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Fall 2009

The **MOTIVATOR**

Bringing Information to People with Multiple Sclerosis

Men's Health

Promoting
Physical and
Emotional
Wellness
with MS



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- An outright charitable gift reduces your taxable income for the year.
- If you are 70½ or older, a charitable gift from your IRA may be a good idea. Check with your financial advisor.
- A gift annuity provides a contractual amount paid by MSAA to you throughout your life, in return for your contribution.

For more information about these giving methods, please see page 40.

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

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

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Douglas G. Franklin

Across the country, many of our supporters have been working tirelessly to help MSAA meet the challenges of the economic situation at hand. These have been exciting and beneficial events for MSAA – including my three-day horseback ride on a cattle drive in Texas! I'd like to mention just a few of these great events for our readers.

From the Philadelphia Flyers ice hockey team, forward Riley Cote held the **2nd Annual Cote Carnival** at Swanky Bubbles Restaurant, located near our national headquarters in Cherry Hill, New Jersey. In only its second year, the event raised over \$27,000 in support of MSAA's programs and services – \$10,000 more than last year's carnival.

The Ronda Gruber Foundation of San Francisco, California held a traditional Labor Day picnic, where they matched dollar-for-dollar any donation, for a total of \$19,000.

In Dallas, Texas, MSAA hosted its first ever charitable cattle drive, **MSAA's Lone Star Roundup**. For three days, participants moved cattle to other pastures on an actual working ranch, netting more than \$16,000 in donations.

As 2009 comes to a close, we thank everyone who has helped MSAA in so many ways. We wish everyone a happy and healthy New Year.

In our Northwest Region, a group of 80 people traveled together to raise awareness of MS and funds for MSAA. Led by two gentlemen, one with MS and the other homeless, the group made the 30-mile trek from Harlem to Turner, Montana. Traveling on foot, bike, and every imaginable type of transportation, this determined group collected \$11,000.

Several more special events are planned for the upcoming months, including the 20th TransMontana Charity Snowmobile Ride in January, the TransWyoming ride in February, and MS Awareness Night with the Philadelphia Flyers in March. For more information about MSAA's volunteer initiative, please see "Program Notes" on page 36. If you have an interest in participating in one of these events or would like to organize your own event, please contact MSAA at (800) 532-7667 or email supportms@msassociation.org.

I would like to thank everyone who has been involved with events such as these. Through the generous support of individuals like you, MSAA is able to continue to provide much needed programs and services to the MS community. Thank you for helping us help others! ♦

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

Men's Health

Promoting Physical
and Emotional
Wellbeing with MS

Written by Maryann B. Hunsberger

Edited by Susan Wells Courtney

Reviewed by Jack Burks, MD

Physical Issues for Men with MS

Separating MS from Non-MS Symptoms

Stephen Z. of Norfolk, Massachusetts has MS and knows the value of good healthcare. He receives regular checkups to maintain his health, while seeing a neurologist every six months and scheduling MRIs as necessary. He also sees a primary care physician and various specialists for overall good health.

Stephen explains, “With any chronic disease, you tend to forget about other medical conditions. Overlooking symptoms is easy because you think they are part of the MS, even if they are not. These can be difficult to separate. Doctors do this as well as patients. It becomes more difficult to get other medical professionals to pay as much attention to you because you have a chronic disease.

“The MS specialists focus exclusively on MS, so you need other doctors to take your other symptoms seriously. This is more difficult to do when the other doctors pigeonhole you into the MS box and think every symptom is due to the MS. They tell you to talk to your neurologist, but then the neurologist says the symptom has nothing to do with the MS. You can fall between the cracks.”

MSAA's Chief Medical Officer Jack Burks, MD, is also the director of program development at the Holy Name Hospital MS Comprehensive Care Center in Teaneck, New Jersey. Dr. Burks states that Stephen's assessment of the situation is, unfortunately, accurate.



Men with MS need to be especially proactive with their healthcare.

“He’s absolutely correct. I hear this over and over again. The key is communication and coordination between the neurologist and the primary care doctor, but this coordination is usually fragmented.

“MS centers pride themselves on giving total care. They can address a greater number of issues, since they have nurse practitioners who are more in tune to the general health side of a patient’s care. But as a neurologist, I realize that most patients don’t have access to MS centers. For this reason, when a patient comes to me with symptoms that are not MS related, I write a note on a prescription pad stating what the issues are and saying that these issues are not related to MS. The patient carries this back to the family care doctor to have the issues taken care of. Patients need to be proactive in asking their neurologists to communicate with their primary care physicians and vice versa.”

Burks also agrees with Stephen on the importance of men getting good general medical care and routine physical checkups to look for non-MS related medical problems. “In certain cultures, ‘real men’ don’t need to see doctors unless they are almost dead. In fact, they consider it a sign of weakness to get medical care. On the contrary, a yearly medical checkup often reveals medical conditions that can be treated early. Men with MS need to be better listeners to their physical condition and realize that good general medical care, along with an approach using preventive medicine, will reduce problems in the future.”

