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MSAA

The MOTIVATOR

Winter 2005

Bringing Information to People with Multiple Sclerosis

Healthcare Beyond MS

Taking Good Care of Yourself

The MSAA MOTIVATOR

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

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Breaking Down Barriers
Building Up Hope

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Up Front

by Douglas G. Franklin

Topping the agenda for this issue's Up Front column is the news of the FDA's approval of the drug Tysabri® in November. This brings the number of approved long-term treatments for MS to six (including Novantrone®, which is a two-to-three-year treatment). How different today is in comparison to less than 15 years ago, before the first of these disease-modifying treatments for MS became available.

Although the approval of Tysabri does not mean a cure for MS at this time, and more studies and data are needed before its long-term safety and effectiveness are fully known, the addition of another long-term treatment for MS is a strong reminder of the ongoing large-scale and impassioned research in the quest to conquer MS. Until the time that a cure is discovered, MSAA will continue steadfast in its mission to ease the day-to-day challenges of individuals with MS and their care partners.

This brings me to the next vital item on the Up Front agenda, which determines how MSAA will continue to accomplish its mission. I'm referring to MSAA's new strategic planning for the upcoming years. This has been in the works for several months, and with the present strategic plan nearly completed and scheduled to run through June 2005, MSAA's Board and staff are poised for embarking upon their new objectives come July 1st.

In mid-January, MSAA held a Board of Directors' meeting, a Healthcare Advisory Council meeting, and a joint-planning session with both groups to discuss needs assessment and ultimately propose new strategic planning for the years ahead. Our leadership must have a clear and realistic picture of the MS community's needs. We also strive to realize our own (MSAA's) capabilities as well as the emerging trends in the MS world. From this, we can develop a clear and consistent strategy and direction for MSAA that anticipates what the priorities will be.

Providing new and valuable assistance in reaching these goals are two new Board members who can offer fresh perspectives through their diverse backgrounds. Jeri Canter is a pharmacist residing in eastern Florida. Her knowledge of the pharmaceutical industry, combined with her commitment to assure that her clients receive safe and appropriate prescriptions, will be of great benefit to our organization. Tracey Edwards is an entertainer and a former Home Shopping Network personality living in southern Florida. Her experience with the media, promotions, communications, and performance will also be a strong asset to our Board. I would like to welcome them both to MSAA while expressing my sincere appreciation for their time and expertise that they have generously volunteered.

I would like to conclude with a few important notes. First, I want to thank

everyone who volunteered to be a part of our annual Sweeten the Season fundraising campaign. Thousands of card candy canes were sent out prior to the holidays and the money raised will be of great help in funding MSAA programs and services.

Second, since its launch last summer, MSAA's redesigned website has exceeded 300,000 visits from individuals browsing the internet. This is quite an accomplishment, and if you haven't been to our website or logged on lately, please visit us soon at www.msaa.com.

Finally, I want everyone to know that preparations for MSAA's 35th anniversary are well underway. Although the official anniversary date is June 5th, we will be having a year-long tribute throughout 2005. Regional events are scheduled throughout the year at our six regions across the nation and a 35th anniversary booklet is now being distributed. A special event honoring Dr. Jack Burks, MSAA's vice president and chief medical officer, will be held on May 19th in Philadelphia. The year 2005 marks a milestone in MSAA's history, and we hope everyone will join in commemorating our organization's work to help individuals with MS, their care partners, and their families. ◆

Douglas G. Franklin has been President and Chief Executive Officer of MSAA since April 1999. Mr. Franklin has 25 years experience in senior association management in the nonprofit sector and is an internationally published expert in the field of social marketing. A former national trainer for the Peter Drucker Foundation, Mr. Franklin has conducted workshops in strategic planning and marketing development in more than 15 countries worldwide. He is a firm believer in the benefits of social investment for both the private and public sector workplaces.

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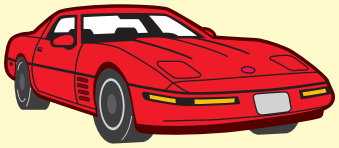

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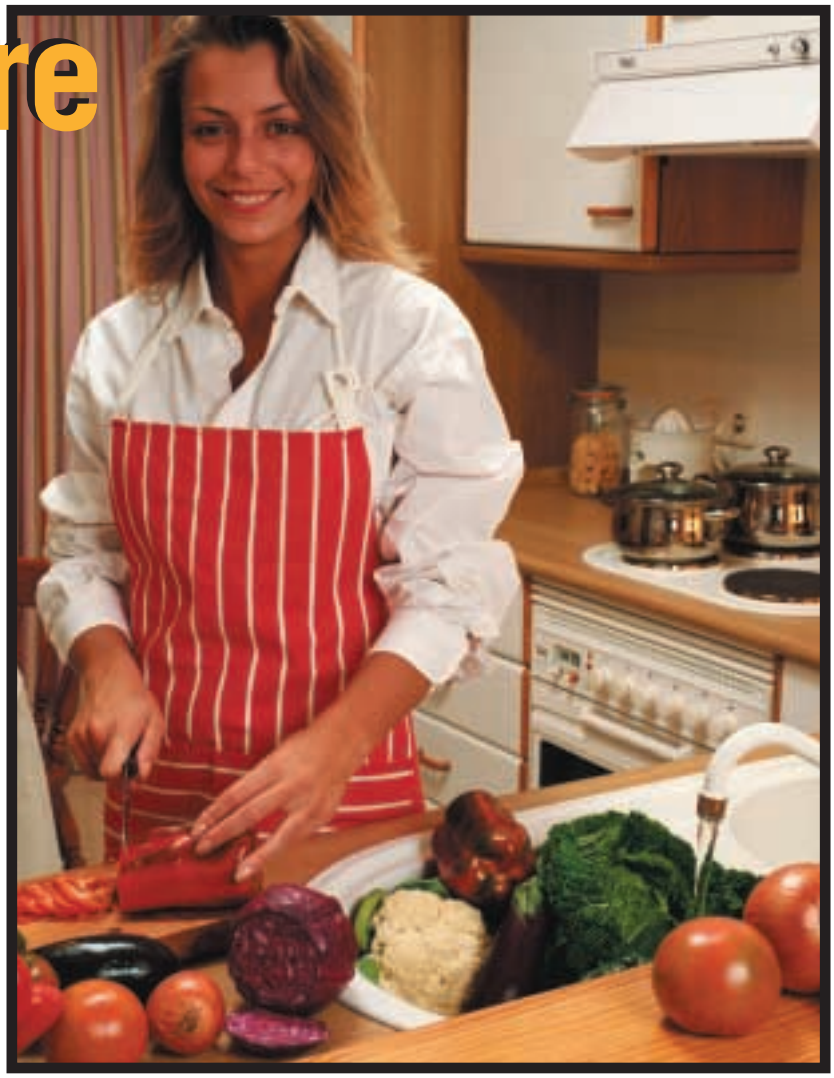

by Susan Wells Courtney

Taking Good Care of Yourself

All too often, someone living with a long-term illness, and those caring for a loved one, focus primarily on treating the disorder. As a result, many other vital aspects of one's health and well-being may be neglected. Individuals with any chronic condition, as well as those caring for them, need to look beyond their diagnosis and care for themselves so they may feel their very best.

MS, its symptoms, and the nerves it affects, are just a portion of one's overall health. It does not preclude one from developing other health conditions… nor does it keep someone from reaping the benefits of a healthy regimen. With or without a chronic illness, people need to take care of their physical health. This may only be accomplished through proper diet, exercise, regularly scheduled health exams and screenings, good oral care, not smoking, and avoiding substance abuse.

Diet and Exercise

The importance of diet and exercise cannot be understated. Controlling weight, preventing certain illnesses, enabling proper body function, and living a longer, more comfortable life, are just some of the many potential benefits derived from a balanced diet and regular exercise.

Dietary Guidelines for Americans 2005

On January 12th, the government released its latest edition of the Dietary Guidelines for Americans 2005. This

report is published every five years by the Department of Health and Human Services (HHS) and the United States Department of Agriculture (USDA). This report, along with many other diet and exercise publications, may be viewed and downloaded by going to **www.healthierus.gov/dietaryguidelines**. Printed copies of this 80-page report may be purchased by calling the United States Government Printing Office's toll-free number at **(866) 512-1800**. A smaller, 12-page brochure based on the report may also be found at the same website, or ordered by calling the Federal Citizen Information Center's toll-free number at **(888) 878-3256**.

Here is an overview of the key recommendations for the general population:

- Eat and drink a variety of foods and beverages that are rich in nutrients within the basic food groups (described later). Limit the intake of saturated and trans fats, cholesterol, added sugars, salt, and alcohol.

- To maintain a healthy body weight, balance the number of calories taken in with the amount of calories used in physical activity.

- To prevent gradual weight gain over time, gradually increase physical activity while making small reductions in the amount of food and beverages consumed. [Editor's note: recommended water intake, which is eight, eight-ounce glasses daily, should not be reduced. Those experiencing urinary frequency may limit fluid intake an hour or two before going out or going to bed, but should make up any missed glasses at other times of the day.]

- Participate in physical activity regularly to promote health, psychological well-being, and a healthy body weight.

- Physical fitness may be achieved through cardiovascular conditioning, stretching exercises for flexibility, and resistance exercises or calisthenics for muscle strength and endurance.

Recommended food groups:

- Fruit and vegetables -- on average, two cups of fruit and two-and-a-half cups of vegetables per day; select a variety, including those with deep colors, to eat several times per week.

- Whole-grain products – three or more ounce-equivalents daily, with whole-grains making up at least half of the total grains consumed.

- Dairy – fat-free or low-fat milk or milk products; three cups per day are recommended.

