multiple Sclerosis Diet Book*, Roy L. Swank, MD, PhD, recommends consuming no more than 15 grams of saturated fat per day. He advocates consuming dairy products with no more than one-percent fat.

Transfats, which raise bad cholesterol and lower good cholesterol, should be avoided. Goodfriend notes, "Transfats are a double whammy. Avoid these as much as possible; it's important to read ingredients. The rule is, if a serving of food has less than 0.5 grams of transfats, the makers can put zero grams on the label, even though it still might have hydrogenated oil in the ingredients."

Margarine contains transfats, while butter contains saturated fats. Transfat-free spreads are a better choice. Goodfriend continues, "Spreads such as Benecol®, Smart Balance®, and Take Control® are great choices. The plant sterols and stanols in them work by blocking absorption of bad LDL cholesterol in the small intestine. Research has shown, however, that the amount of sterols and stanols needed to achieve this health benefit is usually more than people would consume. However, they are still a healthy choice. People need to monitor the serving sizes of these products if their goal is weight control, as these products are high in calories."

Other healthy fats are the ones that stay liquid at room temperature, such as olive oil and canola oil. About five to six teaspoons per day provide essential fatty acids. Weight-conscious individuals shouldn't consume more than this. Avocados, olives, nuts, and seeds also provide healthful sources of fats. "These types of fats raise good cholesterol and lower bad cholesterol," says Goodfriend. However, these foods are high in calories and sometimes sodium. Arthur Agatston, MD, author of *The South Beach Diet*, recommends not exceeding 15 olives and one-third avocado per day. Swank suggests limiting unsaturated fats to 20 to 50 grams per day.

Meats provide protein, but also contain saturated fats and cholesterol. This means avoiding fatty cuts of beef like brisket, prime rib, rib steaks, ground chuck, or chuck roast. Instead, Agatston recommends opting for lean cuts, such as round, sirloin, or flank steaks; extra lean ground beef; top loin; T-bone and tenderloin. Three to four ounces of lean meats at lunch and dinner – about the size of a fist – is a good amount to eat each day.

White-meat poultry contains less fat and cholesterol than dark meat, especially with the fatty skin removed. When eating ground poultry, the extra lean type made from breast meat, is best. Bacon, sausage, lunchmeat and hot dogs made from poultry are less fatty than beef and pork varieties, but still contain high amounts of sodium.

*It's not too late to take the plunge!*

# SWIM 2008 FOR MS

**Anyone with access to a pool can participate!**

Individuals, groups, and swim clubs
can learn more and register online at:

**support.msassociation.org/swim2008**

Or call **(800) 532-7667, extension 8** or email
**volunteer@msassociation.org** for more information.

MSAA™
Multiple Sclerosis
Association of America

# *Submit Your Best Work!*

## 2008 MSAA *Art Contest*

**2007 First Prize**: *Still Life with Oranges*
by Kali Valencia

Art contest paint tube image
by Rachel Slepekis

*Artwork will only be accepted from individuals with MS. Paintings and drawings in oils, watercolors, pen, and ink are acceptable. Artwork will be judged by an MSAA committee, and the winner announced by January 15, 2009*

***Deadline for submissions is December 31, 2008.***

***For complete contest rules, visit***
***support.msassociation.org/artcontest***

*Please submit your artwork to:*

*Kathy Giles, Direct Fundraising Manager*
*MSAA*
*706 Haddonfield Road*
*Cherry Hill, NJ 08002*
*Email: kgiles@msassociation.org*

Loin and tenderloin are the lean cuts of pork. Pork tenderloin has roughly the same amount of saturated fats and cholesterol as skinless, white-meat chicken. Ham is generally lean, but high in sodium. Watch out for fatty cuts of pork, which are just as high in fat and cholesterol as the fattier beef products.

People watching cholesterol can eat egg whites or egg substitute in place of whole eggs. To make a lower-cholesterol egg salad, discard half of each yolk and use fat-free mayonnaise.

## HEALTHY RECIPES

*Hearty, healthy meals use wholesome ingredients. Three of my favorite recipes follow. They incorporate foods that the experts say are best.*

### Breakfast

WHOLE-GRAIN BREAKFAST

*1 slice whole-grain bread*
*1 thick tomato slice*
*1/4 tsp. oregano*
*1 slice fat-free or low-fat cheese*

Toast bread. Top with tomato, oregano, and cheese. Place in broiler until cheese lightly browns. Serve with a piece of fruit.

### Lunch

SPLIT-PEA SOUP WITH SPINACH

*1 bag split-green peas*
*2 onions, diced*
*2 cups carrots, diced*
*4 stalks celery, diced*
*1 box frozen chopped spinach (defrosted, drained, and dried)*
*1 can sodium-free diced tomatoes*
*5 tsp. sodium-free chicken bouillon powder*
*7 cups water*
*3 cups vegetable or low-fat chicken broth*
*1/2 tsp. each thyme and basil*
*1/4 tsp. red pepper flakes*
*1 tsp. Liquid Smoke*

Add all ingredients to a large soup pot. Bring to a boil. Lower heat to a simmer and cover pot. Cook for one hour. Serve with salad. Freeze leftovers in individual containers.