Burks says that any medical conditions that can exist in men without MS can also

exist in men with MS. “I tell my patients that one of my jobs is to make them the most knowledgeable manager of their own health-care needs. Patients need to know which non-MS related tests are important. If a patient is on an interferon, such as Avonex, Betaseron, Extavia, or Rebif, a neurologist will order blood work. However, a neurologist won’t do a cholesterol check, because it’s not MS related. Patients might consider asking their neurologists to write on a prescription pad which routine tests need to be done and take the note to their family doctors.”

Possible Conditions, Recommended Screenings, and Regular Checkups

Earlier diagnosis of conditions not associated with MS allows for earlier treatment, quicker recovery, and potentially fewer complications. Men with MS should be carefully screened for the following non-MS related conditions:

- Diabetes
- Hypertension
- High cholesterol
- Cancer (colorectal, prostate, and testicular)
- Thyroid disorders
- Infections
- Anemia
- Orthopedic issues, such as knee, back and neck pain (from weakness, coordination problems, and overzealous exercising)

Regular checkups should also include:

- Appropriate immunizations against influenza

- Booster immunizations against childhood diseases and tetanus
- Pneumonia vaccines for those prone to this disease
- Electrocardiograms
- Chest x-rays
- Skin exams to check for abnormalities which may possibly develop into a cancer, such as irregular moles

As men with MS age, they may also need care for the following conditions, as they can be compounded by MS with aging:

- Erectile dysfunction
- Arthritis
- Prostate problems

Men with MS are also prone to developing health conditions that men without MS might not develop. Some of these conditions are:

- Osteoporosis from insufficient intake of vitamin D and calcium, certain drug treatments such as steroids, as well as reduced activity and exercise
- Pulmonary problems from poor posture or smoking
- Urinary tract infections due to neurogenic bladder and poor bladder function
- Injuries from falls due to lack of use of appropriate assistive devices or environmental adaptations

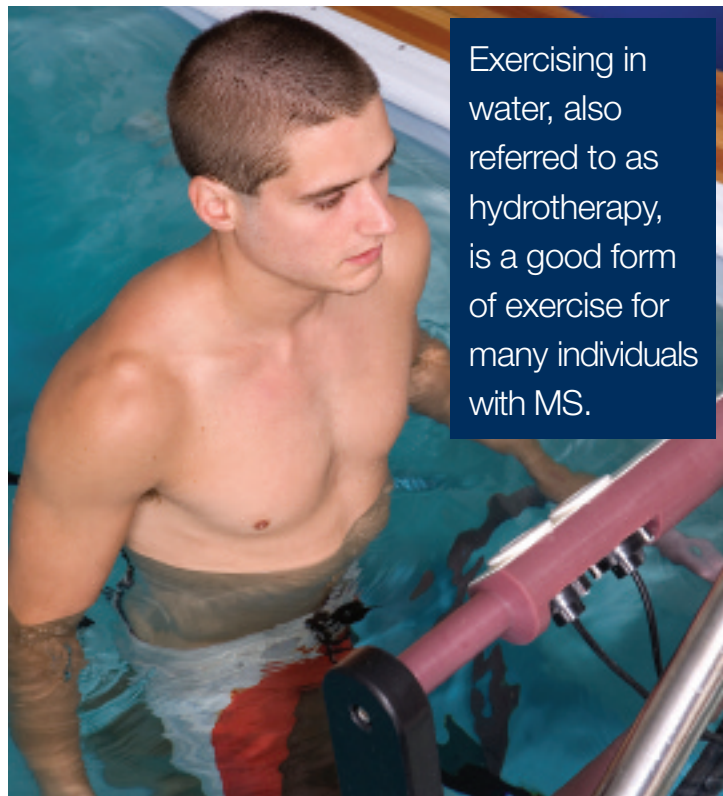
To prevent and monitor these conditions, men with MS should:

- Get bone density scans
- Take vitamin D and calcium supplements as recommended by one's physician

- Increase activity and exercise if possible
- Assess pulmonary function and urinary tract health at their regular checkups
- Employ adequate safety measures, such as consulting a physical therapist for proper fitting and use of equipment, making home modifications, and seeing an occupational therapist if needed

Diet, Exercise, and Physical Therapy for Men with MS

Stephen has learned what most men his age have come to know – that it's easy to gain weight when you hit 60, but not so easy to take it off. "I've never been very good at diets, but eating right has become more critical now. I can't exercise much, so getting the weight off is more difficult. I've spent some time looking for programs with exercises that I can do."



Exercising in water, also referred to as hydrotherapy, is a good form of exercise for many individuals with MS.

Unlike most men, Stephen has the extra challenge of MS to deal with. He recently began physical therapy at a newly opened medical center close to his home. He was excited to learn they had an exercise program for people with disabilities, and he started exercising there at the end of September. He enjoys the program and is happy to note, "They even have a treadmill in the pool!"

Men – with and without MS – are more prone to developing added weight in the abdominal area than women. These large abdomens can put added stress on the back and cause pain. Along with large abdomens comes visceral or intra-abdominal fat, which is fat that surrounds internal organs. Data suggest that visceral fat is associated with heart disease, stroke, diabetes, and hypertension.