- Fats – less than 10 percent of calories should come from saturated fatty acids; less than 300 mg/day cholesterol; avoid trans fatty acid as much as possible (found in foods such as chips, fried foods, cookies and cakes); keep total fat intake between 20 and 35 percent of calories, with most fats coming from sources of polyunsaturated and monounsaturated fatty acids, found in fish, nuts, and vegetable oils; choose lean and low-fat or fat-free meat, poultry, dry beans, and low-fat milk products.

- Carbohydrates – choose fiber-rich fruits, vegetables, and whole grains frequently; choose and prepare foods and beverages with little added sugars or caloric sweeteners; reduce dental problems by practicing good oral hygiene and eating fewer foods with sugar and starch.

- Sodium and potassium – use less than 2300 mg of salt daily, which is approximately one teaspoon; consume potassium-rich foods, such as fruits and vegetables.

Other Recommendations:

Alcoholic beverages should be used in moderation, up to one drink daily for women and two drinks daily for men. These should not be consumed by: individuals who cannot restrict their alcohol intake; women who may be pregnant or lactating; children and adolescents; individuals taking medications that can interact with alcohol; and those with specific medical conditions.

For safe handling of food and to avoid microbial foodborne illness: clean hands, clean surfaces that food comes in contact with, and wash fruits and vegetables; meat and poultry should not be washed or rinsed; separate raw, cooked, and ready-to-eat foods while shopping, preparing, and storing foods; cook foods at a safe temperature to kill microorganisms; refrigerate perishable food promptly and defrost foods properly; avoid raw or unpasteurized milk, eggs, meats, juices, and sprouts, as well as food that might contain them.

The Food Guide Pyramid

According to the Associated Press, even though the food pyramid was developed 12 years ago, not everyone is following the recommendations, as two-thirds of this nation's population is overweight. Agriculture Secretary Ann Veneman states that an estimated 42 billion dollars is spent each year on diet books and products.

The U.S. Department of Agricuture's Food Guide Pyramid may be found by going to **www.nal.usda.gov/fnic**. The pyramid will soon be revised for the first time. The changes will reflect healthier food choices to maintain proper weight and help prevent health problems relating to diet.

Additional Diet Information

Dr. Walter Willett, MD, is the chairman of the Department of Nutrition at the Harvard School of Public Health. He has

directed the Nurses' Health Study since 1976, which presently studies the diet, lifestyle, and health of more than a quarter million participants. In an article that appeared in the October 2004 issue of *MORE Magazine*, he noted several findings about diet and its relation to health and illness. To follow are some key conclusions from the study so far.

- Trans fat (the solid, partially hydrogenated fat found in fried foods, some margarines, and baked goods), along with eating too much refined carbohydrates and sugar, is a big risk factor for heart disease. Eating plenty of fruits, vegetables, as well as omega-6 and omega-3 polyunsaturated fats, can greatly reduce this risk. Polyunsaturated fats also help reduce the risk of type 2 diabetes. Cutting back on refined carbohydrates, reduces the risk of heart disease and type 2 diabetes, while helping to control weight as well.
- Consuming large amounts of red meat and processed meat may increase one's risk of colon cancer. A deficiency in folic acid may contribute to colon cancer too, and especially for women who drink alcohol, lacking this nutrient may increase the risk of breast cancer. In addition, the risk and death rates of breast cancer would be 50 percent less if women avoided middle-age weight gain.
- Regarding supplements, Dr. Willett advises taking a multivitamin if someone does not eat foods fortified with vitamins. Studies suggest that many Americans would benefit by taking vitamin D (Dr. Willett suggests up to 1,000 IUs per day for individuals over 40). He also notes the importance of calcium, but explains that the ideal amount is not known. He suggests about 700 mgs per day as having the most benefit, and many can get this from a diet that includes dairy products, or a supplement to add 500 to 1,000 mgs.
- Dr. Willett mentions active studies to see if high dairy consumption may have adverse effects, citing possible elevated ovarian cancer and prostate cancer risks. Additionally, studies have yet to confirm that increased calcium has any effect on bone fractures. For reducing the rate of bone fractures, vitamin D is recommended (because it helps the body absorb and use calcium), along with regular exercise (cardio and strength training) to build and maintain strong bones.

Some individuals may be interested in vegetarian diets (only to be done under the advice and supervision of a doctor). The

Physicians' Committee for Responsible Medicine has a "Vegetarian Starter Kit" to assist individuals wishing to become vegetarians and to help ensure proper nutrition. This may be found at **www.pcrm.org**. Under "Vegetarian Foods," various health conditions which potentially may benefit from a vegetarian diet are listed (these include a healthier heart, lower blood pressure, controlling diabetes, and possibly preventing certain types of cancer). The importance of calcium, vegetables, whole grains, fruit, and legumes are all discussed.

The Cancer Project (a charitable organization whose website can be found at **www.cancerproject.org**) lists the importance of the same four foods often mentioned: vegetables, whole grains, fruit, and legumes. In their writing, "Foods for Cancer Prevention," they sum-up their findings in two sections titled, "Fiber Fights Cancer," and "Fat Raises Cancer Risk."

Specific Dietary Notes for Individuals with MS

With a cause and a cure still yet to be identified, no concrete scientific evidence (coming from large, multi-center, clinical trials) is available on diet and its effects on MS. Many theories do exist, however, noting data that suggest the involvement of diet.

As some readers may remember, MSAA published three articles by Dr. Ashton Embry in its Health and Wellness section. In these articles, he explains the theories that nutritional factors may play an important role in MS. He believes the "prime suspects" in the cause and worsening of MS include dairy products, gluten grains (wheat, rye, and barley), and legumes (beans, peas, and lentils). Other prime suspects include chronic deficiencies in vitamin D, fish oil, and anti-oxidant vitamins, minerals, and phytochemicals. Please contact MSAA at **(800) 532-7667** to request copies of these articles, or log onto MSAA's website (at **www.msaa.com**) to view or download copies of these articles which appeared in the Winter, Summer, and Fall 2004 issues of *The Motivator*.

In the Consortium of MS Centers (CMSC) publication, *The International Journal of MS Care*, an article titled "Nutritional Management of Multiple Sclerosis" by N. Caldis-Coutris, M. Namaka, and M. Melanson (June 2002), talks about the different dietary elements that may affect MS. This article may be found by going to **www.mscare.org**, then going to past issues, and doing a search for "CPJ/RPC."

In this writing, the authors note that individuals with MS seeking a possible alternative treatment may make decisions that are not always based on sound nutritional recommendations, and some may be putting themselves at risk of adverse secondary conditions and malnutrition. High doses of certain macronutrients (fats, carbohydrates, and proteins) or vitamins may put patients at a risk of toxicity as well as deficiencies. For these reasons, individuals with MS should always consult their physician to ensure they are making good decisions with their food and supplement selections. To follow are a few interesting points from the article.

Saturated fatty acids (SFA) are solid at room temperature and are found in meats, coconut and palm kernel oils, and butterfat. They should be limited to seven to 10 percent of calories per day (roughly 14 to 20 grams). Excess saturated fat has been proposed be involved in the course of MS, possibly altering the stability of the myelin sheath. Studies suggest that lower consumption of SFAs may be related to "significantly fewer exacerbations, slower deterioration, and lower death rates." Higher SFA intake "was associated with increased disability and three times the death rate." And finally, according to the article, "MS patients who adopt a diet low in saturated fat, are likely to show improvements in energy and fatigue profiles."

Monounsaturated fatty acids (MUFA) are found in soft margarine and canola, olive, and peanut oils; MUFAs may be up to 10 percent of one's total daily calories.

The article goes on to note the potential positive affects of polyunsaturated fatty acids (PUFA), described as omega-6 (found in certain vegetable oils) and omega-3 fatty acids (found in cod liver oil, fish oil, and ocean fish). These fatty acids are "essential," because they cannot be made in the body and must come from the diet. Omega-6 fatty acids can be related to immunosuppression, while Omega-3 fatty acids are involved with anti-inflammatory functions.

Controlling Weight

Losing weight and maintaining weight loss is a challenge for most adults, particularly in mid-life. For individuals with MS, the problem may be compounded by the fact that symptoms may prevent them from participating in moderate to vigorous daily exercise.

The Weight-control Information Network (WIN) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health. Readers may contact WIN at **(877) 946-4627**, and they may also visit WIN's website at **www.win.niddk.nih.gov**. This organization has a good deal of helpful information and publications. One publication, *Better Health and You, Tips for Adults*, provides advice for healthy eating and physical activity for all ages.

According to WIN, individuals who are overweight are at a much higher risk for: type 2 diabetes, high blood pressure, heart disease and stroke, certain types of cancer, sleep apnea (when breathing stops for short periods during sleep), osteoarthritis (wearing away of the joints), gallbladder disease, irregular periods, and problems with pregnancy. Individuals may determine if they are at a healthy weight, overweight, or obese by calculating their body mass index (BMI). The publication Better Health and You includes a chart with height, weight, and

BMI figures, with shaded areas showing what determines healthy weight, overweight, and obesity.

Factors that contribute to one's weight gain include poor habits (such as watching TV versus physical exercise), genes, illness, certain medications, one's environment (being tempted by fattening foods at work, home, shopping, social events, etc.), and emotions (people often eat when they are bored, sad, angry, or stressed – even when they are not hungry).

The keys to weight maintenance and loss include:

- Select healthy foods, emphasizing fresh or canned fruits, a variety of colorful vegetables, and whole grains, while avoiding foods containing high amounts of saturated fats and/or sugar.
- Read labels to know how much fat, sugar, and calories are being consumed.
- Eat smaller portions at mealtime, and eat healthy snacks (low-fat, low-sugar) between meals.
- Don't skip breakfast; the best breakfast consists of whole-grain foods (such as oatmeal and cereal); studies show this to be the most beneficial in terms of weight loss and good health.
- Increase physical activity (if able); walking continues to be an excellent activity for losing weight, lowering blood pressure, and lowering blood sugar levels.
- Get plenty of sleep (researchers at the Eastern Virginia Medical School found that individuals getting adequate sleep each and every night have a far greater likelihood of staying thin).