### Dinner

GARLIC-LIME CHICKEN

*4 boneless, skinless chicken breasts*
*2 Tbsp. olive oil*
*1/4 tsp. each black pepper, thyme, and parsley*
*1/8 tsp. each paprika and onion powder*
*2 tsp. garlic powder*
*3 Tbsp. limejuice*

In a small bowl, mix spices together. Sprinkle spice mixture on both sides of chicken breasts. Heat olive oil in a skillet. Sauté chicken until golden brown, about six minutes on each side. Sprinkle with lime juice. Cook five minutes, stirring frequently to coat evenly with sauce. Serve with broccoli and brown rice.

To find more healthy recipes, check the Mayo Clinic's Healthy Recipes Center at **www.mayoclinic.com/health/healthy-recipes/RE99999**.

***– Maryann B. Hunsberger***

According to James Rimmer, a professor at the University of Illinois at Chicago's Department of Disability and Human Development, and the director of the National Center on Physical Activity and Disability, people with MS can gain 'water weight' (when the body retains extra water) from steroids. Since sodium also contributes to water weight, lowering sodium intake is important – particularly if you are taking steroids and if recommended by your doctor. To reduce sodium intake, Rimmer advises to start by removing the salt shaker from the table. Sodium-free bouillon powder and spices are tasty alternatives to salt when cooking. Avoid hidden sources of sodium by rinsing canned vegetables or buying no-salt-added or low-sodium canned vegetables, soups, broths, pasta sauces, and cheeses.

Since bowel dysfunctions are common in people with MS, Rimmer points out that consuming adequate fiber and fluids is important. How much fluid is enough? In his book, *Managing the Symptoms of Multiple Sclerosis*, Randall T. Schapiro, MD, states, "Many experts have advocated drinking eight glasses of water a day, but there is no magic number. Drinking enough to satisfy thirst and prevent dehydration, along with preventing constipation, is necessary and may differ from person to person." Schapiro says the important thing is to drink more water and minimize sugary drinks such as soda.

In addition to sugary drinks, minimizing drinks with caffeine may also be a good idea. Caffeine can affect hydration, which can play

a role in other symptoms as well. Goodfriend stresses the benefit of avoiding caffeine. She notes, "Caffeine is a diuretic that can cause dehydration, and the aftereffect is that it can make fatigue from MS worse."

## How to Shop

The perimeter of a grocery store – the areas along the four walls – is where stores keep fresh fruits, vegetables, low-fat and fat-free dairy products, and lean meats. Stick to the perimeter as much as possible to avoid junk food in the aisles. But you can't get everything you need along the perimeter, and buying nuts, seeds, beans, oils, and frozen vegetables means venturing into that dangerous territory. Therefore, it's best to shop when not hungry and tempted to buy a quick hunger fix.

When buying canned, frozen, or other processed foods, shoppers should learn to read the nutritional and ingredient labels. The healthiest products are those with recognizable foods listed. If a package of chicken breasts lists "chicken breasts,

## HEALTHY CHOICES

*A Quick List of Foods to Maximize, Minimize, and Avoid*

To learn more about recommended daily allowances of each food group, go to the following website: **www.mypyramid.gov**. Click on "how much is needed" under each food group.

*[Editor's note: Before making any changes to one's diet, readers are strongly urged to consult their physician.]*

Generally speaking, the following foods may be "maximized" for healthier eating:

- Vegetables
- Whole fruit
- Whole-grain products
- Beans
- Low-fat or fat-free milk, yogurt, or cheese
- Skinless white meat chicken or turkey
- Fish
- Egg whites or egg substitute
- Olive or canola oil

Generally speaking, the following foods should be "minimized" for healthier eating:

- Fatty meats
- Processed pastries
- White flour products
- Foods high in sodium or sugar
- Empty calorie foods like chips and soda
- Alcohol
- Caffeine
- Full sodium canned soups

Which foods are best to avoid?

- Foods containing hydrogenated oils (which become transfats)
- Foods containing high-fructose corn syrup

*— Maryann B. Hunsberger*

chicken broth, water, and salt" as the ingredients, it's a better bet than a package that needs a chemist to translate the ingredients.

## Will My Family Eat Healthfully?

Nobody wants to cook two meals for picky family members, especially when disability makes meal preparation difficult. If the kids don't like vegetables, you can "hide" them in other foods. Ideas include:

- Make a pot of chicken soup chock full of vegetables, beans and brown rice. Mix vegetables in a blender and add back to the pot.
- Add tomatoes, bell peppers, and low-fat cheese to an omelet.
- Add shredded carrots and zucchini to meatloaf or meatballs.