Nurse Practitioner June Halper, MSN, APN-C, FAAN is the executive director of the Consortium of Multiple Sclerosis Centers and the International Organization of Multiple Sclerosis Nurses in Hackensack, New Jersey. She emphasizes that certain men are more likely to develop a larger abdomen due to family traits, so these individuals in particular need to be more vigilant about preventing weight gain.

Since diet is important to keep weight under control, Halper says that the United States Department of Agriculture (USDA) Food Pyramid is the best place to start when trying to maintain good health. "Their rec-

ommendations are consistent with a healthy lifestyle and weight control. Obviously, as a man might become more disabled and less active, fewer calories are required. It is also important to work with a personal healthcare professional for information about saturated fats and diet, as well as adequate amounts of protein. Getting plenty of fluids, preferably water, is important too."



Following the USDA's Food Pyramid guidelines can help to ensure a healthy diet, which includes an ample supply of fruits and vegetables.

What about single men who are having problems with food preparation? Burks says that a consultation with a nutritionist can be helpful in learning about a nutritious diet. "The nutritionist can also recommend 'quick fix' meals that are healthy, instead of relying on instant meals or fast foods that are loaded with calories and salt."

When preparing meals isn't possible, Halper offers that men with MS should try to find frozen dinners that are well balanced and contain low amounts of sodium and

LIFESTYLE FACTORS

Dr. Jack Burks and Nurse Practitioner June Halper emphasize that men with MS need to be vigilant about lifestyle factors that can help or hinder their health.

The following lifestyle factors can influence health negatively:

- Smoking
- Drinking
- Taking illegal or unprescribed drugs
- Poor diet
- Poor stress management
- Poor sleeping habits
- A sedentary lifestyle



The following lifestyle factors can influence health positively:

- Avoidance of smoking, drinking, and illegal or unprescribed drugs
- A low-fat, heart-healthy diet
- Relaxation techniques
- Good sleeping habits
- Supervised exercise
- Regular medical checkups
- Reaching out to family, friends, and others with MS to share experiences and ideas
- Exploring disease-modifying therapies for MS, beginning very early in the disease course if possible
- Seeking help for depression and anxiety
- Finding ways to maintain a sense of self-esteem

calories. She also stresses the importance of patient education. “Several websites offer valuable advice about nutrition. Additionally, many local hospitals and healthcare facilities provide community-based education about nutrition and wellness. A wellness mentality, along with wellness activities, will help patients sustain a good quality of life despite the problems imposed by MS.”

Since exercise is a valuable component for maintaining strength, flexibility, balance, and weight, Burks recommends a physical therapy evaluation and home program, if possible. “People with disabilities, including those who use a wheelchair, can usually exercise regularly under proper supervision. The key is to exercise without becoming exhausted. The point of exhaustion is often different for each patient, so this requires guidance from a physical therapist. MS exercise programs frequently start with less-rigorous exercises which are increased as indicated. Starting an exercise program with a strenuous regimen may lead to increased symptoms and discourage people from continuing.”

Halper stresses the importance of physical therapy if there is an MS relapse, worsening of function, or disease progression. “Based on insurance coverage, physical therapy is usually time-limited, with set goals such as improving function, safety, reducing spasticity, and addressing pain. Continuing physical therapy strategies is important, even after the person is discharged, in order to maintain the goals achieved.”

She also states that adapting exercise to meet physical needs is crucial. “Men who be-

come more disabled may have to change their exercise routine. A runner may become a swimmer; an outdoor biker may use an indoor stationary bike. Even men in wheelchairs should exercise their upper bodies with light weights, stretching, and Thera-bands for resistance routines. Exercises such as yoga, tai chi, and Pilates, can be adapted to provide movement and exercise even for the more disabled man. Activities such as swimming in a cool pool (no warmer than 82 degrees), horseback riding, walking, and stretching are all important in MS, but the choice is up to the individual, based on personal preference.”

Halper says that men who are minimally disabled from MS should continue exercising as they did prior to their disability, although they need to avoid overheating since symptoms could worsen with heat. Some men with MS join a health club and work with a personal trainer to modify their routines. Halper notes that exercise schedules for mini-

Exercise such as tai chi not only increases strength and range of motion, but also helps to reduce stress and anxiety.



mally disabled men should remain consistent, although she cautions that their schedules may need to be modified in light of fatigue later in the day.