If overweight, losing as little as five to 15 percent of one's body weight (over six months or longer) will do much to improve health. Other helpful tips include: keeping a food diary, shopping from a list and when not hungry, storing foods out of sight, eating at the table with the TV off, setting realistic weight-loss goals, seeking support of family and friends, and participating in regular physical activity (if able).

The United States Food and Drug Administration (FDA) has an article titled "Losing Weight: Start By Counting Calories." Appearing in the *FDA Consumer* magazine in January/February 2002, this article offers a great deal of information about dieting, exercise, weight-loss drugs, and fad diets. A copy may be found at **www.fda.gov/fdac/features/2002/102_fat.html**.

Exercise with MS

Those who cope with the symptoms of MS need to be particularly careful with the activities they choose. Fatigue and weakness are common symptoms of MS, and walking a flight of stairs or parking farther from the

store could well use up valuable energy needed for other, more important functions – such as housework, caring for the children, or working a full day at the office.

Individuals with MS should not begin an exercise program of any kind on their own. Given the nature of MS, each person is unique in his or her needs and capabilities, so a custom exercise plan should be prescribed. Attempting an exercise program on one's own can cause problems – including overworking weak muscles, over-exercising to the point of fatigue, overheating and bringing on a pseudo-exacerbation (a temporary flare-up of symptoms, not relating to new myelin damage), and increasing muscle tightness – possibly causing an increase in spasticity, just to give a few examples.

An individual with MS needs to see his or her doctor, and in most cases, be referred to a physical therapist (PT). A PT can develop a safe and successful exercise program designed specifically for that individual. Depending on the progress made by the individual, and possibly new disease activity, the patient should be re-evaluated regularly to be sure the exercise program is still appropriate.

MSAA's cover story in the Winter 2004 issue of *The Motivator* discussed the many benefits of rehabilitation, including physical, occupational, and speech therapy. For a copy of this issue, readers may call MSAA at **(800) 532-7667**, or go to MSAA's website at **www.msaa.com**.

Another publication that may be of interest is WIN's *Active at Any Size*, which provides exercise instruction for individuals who are very large. Individuals with MS should consult their physician before participating in any exercise program, however, with a doctor's approval, individuals may find that this publication provides many valuable tips for starting slow and minimizing the risk of injury. *Active at Any Size* may be found at **www.win.niddk.nih.gov/publications/active.htm** or by calling **(877) 946-4627**.

"No Boundaries" has Pilates exercises for individuals with limited mobility. These may be found at **ww.noboundaries.tv/pilates.htm**. Again, individuals with MS should get a doctors approval for any exercise program.

While some may feel disheartened that they can no longer perform vigorous exercise as they may have in the past, moderate exercise still offers great benefits. According to the FDA, "Exercise does not have to be strenuous to be beneficial. Some studies show that short sessions of exercise several times a day are just as effective at burning calories and improving health as one long session."

Advisory:

Please note that any change to one's diet and exercise should only be made under the supervision of his or her physician. Some of the recommendations may not apply to individuals with MS, particularly the amount of recommended exercise – individuals with MS should see their physician and a physical therapist for an exercise plan. Additionally, some people may require special diets, which is why everyone should consult his or her physician about the best diet specifically for him or herself.

Preventive Services

The Agency for Healthcare Research and Quality (AHRQ) is an agency of the HHS; readers may visit their website at **www.ahrq.gov**. Their United States Preventive Services Task Force developed a list of recommended clinical preventive services for normal-risk adults. (Children's recommended services may also be found by going to the website.) To follow is an overview of their recommendations for adults.

Periodic screenings

- For blood pressure, height and weight, obesity, and alcohol use, with individuals 18 years and older
- For cholesterol, every five years beginning at age 35 for men and age 45 for women
- For Chlamydia, with individuals between 18 and 25 years of age
- For colorectal cancer, with individuals 50 years and older
- For osteoporosis, with women, routinely after 65 years of age, or after 60 years for those at an increased risk
- For vision and hearing, for those 65 years and older
- A pap smear is recommended every one to three years for women ages 18 to 65, and a mammogram every one to two years for women 40 and older

Immunizations

- Tetanus-Diphtheria (Td), every 10 years for individuals 18 and older
- Measles, mumps, rubella (MMR), one dose for women of childbearing age
- Pneumococcal pneumonia, one dose for those 65 years and older
- Influenza, yearly for those 50 years and older (except for those with allergies to eggs)
- Varicella (VZV), two doses for those 18 years and older who are susceptible

Chemoprevention (using a medication to help prevent an illness)

- Aspirin, to prevent cardiovascular events, should be discussed periodically with men (40 years and older), and women (50 years and older)
- For women at high risk of breast cancer, chemoprevention should be discussed

Counseling

- Calcium intake should be discussed periodically for women 18 years and older
- Folic Acid should be discussed with

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women of childbearing age (18 to 50)

- After childbirth, breastfeeding should be discussed with mothers
- For individuals 18 years and older, the following topics should be discussed periodically: tobacco habits, drug and alcohol use, sexually transmitted diseases (STDs) and human immunodeficiency virus (HIV), nutrition, physical activity, sun exposure, oral health, injury prevention, and polypharmacy (when being treated with more than one drug)

At **www.ama-assn.org**, the American Medical Association (AMA) lists its recommended benefit package that they propose to be provided by public and private programs. (Please note that the AMA is not liable for any of the information provided, and instructs patients to see their physician for diagnosis, advice, and treatment.) Many of the preventative services agree with those listed by the AHRQ. Additional recommendations include:

- Health examinations/counseling with a physician every one to three years for individuals between the ages of 22 and 64 years; yearly exams are recommended for those between the ages of 11 and 21 as well as age 65 and older
- Cholesterol tests every one to three years between the ages of 22 and 64, then yearly from 65 to 70, and in later years, at the doctor's discretion
- Intraocular pressure measurement (IPM) should be done yearly for individuals 40 and older (to help check for glaucoma)
- Dipstick urinalysis yearly for ages 65 and older; fecal occult blood and digital rectal exam yearly for those 50 and older; prostate specific antigen (PSA) every three years from age 50 to 70; sigmoidoscopy (a thorough examination of the last two feet of the lower colon to screen for colon cancer) every three years, from ages 50 to 80, following negative results from two yearly exams
- Thyroid-function tests yearly for women, 65 and older
- Additional tests for high-risk groups

Oral Health

The American Dental Association (ADA) offers a wealth of information that may be found at **www.ada.org**; for those without internet access, the ADA may be reached at **(800) 621-8099**.

According to the ADA, good nutrition is linked to good oral health. They recommend following the USDA Food Guide Pyramid, as well as drinking water often. To further promote good oral health, individuals should not smoke or chew tobacco.

Good oral hygiene and regular dental care is important at any age. Adults of all ages can develop cavities and periodontal (gum) disease, both of which are caused by plaque (a sticky, colorless layer of bacteria).

The ADA recommends that people brush their teeth twice daily with fluoride toothpaste, and clean between the teeth daily with floss. People also need to see their dentist regularly. Some dentists may recommend an electric toothbrush, as well

as floss that is fixed on a handle, for individuals with weakness or mobility problems. [Please note: a press release from Gillette in October 2004 stated that Oral-B CrossAction Power and PowerMAX Toothbrushes and Refills are not recommended for using to assist in brushing the teeth for individuals with special needs; apparently the brush head can become loose and swallowed in certain circumstances.]

Warning signs of gum disease include: gums bleeding while brushing; swollen, red, or tender gums; gums that are separating from the teeth; pus found around the teeth or when pressing the gum; any change to one's bite or how one's dentures are fitting; persistent bad breath or an unpleasant taste in one's mouth. Individuals experiencing any of these symptoms should visit their dentist as soon as possible. The earlier gum disease is addressed, the better the outcome.

Even those with full dentures should still visit their dentist regularly. During the exam, the dentist will screen for oral cancer, while checking the gums, tongue, joints of the jaw, and fit of the dentures. If dentures no longer feel comfortable, something has changed and the dentist should also be consulted before parts of the mouth are irritated.

For those who cannot afford dental care, many dentists offer lower rates to individuals on fixed incomes, and help is also available through dental society-sponsored assistance programs. The local dental society or social services can assist in finding low-cost dental care, including public health clinics and dental schools.

The National Women's Health Information Center at **www.4woman.gov/faq/oral_health.htm** also has much information on oral health. This center may also be reached by calling **(800) 994-9662**.

Common oral health problems include cold sores, canker sores, oral fungal or yeast infections, dry mouth syndrome, and oral cancer. Anyone suspecting that one of the latter (more serious) conditions may be present, should see their dental professional. Care partners of individuals who are more severely disabled need to periodically check for oral abnormalities of which the patient might not be aware.

Smoking and Substance Abuse

Virtually every American is familiar with the dangers and long-term health risks resulting from smoking and substance abuse (including but not limited to alcohol, illegal drugs, and prescription medications). The government and several non-profit organizations offer assistance through the internet, publications, and telephone support to help end addiction.

Smoking

Why quit smoking? The National Cancer Institute lists these benefits:

Immediate changes: blood pressure, pulse, and body temperature elevated by nicotine return to normal (those taking blood pressure medications should consult their physician before making any changes); the body starts to heal itself; risk of heart attack drops; nerve endings begin to re-grow – taste and smell improve;

breathing becomes easier; circulation improves and lungs strengthen; cilia (hair-like structures) on lung lining re-grows, allowing for reduced infection, congestion, coughing, and fatigue.

Other benefits over time: Risk of dying from lung cancer goes down, as well as risk of throat, bladder, kidney, and pancreas cancers.

Smokefree.gov at **www.smokefree.gov** helps people to quit smoking. Callers may also contact the agency at **(800) 784-8669**. The National Cancer Institute, which may be found at **www.cancer.gov**, has a Smoking Quitline at **(877) 448-7848**.