You can also make healthier versions of family favorites:

- Use whole grain pasta, low-fat cheese, and fat-free milk to make macaroni and cheese.
- Buy boneless chicken tenderloins and bread them with seasoned whole wheat bread crumbs for healthier chicken fingers.
- Cut potatoes in the shape of fries, then toss with olive oil, sprinkle with seasonings and bake.

Buying healthier snacks for the whole family is also achievable. Instead of potato chips and candy, purchase popcorn, fruit, carrot sticks, yogurt, fat-free pudding packs, nuts and seeds, part-skim string cheese sticks, low-fat turkey pepperoni, baked tortilla chips, and whole-grain crackers.

## Making Healthful Eating Easier for People with MS

Leftovers are a lifesaver for people who have difficulty cooking. Making an extra serving of dinner to eat for lunch the next day saves time and energy. I always double the amount of side dishes I prepare, so they will last for two days. That way, I only have to prepare a main dish on in-between days.

Some people cook only on weekends. Portioning a large pot of soup, stew, or chili into individual containers and freezing for the week can yield seven days' worth of lunches. Baking a quiche can provide breakfast for five days. Using different cooking methods means two to three main courses can cook at once. While a large meatloaf is baking in the oven, a chicken can spin on the rotisserie and chili can simmer in the slow cooker, providing three main courses for the week.

The person who prefers to cook each day can add broiled chicken breast strips to a large salad for an easy meal. A can of black beans, a package of Success® brown rice, and a package of frozen green beans is an easy vegetarian meal. Salmon cooked on the grill, coupled with frozen broccoli and a salad makes a quick, healthy dinner. Pork loin chops baked in the same roasting pan with fresh mushrooms and carrots is easy to do.

Changes need not be immediate or overwhelming. I needed two years to change my family's eating habits. According to Davis, eating even small amounts of fruits and vegetables at each meal will have beneficial effects. ◆

# 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)
**Bayer HealthCare Pharmaceuticals**
**Bayer USA Foundation**
**EMD Serono, Inc. and Pfizer Inc**
**Genentech Foundation**
**Novartis Pharmaceuticals Corporation**
**Teva Neuroscience**

**VISIONARIES** ($50,000 to $99,999)
**Acorda Therapeutics**
**Medtronic Foundation**

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

**ADVOCATES** ($10,000 to $24,999)
**Avanir Pharmaceuticals**
**Biogen Idec**
**The Chatlos Foundation**
**Genentech, Inc.**
**Grand Lodge Daughters of Scotia**
**The Horizon Foundation for New Jersey**
**The Wal-Mart Foundation**

# RESOURCE DETECTIVES℠ NEEDED

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

For more information, please contact Bonnie Yares at **(800) 532-7667, extension 132** or visit **support.msassociation.org/detectives**

You may also email Bonnie Yares at **byares@msassociation.org**

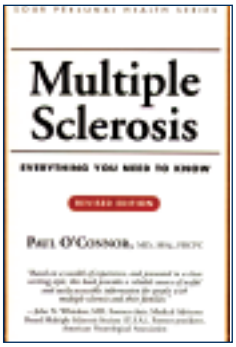
*The Resource Detectives Program is supported through a grant from Novartis Pharmaceuticals Corporation.*

# Spread the Word

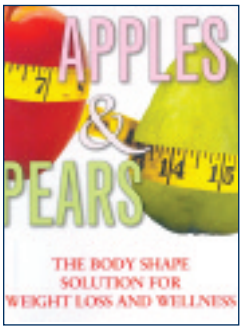
*Life is an Adventure*
*Written by Teresa M. Campbell*
*Published by 1st Books Library*
**MSAA Book #233**

This author takes the reader through an exciting journey around the world, both before and after her diagnosis. She addresses many issues from dealing with symptoms to staying physically fit, while emphasizing the importance of humor, staying active, and finding adventure.

*Multiple Sclerosis: Everything You Need to Know*
*Written by Paul O'Connor, MD, MSc, FRCPC*
*Published by Firefly Books*
**MSAA Book #272**




Dr. O'Connor provides an excellent overview of MS, including useful information on the potential causes and effects of MS, as well as diagnosis, treatments, and the social aspects involved with MS. The text is easy to understand and many helpful tips are highlighted.




*Apples & Pears: The Body Shape Solution for Weight Loss and Wellness*
*Written by Marie Savard, MD, with Carol Svec*
*Published by Atria Books*
**MSAA Book # 244**

Featured in the Winter 2005 issue of *The Motivator*, this book has become a well-known resource for making informed, healthy choices about food and exercise. Dr. Savard emphasizes the importance of body shape and how it relates to health. For more information about Dr. Savard and her books, visit **www.msassociation.org/publications/winter05/fruits.asp** or call MSAA at (800) 532-7667 to request a copy of the article.

## *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)**