RESOURCES: PHYSICAL HEALTH

WebMD Men's Health: men.webmd.com

Mayo Clinic, Men's Health: www.mayoclinic.com/health/mens-health/MY00394

National Institutes of Health, Men's Health:
health.nih.gov/category/MensHealth, (301) 496-4000

Centers for Disease Control and Prevention, Men's Health: www.cdc.gov/men, 800-311-3435

United States Department of Agriculture (USDA) Food Pyramid:
www.mypyramid.gov, (888) 779-7264

Men's Health Network: www.menshealthnetwork.org, (202) 543-6461

Emotional Issues for Men with MS

Depression, Identity, and Adjustment

Men with MS face the same emotional issues as most people with a chronic disability. Still, an MS diagnosis can be daunting. Adam Kaplin, MD, PhD, holds several positions at the Johns Hopkins University School of Medicine, including chief psychiatric consultant to the Multiple Sclerosis and Transverse Myelitis Centers; and assistant professor in the Departments of Psychiatry and Neurology. Kaplin says that the unpredictable nature of MS can cause problems. He explains, “Ten percent of the time, MS is a benign condition that doesn’t cause any significant disability. For others, it is an unrelenting progressive illness. The unknown is tough to deal with. Clinical depression with MS can come both from adjusting to life under altered circumstances, and from inflammation in the brain. It’s a clinical syndrome that has been correlated with a worsening case of MS, since people who are depressed have a more aggressive immune system.”

According to Kaplin, although MS is roughly three-times more common in women than men, clinical depression is found equally in both genders with MS. “This differs from the general population, where women are twice as likely to have depression. However, men are more likely to view depression as a source of shame and are less likely to seek assistance.”



Some men find that adjusting to life under altered circumstances to be overwhelming, especially when a man’s disability is severe enough to change his lifestyle. David Rintell, Ed.D., is a psychologist at Partners MS Center, Brigham and Women’s and Massachusetts General Hospital and clinical instructor of psychiatry, Harvard Medical School. Rintell notes that this difficulty with adjustment can cause problems. “Men are brought up to be protectors, doers, wage earners, and people who maintain control of their situations. This is how male identity is formed, and it makes MS difficult, because MS may interfere with one’s ability to earn money and protect his family.”

Rintell can relate to the fact that many men are oriented around fixing things, and he explains that problems can occur because men can’t fix MS. “Because of our orientation as doers, men sometimes experience a loss of self-worth and develop frustration, anger, and depression when we can’t do things,” says Rintell. “There is more difficulty in maintaining our identity. We aren’t usually comfortable talking about our emotions, so men often

keep their personal struggles inside. This makes men more vulnerable to getting derailed by the problems facing them with MS.”

Men may need to redefine their roles in the family to facilitate a smooth adjustment. However, most men struggle to keep things the same. “This is where people end up with trouble,” says Rintell. “My father had MS. He was the family driver who drove anywhere we went. After many years, my mother had to take over. It was a blow because that role was important to him to be captain of the ship, so to speak.”

When a man is so attached to a particular function, it's difficult to replace that and regain his feeling of value in the family. Rintell explains, “If a man feels like he is less of a person, he may feel that he doesn't have as

much to offer to his family. He may disconnect or take less of a role, even if he isn't physically disabled from other roles. He can become disabled psychologically.”

One becomes disabled psychologically when one doesn't adjust to change. “Fathers may feel that if they can't do one thing, they can't be a good parent, so they withdraw from the other really important activities. This disables them emotionally,” says Rintell.

Kaplin is familiar with this scenario, but says it can be resolved. One patient sadly said his days of coaching his girls' softball team were over because his need for a cane prevented him from sliding or running the bases. Kaplin suggested that he find other ways to help the team. The patient found an assistant coach to do the physical work while he verbally coached the girls from the sidelines. “Sometimes, people become so committed to a failed solution that they can't see they need to step back and find a different solution. This man found that just showing up to each game with a cane was teaching the girls not to give up – and this must have worked, because his team won! It was a life lesson far above anything about fielding a ball.”

According to Kaplin, the key to adjusting successfully is constantly adapting and learning new strategies. “Just as having children causes you to reprioritize and to constantly readjust and learn new strategies at each stage of a child's development, with MS, you have to constantly adapt and learn new approaches.”



MS can sometimes challenge a man's identity as the provider and protector of his family. Adapting to changing roles and learning new strategies are key to good emotional health.

Adapting to Life with a Disability

Greg W. from Westford, Massachusetts knows about the importance of adapting to learn new approaches. After his progressive MS symptoms hindered his ability to kneel in his large garden to care for his plants, he began researching various ways of gardening. "I made up my mind that I was going to figure out a way to keep my hobby going without letting my MS get in my way. I researched gardening for disabled people online and learned about container gardening. I called schools and asked if their custodians had any five-gallon containers they didn't need. To my surprise, I got one hundred! I started the containers with soil and seeds in my basement. I put the containers under grow lights and then would transfer them to my yard."

Discovering new activities and learning ways to adapt them for your specific needs can make life more enjoyable.



When Greg's disability progressed to the point that he couldn't access the basement any longer, he began buying small plants and transplanting them in the containers in his yard. He created paths between containers of Brussels sprouts, squash, broccoli, tomatoes, eggplant, and green beans so he could use his power scooter to water and weed his plants. He pays a student to mow the lawn and move the heavy containers. "Nothing is impossible if you really want to do it badly enough. You have to study a lot to figure out new ways to do things. I'm going to write about my gardening for my church's website to share with other people how to do container gardening."

Greg's willingness to change was crucial to successfully living with a disability. Rintell says this is the key for helping anyone with MS to adjust. "Try something new. Look back at the things you used to enjoy doing that you didn't have time to do, or gave up doing, because you were too busy. Tackle those. You can also find a way to do something about MS, such as volunteering your time to an MS organization or facilitating a peer support group. Educate yourself. Be a support person for one of the fundraising events. It's not so much what you do, but that you do something."