Substance Abuse

Alcohol, drug, and other substance abuse carry many health risks, personal problems, and dangers to others. Health risks range from damage to the heart and other organs, to cancer and stroke – just to name a few. Personal problems resulting from substance abuse can lead to a host of issues – including family break-up and social isolation, depression and psychological illness, financial ruin, and even loss of employment and trouble with the law. Danger to others usually occurs when someone attempts to drive while under the influence, but someone in an altered psychological state can also incur physical and emotional abuse to those around them.

Street drug abuse is particularly dangerous. Not only are these drugs illegal, but such drugs are toxins to the brain. With a condition such as MS, which affects the nerves of the brain, no one should endanger their health and well-being through the use of illegal drugs.

If someone believes that he or she may have a substance abuse problem (including prescription drugs), or if a loved one appears to be in this situation, help should be sought immediately. Individuals may contact their physician for immediate, one-on-one help. Several help lines can also provide assistance. These include:

- Alcohol and Drug Helpline (800) 821-4357
- American Council on Alcoholism (800) 527-5344
- National Council on Alcoholism and Drug Dependence, Inc. (800) 622-2255

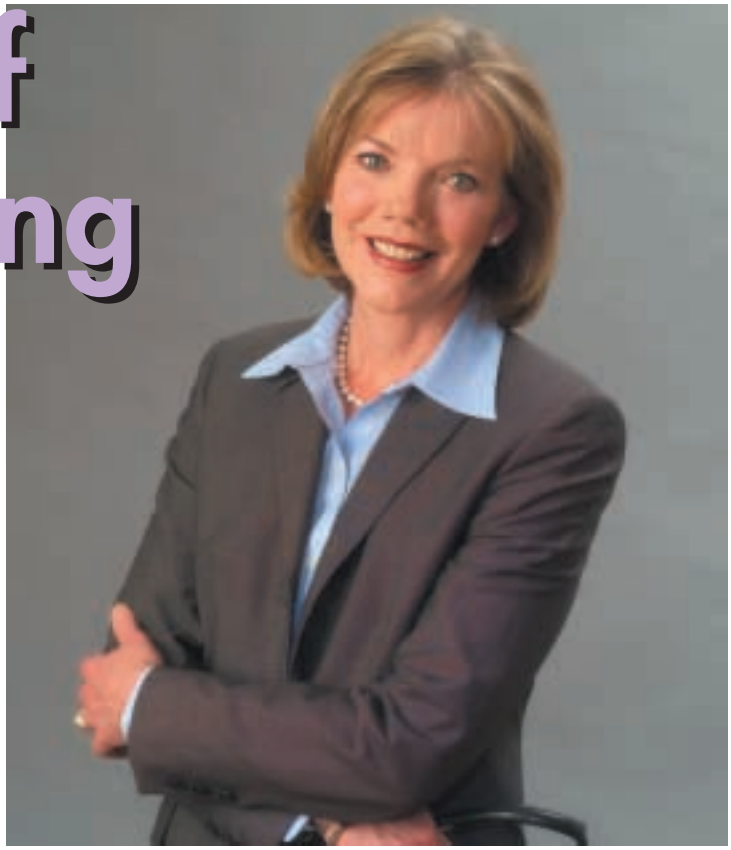
Other resources are available. Please call MSAA at **(800) 532-7667** for additional assistance if needed.

Taking Good Care of Oneself

While this article could not include every aspect of staying healthy, it does address some very important issues. By following these guidelines (under the supervision of one's physician), members of the MS community may ensure that they are doing everything they can to promote good health, which in turn will enhance their quality of life.

Readers are also encouraged to seek fulfillment in the other areas of their health as well – including recreational activities for social and emotional well-being, and spiritual fulfillment for those who are inclined. Anyone experiencing depression or other emotional challenges should contact a medical professional. Good physical health also requires good emotional health. ◆

The Fruits of Healthy Living



Dr. Marie Savard's *Apples and Pears* is her Latest Book Aimed at Promoting Good Health

Dr. Marie Savard is a nationally known internist, women's health expert, and advocate for patients' rights. She has written two helpful books to assist patients in recording, understanding, and overseeing their own healthcare. In January of 2005, Dr. Savard announced the arrival of her newest book, *Apples and Pears,* which explains how body shape is the best predictor of one's future health.

How to Save Your Own Life was Dr. Savard's first book on controlling one's own healthcare and was published in 2000 by Warner Books. This 240-page paperback book explains the importance of collecting copies of one's own medical records and having a working knowledge of any conditions. It also lists texts, exams, and immunizations that everyone should routinely receive. The book goes on to instruct readers on how to be an active partner with their doctor, and how to work with the system – including hospitals and insurance companies.

Dr. Savard's second book on this same topic is *The Savard Health Record: A Six-Step System for Managing Your Health Care.* Published in 2000 by Time-Life Books, this information is packaged in a three-ring binder – complete with a user's manual and heavy-weight-paper instructions, forms, and pocket pages for filling in and organizing vital health forms.

Both *How to Save Your Own Life* and *The Savard Health Record* provide numerous samples of medical reports and letters. They also include definitions of common medical abbreviations and terms.

Her most recent book, *Apples and Pears* (written with Carol Svec), explains how fat around the middle, i.e., "an apple shape," is dangerous, whereas fat around the lower portion of the body (below the waist), i.e., "a pear shape," is protective. Specifically, Dr. Savard instructs readers on how to determine if they carry extra weight in the middle – with a bigger gut area, or if they carry extra weight in the hips, buttocks, and thighs. The book is primarily directed to women, but according to Dr. Savard,

men may also benefit by following the same dietary and exercise recommendations.

In *Apples and Pears*, Dr. Savard states that health is measured by inches and not by the pound. Apple-shaped women are more likely to develop disorders such as heart disease, stroke, diabetes, and breast cancer, while pear-shaped women are more susceptible to problems like osteoporosis, cellulite, and varicose veins. This book gives information on healthy diets for the different body shapes and lists foods that help protect against disease. It talks about easier weight loss and stresses the importance of exercise. For more information about this book, readers may call **(717) 747-0936** or go to **www.applesandpears.org**.

Dr. Savard explains, "My life's mission is to empower every woman to take charge of her health. If the woman is my patient, I can sit her down, explain the importance of body shape, warn her of her specific disease risks, and tell her exactly what she needs to do in order to live longer, look better, and feel healthier. For the millions of other women, the ones I can't treat personally, I am putting that same power in your hands with *Apples and Pears*."

Dr. Savard's background includes receiving a Bachelor's degree in nursing (BN) and a medical degree (MD), both from the University of Pennsylvania. She has held many positions, including hospital director, associate professor, technical advisor, and Board member, for a number of prestigious medical centers, universities, and associations. She has been featured in many national publications and has appeared on The Today Show. Dr. Savard speaks frequently before a variety of groups and government hearings. She is currently the senior medical director of the Cabrini Nursing Home and is also the senior medical advisor to Lifetime Television's "Strong Medicine."

Some readers may remember that Dr. Savard was featured by MSAA in an earlier article in *The Motivator*. This was titled, "Women's Issues and MS," appearing in the Spring 2002 issue. Anyone wishing to receive a copy of this article may call MSAA at (800) 532-7667.

All three of Dr. Savard's books are available through www.amazon.com and Barnes & Noble at www.bn.com. Books may also be ordered by calling Barnes & Noble at (800) 843-2665. *How to Save Your Own Life* may also be borrowed through MSAA's Lending Library (MSAA book #172; for information on how to obtain books from the Lending Library, please refer to page 56 of this issue). Readers may also visit Dr. Savard's website at www.drsavard.com, or contact her via email at **info@drsavard.com** or phone at (717) 747-0936. ◆

Please note that MSAA does not endorse any specific product or treatment. The information about these books is given to raise readers' awareness about what is available; the books are not necessarily recommended by MSAA. Readers are strongly advised to consult their medical professional before making any changes to their diet, activity level, or treatment regimen.

Minimizing the Digital Divide for Individuals with MS:

Computer Hardware Assistive Technology

Part two of a three-part series on strategies, equipment, and software to increase computer accessibility

By Carrie Bruce, MA, CCC-SLP, ATP

Research Scientist, Center for Assistive Technology and Environmental Access (CATEA) at the Georgia Institute of Technology in Atlanta, Georgia; Speech Therapist, Shepherd Center in Atlanta, Georgia; and MSAA's Healthcare Advisory Council Member

Assistive technology for the computer is vital in helping individuals with physical limitations or discomfort gain easier access to their computer and the internet. This topic was highlighted in the first article of this three-part series, appearing in the Fall 2004 issue of The Motivator. The term "assistive technology" (AT) refers to any product that is used to increase, maintain, or improve the functional capabilities of an individual (adapted from PL 100-407, the Technology-Related Assistance for Individuals with Disabilities Act).

The earlier article noted that computers can be a bridge to independence and an outlet for expression for individuals with a chronic illness or disability. It featured various seating, table, and workstation systems which increase function and comfort for the computer user. To request a copy of the Fall 2004 issue of The Motivator, readers may call MSAA at (800) 532-7667. To view or download a copy of the article (or the entire issue), readers may visit MSAA's website at www.msaa.com.

In this second part of the series, different types of computer hardware AT will be highlighted. Computer hardware primarily includes the monitor, mouse or cursor control, and keyboard. It may be a stand-alone product or a product that attaches to a standard device. Options are available for both Windows and Macintosh platforms and range in price. Many of the products are also interchangeable between desktop and laptop computers.

Monitors

Vision can be affected by MS in terms of acuity (sharpness), color perception, and contrast sensitivity. Individuals may also have blurred vision or nystagmus (fast, involuntary eye movements). Many times, vision issues related to MS are intermittent and resolve over time.

If a person is having difficulty seeing information on the computer, increasing the size of the monitor or adjusting the monitor's properties (contrast, brightness, and size) may alleviate some of these visual issues. Glare filters and attachable magnifiers may also be beneficial.

Keyboards

Typing or text input is required for most activities on the computer and can be seriously impacted by numbness, stiffness, and pain in a person's hands and fingers. AT for typing can be broken down into the categories of alternative keyboards, keyboard accessories, and software. The first two (keyboards and accessories) are featured in this article, while software to assist with typing will be addressed in part three of this series, which will appear in the Spring 2005 issue of The Motivator. To follow is a listing of some hardware AT options for keyboarding:

This split keyboard is attached to a desk chair, and allows the person to maintain a more natural and relaxed position.

Natural or split: The keyboard is split in half and angled to promote left and right hand use in a more ergonomic position. Placing your hands farther apart and in a semi-angled position may help reduce shoulder discomfort and/or wrist pain.

Articulating or multi-plane: The keyboard is split in half and the separate sides can be adjusted in various positions. Letters can be placed in a vertical orientation so that an individual's wrists and palms are facing each other. These keyboards can be adjusted as the user's needs change.

Light touch or membrane: The keys do not require much pressure. They are activated by minimal touch and can be less painful for individuals with finger pad sensitivity, weakness, or fatigue. These keyboards may also be easier for an individual using an alternative pointing device for typing (e.g., headstick or mouthstick). Some of the membrane keyboards are moisture resistant.

Large print or contrast: These keyboards have large or contrast letters for easier viewing. This can be helpful for individuals with visual problems.

Large button: These keyboards have larger targets and can be easier to use for an individual who works with an alternative pointing device for typing, has tremors, or has difficulty with accuracy.

This articulating keyboard can be adjusted to allow for the most comfortable hand position.

Several different layouts are available for keyboards. The top keyboard uses an alphabetic layout. The lower keyboard has keys arranged according to their frequency of use.

Copyright 2005 CATEA

Alternative layouts: A variety of alternative layouts for letter and function keys are available. Certain layouts are better for speed and reduce range of motion required for typing. More frequently used keys can be spaced closer together for quick access. One-handed keyboards have layouts that make typing more efficient for individuals who have lost the use of one of their hands. Additionally, alphabetic layouts may be easier for individuals who are not as familiar with the standard (QWERTY) layout and can assist individuals who have cognition issues.

Onscreen keyboard: Onscreen keyboards are truly software versus hardware AT. Basically, a program simulates a keyboard on the screen of the computer and an individual directs the cursor to select letters or functions. The software programs vary in features and customization capability. Individuals with MS may find that using an onscreen keyboard reduces the pain and fatigue associated with standard typing. These programs can be used in combination with most of the mouse alternatives listed in the following section.

Other: Many other keyboards are available to assist individuals when typing. Some of these include:

- Chording (similar to pressing multiple keys on a piano to achieve different notes)
- Morse code (using two elements or keys to denote letters, numbers, and symbols)
- Small or compact (keyboard layout is reduced in size or with several letters on one key, minimizing finger travel)
- Braille or tactile (having raised symbols for easier identification)
- Scanning/switch controlled (keyboards that have an access plug for an alternative switch, which enables a user to select letters as they are individually scanned)

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Stickers that make the letters larger and more contrastive can be attached to a standard keyboard.

Accessories for standard or specialized keyboards are also considered AT. These include wrist rests and mobile arm supports that can be used for better positioning to reduce fatigue, ease pain, and minimize the possibility of further distress. The materials used for these devices have a range of cush-

ioning capabilities and may even have cooling properties to reduce the swelling of joints. Key guards can isolate keys and increase accuracy for individuals who accidentally hit other keys or need to rest their other fingers while typing.

A variety of mouse alternatives are available, including trackballs (left and right), a track pad (top), and a contoured mouse (bottom).

Mouse or cursor control

The internet has created a computer environment that can be very dependent on mouse use or cursor control. For individuals with MS, the shape, movement, and almost constant motion of the mouse can be a barrier to accessing the computer. To follow is a listing of the most common alternatives to the standard mouse. Some of the options are simply hardware devices, while others require software to work in conjunction with the hardware.

Trackballs: These devices have a ball mounted on the top or side versus the bottom. The ball can range in size from a pea to as large as a baseball. The user rolls the ball around to achieve cursor movement. Trackballs can be helpful for individuals who have limited range of motion in their arm, but are still able to move their fingers. Individuals who have a controlled movement at their palm, wrist, forearm, elbow, foot, toes, knee, or chin can also use trackballs.

Joysticks: These mouse alternatives provide directional control through an upright stick that users grip or a set of buttons that are held down. Joysticks do not require much hand movement and are sometimes easier for individuals to use when they have mild tremors or when they are using other body parts for cursor control.

Infrared or head tracking: Head trackers have become popular over the last few years with the decrease in cost and the increase in accuracy. Infrared control and camera-based are two frequently used technologies for head tracking. Infrared control is based on the user wearing a reflective sticker or a transmitter somewhere on his or her face, head, or glasses. The receiver is usually mounted on the monitor and helps turn head movements into cursor movement. Camera-based systems rely on video

A head tracker receiver located on top of the monitor follows the movement of the user's head, which is then used to guide the cursor.

cameras that track a predetermined facial feature (typically the nose). Head tracking is not a technology that works for everyone and can be difficult to control. However, for individuals whose most controlled, consistent movement is with their head, infrared tracking can be a powerful access method.

Eye gaze or eye tracking: Eye gaze technologies have also increased in popularity over the years. A specialized camera is mounted on the monitor and tracks movement of the eye. This type of technology works best for individuals who have very little movement in the rest of their body, but who can be accurate with eye movement.

Touchpads or stylus pads: These devices work by the user moving his or her finger or stylus across a sensitive pad to move the cursor. A touchpad can be helpful for individuals who have accurate movement limited to one finger or knuckle. A touchscreen also works in the same manner and is more concrete for individuals who have visual or cognitive issues.

Keyboard arrows ("MouseKeys"): Windows and Macintosh operating systems have an accessibility program built in that enables an individual to use the arrow keys on the number pad of the keyboard to move the cursor. The speed of the cursor movement is adjustable and will react to the arrows being held down or pushed in increments. This access method is useful to individuals who need an inexpensive mouse alternative or who use an alternative pointing device (e.g., headstick or mouthstick).

Switch or "click" controlled (with an automatic cursor): Through this access method, an individual can use a keyboard button, mouse "click," or external switch to start and stop an automatic cursor. Once started, the automatic cursor typically runs in a rotary (clock hand) or planar (along a horizontal or vertical path) movement on the screen until the user stops it. After it has been stopped, the cursor moves in a direct line away from that point until the user stops it again on a target area (e.g., icon or shortcut to a program or internet site). Individuals whose access is limited to a gross-motor or single-controlled movement may benefit from this type of mouse alternative.

For More Information

Part three of "Minimizing the Digital Divide for Individuals with MS" will appear in the next issue of *The Motivator* (Spring 2005). It will feature AT software programs and other ways to use the computer to enhance one's quality of life.

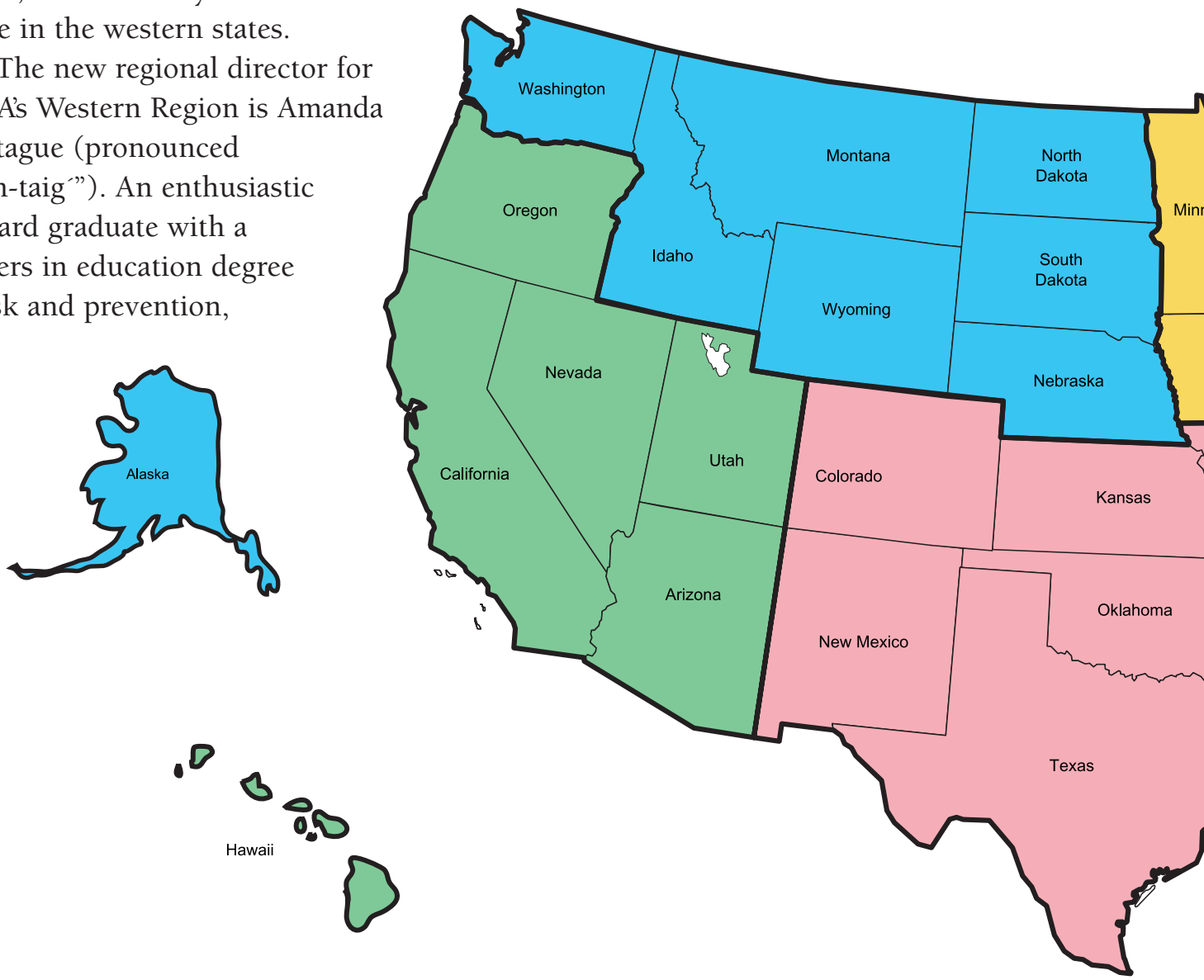
For additional information on assistive technology or computer access, please contact the Center for Assistive Technology and Environmental Access (CATEA) at Georgia Tech at **(800) 726-9119**.
Many of the products discussed in this article can also be found by searching at www.assistivetech.net. ◆

MSAA Restructures Regional Coverage

As readers of *The Motivator* may already know, MSAA opened its new Western Regional Office this past fall. While MSAA's programs and services have always reached individuals in all 50 states, this new office gives MSAA a stronger presence in the western part of the nation, allowing for more interaction with clients and their families, regional businesses, and the many volunteers who reside in the western states.