Since many men excessively focus on work, they often have difficulty adjusting to leaving the workforce. Rintell stresses, however, that many men make this transition successfully with the help of a support group. "This is more difficult for men with MS than men who retire, because their peers are still working. That's why support groups for men

are so important. I formed such a group after meeting a number of men with MS who needed to reformulate their goals and figure out what to do next. Men are more likely to open up emotionally with other men than in mixed groups.”

Rintell says that many of these men have capably evolved to becoming the primary parent and maintaining the household. “A successful transition often involves changing a man’s focus to his family, connecting with friends, setting new achievable goals and working on them. It’s important to work on doing something about MS, whether it be volunteering, fundraising or participating in a clinical trial. A man can have goals and work to achieve them.”

One of the most important sources of self-esteem is having a feeling of accomplishment. Making progress toward goals is crucial to this. Rintell says, “Sometimes, people can’t achieve their previous goals, and they are not replaced by achievable goals, which causes self-esteem problems. To be successful, goals must be achievable and the progress can be gradual. If the goal is to clean out the attic, it needn’t be done in one day. For instance, if the attic is full of boxes and you are overwhelmed by the work involved, you may feel as though you can’t do anything about it. But if you open one box per week and look through it, you will make progress toward your goal. Eventually your attic will be box-free.”

Kaplin says that many men successfully transition to a new lifestyle by using a team method. “You are now the CEO of a condi-



Men may feel more comfortable talking with other men – rather than women – about their feelings and concerns.

tion that requires a team approach. Men traditionally deal with things on their own, but that doesn’t work with MS. They must learn to be the head of a team and request help from their ‘employees.’ They need a team of clinicians, friends, and family members. They must be willing to ask for help to adjust to all the things MS will throw at them.”

Greg says his friends and family members are more than willing to be part of his team. Because he doesn’t feel sorry for himself, his friends don’t feel uncomfortable around him. “I have found that my friends love to help me. It’s difficult to visit other people, but my friends carry me and my wheelchair into their houses. One friend even built a ramp onto his home so I could spend time at his house.”

The most important member of Greg's team is his wife, Nancy. "She's so strong and so special. She's the love of my life. She laughs all the time. I think the secret to dealing with MS is my wife. She showed me how to not ever feel bad about needing help. Our relationship has gotten stronger through my having MS. Everyone says I'm lucky to have Nancy because they don't know if another woman could handle everything."

Stephen also says that his wife, Sarah, is his strongest supporter. To keep the romance alive, they share a passion for visiting museums and historic sites, and they take advantage of weekend getaway trips to accessible locales.

Kaplin says that despite his 27 years of schooling,

the vast amount of his education has come from his patients. "I have learned 70 percent of what I know about MS from patients, not from all my years of school. Working with patients who are confronted

by life under altered circumstances shows me what's really important.

"Life isn't about having the fastest car or the biggest house. It's about caring about others and letting them care about you. I wouldn't want to live in a society that didn't have room for people who have learned from adversity and come through the other side. Living with MS isn't about life being over. It's about learning how we as people can always adapt and never give up."

"Life isn't about having the fastest car or the biggest house. It's about caring about others and letting them care about you."



RESOURCES: EMOTIONAL HEALTH

SAMHSA's National Mental Health Information Center:

mentalhealth.samhsa.gov/topics/explore, (800) 789-2647

WebMD Mental Health: www.webmd.com/mental-health

MedicineNet.com emotional health: www.medicinenet.com/emotional_wellness/article.htm

Helpguide: www.helpguide.org/mental/mental_emotional_health.htm

Men's Health Consulting – for publications: menshealth.org/code/publications.html, (800) 935-5636

National Institute of Mental Health: health.nih.gov/topic/MentalHealth, (301) 496-4000

The Special Challenges of a Male Care Partner to Someone with MS

According to the National Family Caregivers Association (NFCA), more than 22.4 million United States' household members are family caregivers. A 1997 survey conducted by AARP and the National Alliance for Caregiving found that 27 percent of caregivers were men. By 2004, the percentage of male caregivers had risen to 40 percent. Because more women have MS than men, the percentage of male caregivers may be even higher in households with MS.

Sixty percent of male caregivers work full time. According to the National Alliance for Caregiving, it's common for these men to routinely awaken in the middle of the night to help their wives use the bathroom. They may also arrange their days off around their partners' medical appointments. Rintell says this creates a difficult situation. "Many men work all day, keeping telephone contact with their partner and then going home and providing personal care."

Finding good home healthcare to supplement a man's work as a care partner is difficult, since caregiving families have median incomes that are more than 15-percent lower than non-caregiving families. Rintell says, "There is less assistance available for people who have an income, making it harder to hire an aide. In Massachusetts, which is progressive in terms of healthcare, only people



on Medicaid are currently eligible for home healthcare."