The new regional director for MSAA's Western Region is Amanda Montague (pronounced "Mon-taig´"). An enthusiastic Harvard graduate with a masters in education degree in risk and prevention, Amanda has a solid background in social services and needs assessment. MSAA is fortunate to have this qualified individual join our team of hard-working regional directors from the other five MSAA regions.

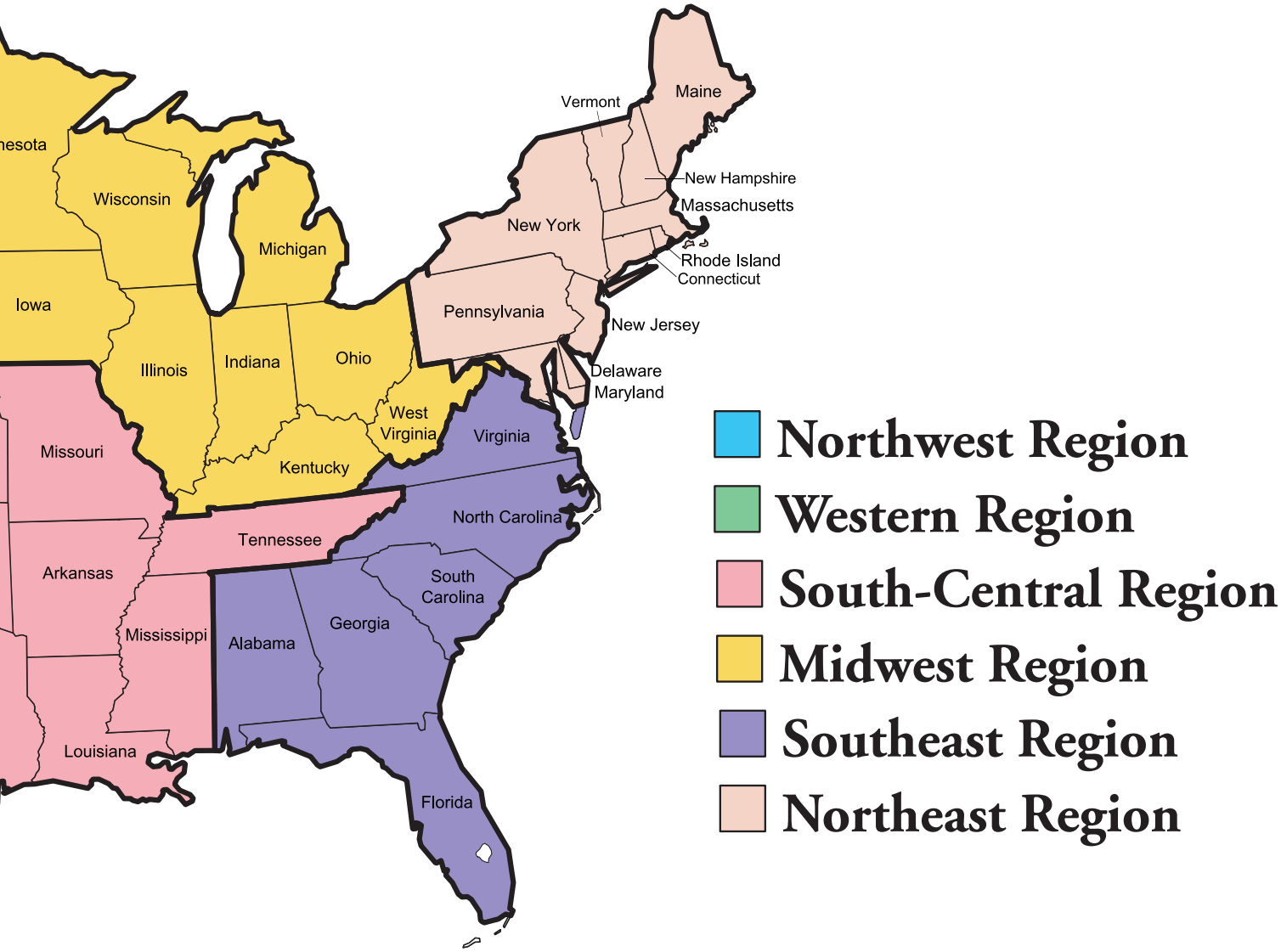
Presently, Amanda is busy at work establishing MSAA activities in the Western Region. She has talked with many people who are interested in forming support



As New Western Regional Office Opens

groups, and would like to invite anyone within her region to contact her about joining a support group, serving as a support group leader, or volunteering to help with MSAA's programs and fundraising. The Western Regional Office may be contacted by calling (800) 532-7667, ext. 155.

With the opening of this new regional office, MSAA has re-allocated some of the states to different regions to optimize the programs and services directed to each state. All six of MSAA's regions are shown on the color-coded United States' map below, along with the states that belong to each region. Individuals wishing to participate in MSAA's regional events, support groups, other regional activities, or volunteer opportunities, should check their state and corresponding region. Contact information for all six regions is listed later in this issue in Regional News, which begins on page 52.



Ask the Doctor

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

Q: Please explain how Tysabri® is administered so I know what to expect. Do I need to prepare in any way? What effects might I feel during or immediately following the procedure, and what side effects might I experience during the time between doses?

A: Tysabri (formerly Antegren) is given in the vein every four weeks in an "infusion center" or at the doctor's office. No patient preparation is required. The infusion lasts about one hour and you must wait for another hour to observe for a potential allergic reaction, such as wheezing. These reactions are not common but can be serious and require immediate attention. Hives is another uncommon side effect. Headaches, menstrual disturbances, fatigue, and infections are other potential side effects. However, most people tolerate the treatment well. More complete information will be available when the final two-year data is released later this year.

Q: Should individuals already on a self-injected immunomodulating therapy (Avonex®, Betaseron®, Copaxone®, or Rebif®) ask their doctor about adding Tysabri to their treatment plan?

A: Discussing the role of Tysabri with your doctor is an excellent idea. Only one-year data is available on adding Tysabri to Avonex and no data is available for combining Tysabri with Betaseron, Copaxone, or Rebif. Tysabri plus Avonex was more effective than Avonex plus placebo at one year in a group of patients on Avonex who were having attacks or new MRI activity. In my opinion, this is a very selected group of patients and may not be relevant to Copaxone or high-dosed interferons. More studies are needed before the effectiveness, and/or potential complications of combination therapy using Tysabri, are known.

Q: Why don't doctors routinely order an MRI of the brain and the spine, versus just the brain alone? I have heard of people having few lesions in the brain but many along the spine.

A: The two major reasons for ordering an MRI of the brain are (1) to make a diagnosis of MS and (2) to evaluate possible progression of the disease. The brain MRI is usually more sensitive for these two indications than a spine MRI in patients with relapsing-remitting and secondary-progressive MS. I order spine MRIs if the brain MRI is inconclusive and/or I suspect another disorder may be present in the spine (such as a herniated disc), causing neurological symptoms. Also in primary-progressive MS, the spine MRI may be more sensi-

tive than the brain MRI in some patients. In summary, the rationale for the doctor ordering a spine and/or brain MRI depends on the specific clinical situation. ◆

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

To Submit Questions to Ask the Doctor…

Please mail your question(s) to:

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

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

¿Habla Usted Español?
{Do You Speak Spanish?}

As announced in the previous *Motivator*, MSAA has added a bilingual Helpline Consultant to the Client Services Department. Helpline Consultant Richard Palacio reports that calls from Spanish-speaking MS clients and a growing network of social workers are steadily increasing each month, as awareness of service expands throughout the United States and Puerto Rico. MSAA is offering this service in an effort to assist individuals affected by MS in the Spanish-speaking community receive vital information, referrals, and reassurance in the fight against this disease.

Interested individuals may contact MSAA's Helpline at (800) 532-7667, extension 108. This Helpline service is another way MSAA strives to ease the day-to-day challenges of all individuals with multiple sclerosis and their care partners.

Call the Helpline for:
- MS Information
- Disability/Insurance Issues
- Reassurance and Support
- Connect to Other MS Resources

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

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

Research News

FDA Approves Tysabri®

The United States Food and Drug Administration (FDA) has approved Tysabri® (natalizumab), formerly known as Antegren®, for the treatment of relapsing-remitting forms of multiple sclerosis (RRMS). This approval was officially announced on November 23, 2004 and represents the sixth drug now approved for long-term treatment of MS. The other five are Betaseron® (interferon beta-1b), Avonex® (interferon beta-1a), Copaxone® (glatiramer acetate), Rebif® (interferon beta-1a), and Novantrone® (mitoxantrone).