NFCA states that in 2000, the typical working family caregiver lost \$109 per day in wages and health benefits because of providing care at home. Additionally, many families lose income when a disabled family member must give up working. Bob J. of Cape Cod, Massachusetts, can relate. "The fact that my wife had to stop working just as she was entering her prime professional years has made a big difference. These are the years when we expected to be the most comfortable financially. We've adapted by living a modest life."

Sixty-two percent of care partners have had to alter their working situation, ranging from arriving late at work to giving up work entirely, according to NFCA. Bob says, "Because my wife has MS, it means that I can't travel for work anymore. My wife's wellbeing is always on my mind when I'm not at home. It's very limiting."

Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depres-

sion or anxiety. NFCA says the rate is six times higher for spouses. Bob states, "My wife's MS is the defining factor in both of our lives. Our friends are going on with full, active lives, but we're stuck at home most of the time. I can't do most of the fun things that my non-caregiver friends do regularly and take for granted. This makes me feel extremely isolated. I've had to either cut back or completely give up my independent recreational activities, because my wife is dependent on me for everything. And I would feel guilty if I were out having fun while she's at home alone. She doesn't do anything without me."

Male care partners may have more difficulty adjusting to their roles because they are less communicative than female care partners. Kaplin points out that this makes it harder for men to ask for help. "Men don't have the same fluency at communicating their needs with others as women do.

As caregivers, men don't do as well at explaining what support they need. Men commonly confide in their wives, but now they don't want to burden their wife with sharing that their newfound responsibilities are difficult. They have no outlet. This is something they need to work on. The men I know who get

together and confide in others tend to do better in this area. A group of guys can get together and play poker, talking while they play. It is so important to talk to someone else who is going through this."

Rintell says that despite lapses in male communication, many men eventually excel at caring and nurturing. "Some men are frustrated because they are new to some of the tasks that 'Mom' used to do. They need to learn a lot of new things. However, most men are up to that challenge and find that what used to be Mom's work is pretty satisfying to them."

Men who are care partners may need to learn new tasks, although they may also find that doing such work can be very satisfying.

In some cases, a cognitive impairment may impact a patient's ability to make decisions, leaving the full responsibility on

the patient's partner. Bob explains, "I always did a lot around the house, so that has not changed. However, I need to make parental decisions alone due to my wife's MS-related cognitive impairment. I miss being able to talk things over and arrive at decisions together."



Bob stresses that male caregivers and their partners should take part in fun activities as often as possible. “We try to be positive, have a good sense of humor, and do what works. Not dwelling on the MS-imposed restrictions works best for us as a couple. We make sure to go out together once or twice a week, even if the destination isn't particularly exciting or varied.”

Rintell recommends that couples also create a special space for romance. “A lot of people's bedrooms become outposts of the local pharmacy with pill bottles and catheters around. That's not romantic or sexy. Get away from the medical stuff. Have a romantic rendezvous in a special spot in your own home at a time of day when your partner has

more energy.”

Bob suggests accepting help offered by others as a way to reduce stress. He also recommends being realistic about limitations. “I avoid reading or exposing my wife to articles about people with MS who do exceptional things. Such articles are well intended, but in my opinion, they make the more typical MS sufferer feel badly because they can't do those exceptional things. And such articles misinform those who don't know about MS, leading them to think that ‘if she would only try harder, she could do those things too.’ It is very aggravating listening to comments like that.”

Despite the difficulties, Bob says his wife's MS has strengthened their marriage. “I think coming to terms with the limitations imposed on us by my wife's MS has made us both more serene and accepting. We no longer have petty arguments. In many ways, our relationship has improved.”

Burks was asked to comment about people with MS doing exceptional things. He remarked that while most MS patients probably won't bicycle across the country, people need to rethink what exceptional means.

Burks explains, “Our MS patients are the most exceptional people that I've ever met,



Challenges such as MS can often bring couples closer, strengthening their bonds. As Bob J. notes, “... my wife's MS has made us both more serene and accepting... in many ways, our relationship has improved.”

and they do things all the time that they might not consider exceptional. However, making the adjustment to remain productive in one's life when faced with these challenges is exceptional. Productivity doesn't mean making a certain dollar amount each year. People with MS can be productive by maintaining good relationships, participating in the loving care of children, and teaching their children to become the best people possible.

"People with MS can be productive by writing letters to newspaper editors or elected officials about issues people with disabilities face. They may also help at church or volunteer for an MS organization. The creative ways most people with MS manage their disease and their lives to make the world a better place is inspirational to me." ♦

"The creative ways most people with MS manage their disease and their lives to make the world a better place is inspirational to me."

– Dr. Jack Burks,
MSAA Chief Medical Officer

People with MS can be productive by teaching their children to become the best people possible.