Marketed by Biogen Idec and Elan Corporation, Tysabri is the first humanized monoclonal antibody to be approved for the treatment of MS. It works by inhibiting the action of adhesion molecules on the surface of immune cells, and is thought to prevent damaging immune cells from crossing the blood-brain barrier from the bloodstream and entering the brain and spinal cord. Tysabri is administered via intravenous infusions every four weeks by a medical professional.

The FDA granted accelerated approval for Tysabri based on one-year data from its two ongoing, two-year phase III trials. Previously, drugs for MS were approved only after two years of phase III trials were complete. The one-year data for Tysabri showed a 66 percent reduction in relapses compared to those on placebo (in the AFFIRM monotherapy trial) and a 54 percent relative reduction in relapses for those taking Tysabri in combination with Avonex, as compared with those taking Avonex plus placebo (in the SENTINEL add-on trial). The FDA requested that the name be changed from Antegren because another drug on the market has a similar name.

Biogen Idec and Elan report that antibodies were detected in approximately 10 percent of participants taking Tysabri at least once during treatment; six percent of participants developed antibodies that remained persistently positive. Persistently positive antibodies were associated with a substantial decrease in efficacy and an increase in certain infusion-related adverse events. Common side effects included headache, fatigue, urinary tract infection, depression, lower respiratory tract infection, joint pain, and abdominal discomfort. The most frequently reported serious adverse reaction was infection (2.1 percent in the treatment group versus 1.3 percent in the placebo group) and included pneumonia. Tysabri had a less than one percent risk of serious allergic reactions in this study.

According to MSAA Vice President and Chief Medical Officer Jack Burks, MD, "The FDA approval of Tysabri creates excitement and caution. Excitement stems from the availability of a new class of therapy for MS. Tysabri, a monoclonal antibody, reduced the relapse rate by 66 percent over placebo and 54 percent over Avonex alone in a separate trial, when Tysabri was added to Avonex treatment. The MRI data also favors Tysabri."

Dr. Burks notes that caution is advised because:

- Tysabri is not a cure. Some patients still had attacks and ongoing MRI damage while being treated with Tysabri
- The ongoing study only has one-year data on effectiveness
- Data on the effects that Tysabri may have on disability progression will not be available until later in 2005
- While Tysabri appears stronger than Avonex, it has not been compared to other currently available MS treatments (Betaseron, Copaxone, Rebif or Novantrone)
- Longer-term safety data is important

Dr. Burks goes on to say, "In summary, we welcome this new unique MS therapy with excellent one-year data on relapses, MRI, and safety. Where it 'fits' with other MS treatments is not known. These trials cannot be directly compared to clinical trial results using other MS treatments, because the patients in the current trial had milder disease, which tends to respond better to any treatment.

"The other therapies also have FDA approval plus more than 10 years of safety and efficacy data. Additionally, four of the five drugs are self administered. Will Tysabri be a 'stand alone' treatment or will patients benefit more if it is added to their current therapies? As usual, more questions are generated by each successful clinical trial. The great news is that we have another treatment option for MS patients and we are learning more about the disease." ◆

Please note that the information given in this or any of MSAA's publications should not be used to determine one's course of treatment. Any changes to medications or other treatments should only be done under the guidance of a medical professional.

CLEAN THAT CLOSET

AND BENEFIT MSAA

MSAA has colorful Clothing Recycling bins throughout the Delaware Valley.

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

You'll be doing yourself and MSAA a favor.

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Program Notes

Some Uplifting News for Clients

MSAA is pleased to announce that it has added an innovative and much-needed piece of assistive equipment to its comprehensive inventory of products designed to enhance client safety and mobility. Through MSAA's free Equipment Distribution Program, clients can now receive a Power Lift Seat to help them rise up from any chair or sofa in the house.

The electric-powered Lift Seat is designed to slowly and safely lift 100% of the user's weight, up to 300 pounds, and the two detachable power levers allow for use with either the right or left hand. The Power Lift Seat is a viable and much-less expensive solution to the more common lift chair, which can range from $800 to $1,000 and is often not covered by insurance. For those interested in more information or to request an application, please call **(800) 532-7667, ext. 102**, or download the form from **www.msaa.com**.

Winter is Here, but Summer is Not Far Away…

As the winter chill continues to fill the air and snow may be blanketing most of the country, MSAA is preparing for . . . the heat of the summer! And with the summer, comes an avalanche of requests for our cooling equipment. Therefore, MSAA would like to take this opportunity to remind clients that the cooling program is offered year-round—and there's no better time to place your order or call for more information than today.

For those who may not be aware, the MSAA Cooling Program offers a wide range of free vests, collars, and accessories designed to bring temporary relief from heat and humidity. Due to the numerous products and types of cooling methods, MSAA recently developed a Cooling Catalog to help aid in the selection of these items. To receive a cooling application and catalog, please call **(800) 532-7667, ext. 102**. The application and catalog are also available on MSAA's website at **www.msaa.com**. ◆

—Peter Damiri

Symptom Awareness

The Symptom Awareness article in the Fall 2004 issue of *The Motivator*, focused on both pharmaceutical and non-pharmaceutical medical treatments for the types of pain that individuals with multiple sclerosis commonly experience. Please note that the treatments mentioned in Symptom Awareness articles do not affect one's level of disease activity and myelin damage, but rather address the specific symptom to help provide temporary relief.

Readers who did not see the previous article may call MSAA at (800) 532-7667 to request a copy of the Fall 2004 issue, or they may also log onto www.msaa.com and go to "publications" to view or download and print the article or full magazine. As a follow-up, this Symptom Awareness column explains how to prepare a pain diary. In the next issue, complementary and alternative medicine (CAM) therapies that may help reduce pain will be discussed.

Monitoring Your Pain

The first step is to acknowledge your pain; only you know how severe and persistent it is. The key is to work with your doctor to develop a pain-management plan. Chronic pain can become a quality-of-life issue, affecting not only how you feel, but also how you live your life.

Pain was the topic of the cover story in the Winter 2002 issue of *The Motivator.* (Please call MSAA at **(800) 532-7667** if you would like a copy.) The article featured Dr. Ann Berger, RN, MSN, MD and chief of pain and palliative care services at the Clinical Center at the National Institutes of Health (NIH). In this article, Dr. Berger expresses the importance of acknowledging your pain and managing it with the help of your doctors. Dr. Berger also gives suggestions on how to identify your pain and how to express to your doctor what you are feeling.

Dr. Berger notes some things to consider when monitoring your pain. She states, "Pain is individual. It's different for each person. That means modalities will be different for all people, and on an individual basis, we need to address the spiritual, psychological, and psychosocial aspects, in addition to the physical side of pain."

Dr. Berger continues, "People should be careful to note the site of the pain, its severity, the date of its onset, its duration, any aggravating or relieving factors, and its effect on physical and social function. To judge the quality of pain, one should determine if it's sharp, stabbing, dull, cramp-like, aching, throbbing, shooting, burning, numbing, pulling, radiating, tight, or responsive to pressure. One should also pay attention to factors that exacerbate or calm the pain. These could be movement, bending, sitting, lying flat, standing, walking, eating, or swallowing, as well as changes in the weather, a specific time of day, or distractions."

One way to track this information is to keep a "pain diary," which will help your doctor in managing your pain, as recommended by The American Pain Foundation.

In a pain diary, a person chronicles the following: where a pain is, how it feels, if it was present upon waking, if it changed during the day, if anything (including medication) makes it feel better or worse, if any medications were stopped because of their side effects, if anything aside from medicine helps the pain subside, if sleep is disturbed or made impossible by the pain, if the pain precludes spending time with family and friends, if it makes one skip meals, and if has changed the person's life. By keeping a consistent and accurate diary, you will be providing your doctor with valuable information, which can help with your diagnosis and treatment.

The American Pain Foundation provides a Pain Action Guide on their website (**www.painfoundation.org**). They may also be contacted at **(888) 615-7246**. With a pain diary, you will be able to share with your doctor specific details about your pain that you might not otherwise recall or realize. Here are some of their guidelines:

1. Speak up; tell your doctor, nurse or social worker that you are in pain. Talking about pain is not a sign of weakness.

2. Tell your doctor, nurse or social worker exactly where it hurts. Ask yourself if you have pain in one place or several places, and if the pain seems to move around.

3. Describe how much your pain hurts. Use a scale from zero to 10, where zero means no pain and 10 means the worst pain you can imagine. Explain where the pain is the highest, lowest, and how it is at that moment.

4. Describe what makes your pain better or worse. Is the pain always present? Does it get worse when you move in certain ways?

5. Describe what your pain feels like. Use specific words like sharp, dull, aching, burning, tingling, throbbing, etc.

6. Explain how pain affects your daily life. Do you sleep well? Are you able to work, concentrate, exercise, and participate in social activities? How does it affect your mood?

7. Tell your doctor, nurse or social worker about past treatments for pain. Have you: taken prescription medicine or had surgery; tried massage, applied heat or cold, or exercised; have you taken over-the-counter medications or vitamin supplements?

You can help to take charge by understanding your pain and learning about treatment options. The first step toward feeling better is to recognize that the pain is real. The next steps are to monitor the pain through a pain diary and to visit your physician. ◆

—Amanda Bednar

Health and Wellness

FDA Advisories in 2004

FDA-issued warnings have been in the news, informing physicians and consumers about possible drug risks. To follow is a brief overview of some of the advisories in 2004.

In January 2004, the FDA launched a consumer educational campaign regarding the safe use of over-the-counter (OTC) pain products and fever reducers. These include acetaminophen and non-steriodal anti-inflammatory drugs (NSAIDs), which include aspirin, ibuprofen, naproxen sodium, and ketoprofen.