RESOURCES FOR CARE PARTNERS

Family Caregiver Pen Pal Program:

www.thefamilycaregiver.org/connecting_caregivers/pen_pal_program.cfm

Family Caregiving 101: www.familycaregiving101.org

National Alliance for Caregiving: www.caregiving.org

National Family Caregivers Association: www.thefamilycaregiver.org, (800) 896-3650

The Caregiver Community Action Network: ccan.lotsa.net

Well Spouse Association: www.wellspouse.org, (800) 838-0879

Distinguishing a Diagnosis of Lupus from MS



Dr. Jack Burks

Q: My daughter was diagnosed with lupus, and then diagnosed with MS on the very next day. She was treated for MS and put on a disease-modifying therapy, but she had a reaction to the

shots and needed to discontinue her treatment. After seeing many doctors in Tampa (including the specialists at the University of South Florida), we were finally able to go to Mayo Clinic in Minnesota.

She had lesions on the front right of her brain, which have affected her short-term memory, and at times, her emotions. At Mayo, they are pretty sure about the lupus, but not as sure about the MS. She has had three spinal taps and no bands have shown up on any of them. The doctors at Mayo said she is a very difficult case.

She has received almost a year of chemotherapy (which is the maximum), and while she seemed to be doing better at first, she has progressively gotten worse over the last few months. Is it possible that my daughter does have MS as well as lupus, and the MS is causing her elevated numbers on the blood tests, even though she is on the chemo?

Do you have any suggestions for where we should go or what we can do from here? We are wondering if the lupus and MS are

fighting each other, and if anything can be done to treat both.

A: You are right in that your daughter presents the sometimes difficult task of diagnosing MS in the presence of a lupus diagnosis. It would be unusual that lupus and MS might affect someone at the same time, but it is possible. Young women are more prone than men to develop these conditions.

In distinguishing these two diseases, MS is limited to the central nervous system, while lupus may also affect the skin, joints, heart, and other organs. However, lupus can affect the brain only and resemble MS initially. Specific blood tests for lupus may be helpful in differentiating these two diseases. MS cannot be detected through blood tests at this time, although some MS patients can have blood-test abnormalities resembling lupus. MS and lupus both involve an over-active immune system.

You have explained that your daughter has been given chemotherapy, although I don't know which type specifically. Some chemotherapies are helpful in both illnesses. In addition, steroids can help with both conditions during acute flare-ups.

I am not able to give specific patient-related opinions without a complete evaluation. However, if her doctors are puzzled in regards to therapy, you can always seek other opinions. For example, in addition to Mayo Clinic in Minnesota, Mayo Clinic in

Jacksonville, Florida has expertise in multiple sclerosis.

The book, *Lupus Q & A, Everything You Need to Know*, by Robert G. Lahita, MD, PhD, and Robert H. Phillips, PhD (Avery, 2004) may be a useful resource and is available through MSAAs free Lending Library. This publication is featured in this issue's "Spread the Word" column on page 48, where you will also find instructions for borrowing a copy of the book.

Q: My husband was exposed to Agent Orange in Vietnam, but the VA still denies this causes MS. About a year ago we learned that while we were living at Camp Lejeune, the well water was contaminated by chemicals from a dry cleaning plant adjacent to the base. Could this have caused his MS?

A: Toxic exposure has been suspected in many "outbreaks" of MS. Extensive investigations have not proven any cause and effect. However, I would ask your State Health Department or the federal agency called the Center for Disease Control (CDC) in Atlanta for guidance. You may visit their website at www.cdc.gov, or call them at (800) 232-4636. If your husband's MS symptoms began within seven years of military discharge, he may be eligible for "service connected disability" for his MS. The Paralyzed Veterans of America (PVA) may also be able to help you. For more information, you may visit their website at www.pva.org or call them at (800) 555-9140.

Q: I am 80 years old and was diagnosed with MS 23 years ago. I have been on Betaseron® (interferon beta-1b) since 1993 and I am able to walk for short distances with a walker or two canes. However, I have problems sleeping most nights. I hesitate to take drugs, but occasionally take an over-the-counter sleeping aid such as Excedrin PM®, which is somewhat helpful. It seems like I have no trouble napping in the day time for short periods of time. Do you have any suggestions?

A: When I read your question, my first thought was "congratulations." At age 80, you are still walking after 23 years of MS and 16 years on DMT's. AND, you're still actively seeking help to make your life better.

In brief, I believe that sleep disturbances in MS are more common than recognized. Some problems that you are experiencing may be directly related to MS, but many can

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.

be related to other issues such as sleep apnea, medications, heart failure, depression, anxiety, and/or other factors which can be identified by sleep disorder experts.

Your doctor can help you to find experts in your area for these types of conditions. The diagnosis is important before settling on a specific treatment. The occasional use of sleeping pills may be helpful, but continued use can lead to loss of effectiveness, and other side effects are possible.

I can also refer you to the “Symptom Awareness” column on page 41 of this issue. This article discusses the strategies and treatments for improving sleep, as well as the health benefits that sleep provides. MSAA also has books on these topics, which may be borrowed at no charge through MSAA’s Lending Library. For more information, please refer to “Spread the Word” on page 48.

Q: I was diagnosed with relapsing-remitting MS in 2008. My initial acute symptoms of numbness from my knees on down were improved somewhat with a three-day IV of Solu-Medrol® (intravenous steroids), followed by a tapered dosage of (oral) prednisone for 12 days. While that improved the symptoms somewhat, I never fully regained feeling in this area – although my balance has improved considerably.