The FDA wants consumers to read labels carefully and check with their physician or pharmacist to ensure proper dose, minimizing the risk of an accidental overdose. For instance, acetaminophen is found in more than 600 OTC and prescription medications (such as pain relievers, cough suppressants, and cold medications). Used correctly, this medication is safe, but too much can lead to liver damage, particularly when combined with alcohol. NSAIDs can cause stomach bleeding for some, as well as an increased risk of kidney problems.

In March 2004, the FDA recommended close observation of patients for worsening depression or the emergence of suicidal thoughts when treated with antidepressant medications. While these medications can be extremely beneficial, physicians and patients need to be aware of this potential danger.

In June 2004, the FDA issued a public health advisory for Crestor®, a drug used for lowering cholesterol. Doctors were cautioned to follow dosing instructions closely due to reports of serious toxicity (including a muscle-destroying disease and fatal kidney damage) in some patients.

In September 2004, the FDA issued an advisory as Merck & Co. voluntarily withdrew its product Vioxx® from the market because studies suggested an increased risk of serious cardiovascular (CV) events, including heart attack or stroke.

In December 2004, the FDA announced that a clinical trial using larger doses of Celebrex® was stopped due to the increased risk of CV events. Bextra® has also shown a greater risk for CV events in patients following heart surgery. Additionally, preliminary trial results suggest that long-term use (three or more years) of naproxen may also be associated with an increased risk of CV events.

Please note that the only drug to be taken off the market is Vioxx, and this was done voluntarily by the drug company. No one should make a change to his or her treatment regimen without a doctor's approval, and anyone concerned about these advisories should speak with a doctor or pharmacist. Several of these drugs can be taken safely at proper doses, so closely following the doctor's instructions (and OTC drug labels) is crucial. Consumers may keep apprised of FDA warnings and recalls by going to **www.fda.gov** or by calling the FDA information line at **(888) 463-6332**. ◆

Regional News

For information on events and newly formed support groups, please call the phone numbers listed. When specific numbers are not given, please contact the MSAA Regional Office appearing below each listing. Established support groups are held in many other cities; please call the nearest MSAA Regional Office for details. All activities are free of charge unless otherwise noted. For MSAA Health Fairs, please contact Coordinator Anne Negrin at (800) 532-7667, ext. 105.

Northeast Region

Upcoming Events:

- Saturday, March 12th, 11:00 am to 3:00 pm, Fashion Show, Hilton of Cherry Hill, New Jersey; reservations required, please call the Northeast Regional Office
- Tuesday, March 15th, 8:00 pm to 9:00 pm (EST), Teleconference Series on Care Partnering; please call office for dial-in instructions
- Wednesday, March 16th, 7:00 pm to 8:00 pm (EST), Teleconference on Spasticity with Dr. Greenstein; please call office for dial-in instructions
- Saturday, March 26th, "Movement for Living" Medtronic Workshop, northern New Jersey
- Tuesday, April 19th, 8:00 pm to 9:00 pm (EST), Teleconference Series on Care Partnering; please call office for dial-in instructions
- Saturday, April 23rd, "Women's Issues and MS" Educational Workshop, Massachusetts
- Saturday, April 30th, Educational Workshop featuring speakers focusing on care partner issues, Maryland

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

Midwest Region

Upcoming Events:

- Saturday, April 23rd, MS Awareness Conference, Huntington, West Virginia
- Saturday, May 7th, MS Awareness Conference, Luddington, Michigan
- Saturday, May 28th, MS Awareness Conference, Chicago, Illinois
- Saturday, June 11th, MS Awareness Conference, Cleveland, Ohio

Newly Formed Support Groups:

- (Northeast) Cleveland, Ohio; contact Arnetta Pryor at (216) 707-0518
- Naperville, Illinois; contact Susan Kedzorski at (630) 753-0168
- Lake Orion, Michigan; contact Julie Cooke at (248) 935-4733
- Park Forest, Illinois; contact Coni Howard at (708) 747-2129

MSAA Midwest Regional Office:
Renée Williams, Director
13938A Cedar Road, #243
University Heights, Ohio 44118

(216) 320-1838
(800) 532-7667, ext. 140

MSAA Midwest Field Office:
Charmaine Cothran
Client Services Coordinator
PO Box 43504
Chicago, Illinois 60643
(773) 544-8751
(800) 532-7667, ext. 140

Southeast Region

Upcoming Events:

- Saturday, April 2nd, "Loving Life with MS," with Dr. Jay Simsarian, Arlington, Virginia

Support Groups Forming:

Support and therapeutic groups are planned for Alabama (new to the Southeast Region). To start a group, or if an existing group needs assistance, please contact the Southeast Regional Office.

Senate Majority Leader Dennis L. Jones, DC, donated $1,000 of his remaining campaign money (after running for his Senate District seat unopposed) to MSAA's Southeast Regional Office in October 2004. Accepting the check is MSAA's Southeast Regional Director Linda Chaney. This money will be used toward programs and services for individuals with MS in the Southeast Region.

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

South-Central Region

Upcoming Events:

- Thursday, March 3rd, 6:00 pm, "MS: Behind the Scenes," Dallas, Texas
- Saturday, March 5th, 10:00 am to 3:30 pm, "MSAA Health Fair," Renaissance Hotel, Austin, Texas
- Saturday, May 14th, 9:00 am to 12:00 noon, "Taking Charge of YOUR MS," Fort Worth Zoo, Fort Worth, Texas

Newly Formed Support Groups:

- Alpine in Brewster County, Texas; contact Ginger Roberts at (432) 837-1231
- Dallas in Dallas County, Texas; contact Jeff Chenoweth at (214) 697-7974
- Houston (Newly Diagnosed) in Harris County, Texas; contact Dorothy Nisbet at (713) 334-1765
- San Antonio in Bexar County, Texas; contact Adam Roberts at (800) 532-7667, ext. 153
- Texarkana in Miller County, Arkansas; contact Karen Coker at (870) 653-2255
- St. Louis in St. Louis County, Missouri; contact Frances Lenoir at (314) 985-0820
- San Antonio in Bexar County, Texas; contact Wende Jones at (210) 691-9455

- Breckenridge, Colorado
- Fort Worth, Texas
- Tahlequah, Oklahoma

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

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

Northwest Region

Upcoming Events:

- "MS Update" with Dr. Bret Lindsay, Kalispell, Montana (date to be determined)
- April 2005, Educational Program, Wenatchee, Washington (speaker and date to be determined)
- May 2005, Public Awareness Program, Omaha, Nebraska (speaker and date to be determined)
- June 2005, "Living with MS," Yakima, Washington (speaker and date to be determined)

Newly Formed Support Group

- Lewiston, Idaho/Clarkston, Washington; contact Dennis Opdahl at (208) 743-3634

Support Groups Coming Soon:

- Bozeman, Montana
- Harlem, Montana
- Meridian, Idaho
- Thermopolis, Wyoming

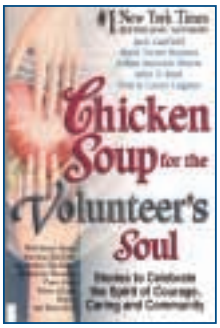
MSAA Northwest Regional Office:
Sue Pencoske, Director
600 Central Plaza, Suite #13
Great Falls, Montana 59401
(406) 454-2758
(800) 532-7667, ext. 131

Western Region

MSAA's newest region is making plans for support groups, events, and activities. The Western Regional Director Amanda Montague (pronounced "Mon-taig´") is looking for calls from individuals who would like to be involved with support groups – as a participant or as a leader. She's also seeking individuals who would like to take part in any therapeutic programs or other regional activities, as well as volunteers who would like to help with events, activities, and/or fundraising. Anyone interested should call Amanda at (800) 532-7667, ext. 155.

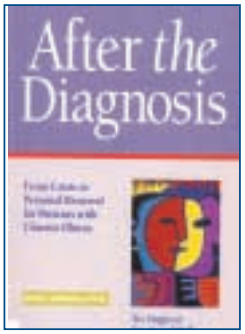
MSAA Western Regional Office:
Amanda Montague, Director
1819 Polk Street
Mailbox #326
San Francisco, California 94109
(415) 260-6420
(800) 532-7667, ext. 155 ◆

Spread the Word



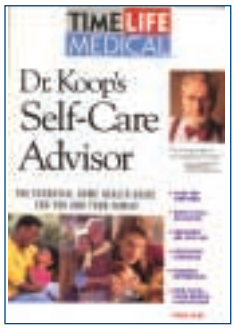
Chicken Soup for the Volunteer's Soul
Written by Jack Canfield, Mark Victor Hansen, Arline McGraw Oberst, John T. Boal, Tom Lagana, and Laura Lagana
Published by Health Communications, Inc.
MSAA Book #251

This collection of writings in the well-known "Chicken Soup" style provides numerous heartwarming and inspirational stories about everyday people who care for those in need, both in the United States and around the world. One does not need to be a volunteer to enjoy this book – it will lift the spirits of anyone who finds pleasure in hearing stories of courage and caring.



After the Diagnosis
Written by JoAnn LeMaistre, PhD
Published by Ulysses Press
MSAA Book #179

Written by a clinical psychologist who was diagnosed with MS six weeks after she finished her training, Jo Ann LeMaistre guides readers through the six stages of emotional reaction to an illness. She then takes readers to a stage of renewal, where individuals with illness may learn to "live life with passion and style again." This book is written for individuals with an illness as well as their care partners.



Dr. Koop's Self-Care Advisor
Medical Advisors: C. Everett Koop, MD and Florence Comite, MD
Published by Time Life Medical
MSAA Book #231

With an easy-to-read format and colorful graphics, Dr. Koop's Self-Care Advisor gives advice on more than 300 common health problems. From emergency and first-aid care to a listing of conditions for virtually every part of the body, this book provides signs and symptoms, instructions on immediate treatments and when to call the doctor, plus strategies to help prevent problems from re-occurring. (While it covers a vast amount of health information, please note that it does not give information on MS.)

MSAA Lending Library

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

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