I am currently taking Copaxone® (glatiramer acetate) injections daily and a six-month follow-up did not show any progression of the disease. There are days where the numbness is worse than others, and I’m wondering if another Solu-Medrol

IV treatment would improve this, or if this is as good as it gets? Since this is all new to me, I am unclear as to when, or if, further Solu-Medrol IV treatment should be sought.

A: Solu-Medrol IV treatment is used when there is evidence of a new MS relapse, as indicated by new MS symptoms or worsening of one or more previous MS symptoms lasting at least two days. However, other factors must be considered. For example, a urinary tract infection without obvious bladder symptoms, may cause a similar increase in MS symptoms. This is called a “pseudo MS relapse.”

Unless you are experiencing a true MS relapse (also referred to as an “exacerbation”), IV steroids such as Solu-Medrol are not usually recommended. These are best reserved for times of documented disease flare-ups. IV steroids have been shown to speed the recovery time from an exacerbation, but their long-term benefits have not been established. Therefore, disease-modifying therapies (DMTs), such as the one you are taking, are advised for most individuals with relapsing forms of MS.

Aside from Solu-Medrol, symptomatic medications can sometimes be helpful if your numbness creates a painful sensation. Your doctor can give you specific recommendations. A drug called Neurontin® (gabapentin) is often my first line of therapy for these painful numbness symptoms.

Q: I have had MS for 25 years and have suffered from severe vertigo during the last few months. My neurologist has put me on both Antivert® (meclizine) and Valium® (diazepam). Neither has helped me. Now my neurologist wants me to see a physical therapist for some help. Have you ever heard of this? How would that help with my vertigo?

A: Dizziness and vertigo can often be symptoms of MS. However, there are other causes of these symptoms as well. When I hear your symptoms, I ask myself if there may be another diagnosis which is not related to MS. For example, dizziness or light-headedness can result from side effects from certain medications; allergies; low blood sugar; low

blood pressure; anemia; thyroid problems; ear infections; anxiety; and less commonly, heart problems. Vertigo may be caused by inner ear disorders (such as Ménière's disease) or other conditions, such as migraine headaches.

Different systems within the body and brain work together to keep an individual balanced. These include vision, sensory functions, and functions of the inner ear. When signals are affected between the systems, one's balance can be affected.

In regard to the medications you were prescribed, these are the standard treatments for dizziness and vertigo. These symptoms may indicate an exacerbation of your MS, in which case your doctor may consider a

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course of steroid therapy. On the other hand, you should also look into the other causes of such symptoms to make sure you are not experiencing any of the conditions mentioned earlier.

Yes, treatments for dizziness and vertigo can include rehabilitation therapy. In fact, some rehabilitation therapists specialize in treating these symptoms. They try to improve balance by using certain types of equipment or other techniques aimed at retraining the areas of the brain that send signals to assist with balance.

Q: I was diagnosed with MS in 2004. I recently was changed to a different insurance company which does not cover Provigil® (modafinil) for the treatment of my MS-related fatigue. My doctor substituted Ritalin® (methylphenidate). I have noticed a difference in my fatigue. What are your thoughts?

A: Provigil is now being covered by most insurance companies, although many require a preauthorization from your healthcare professional, who must contact the insurance company directly. If Provigil is not covered, a new drug, Nuvigil® (armodafinil), which is similar to Provigil, may be covered. Check with your doctor to see if this drug is appropriate for you.

You mention that you have noticed a difference in your fatigue since taking the Ritalin. (From your original question, I believe you were given “methylphenidate,” which is the generic version of Ritalin.) I am assuming that by “difference,” you mean an im-

provement? If so, I am happy that you have a treatment that may be helping you. If not, you and your doctor will need to discuss other treatment options.

While drugs for fatigue may be of help, they do have limitations. For instance, side effects can be a concern, and their effectiveness can diminish over time. Other strategies for treating fatigue may also be of help to you. These include improving sleep, reducing stress, treating depression and anxiety, energy conservation, exercise, avoiding heat, and using cooling therapies.

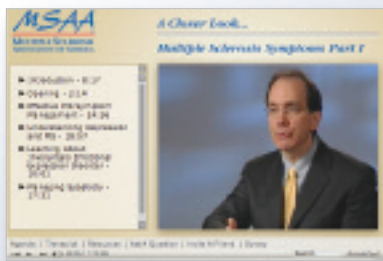
Many neurologists and MS centers in your area are familiar with various treatments for fatigue. To find the nearest center to you, please visit www.mscares.org (once on this site, roll the mouse over the “CMSC Online” heading for the dropdown menu, then roll over “About CMSC” for another dropdown menu, and then select “Center Directory”). If you do not have internet access, you may speak with an MSAA Helpline consultant by calling (800) 532-7667. He or she can provide information to you about local MS centers. ♦

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

MSAA Receives Honors for Communications Excellence

MSAA recently received five communications awards:

MSAA's home page received a Grand APEX Award in the category of Home Page Design for Web & Intranet Sites.



MSAA's educational video *A Closer Look at the Benefits of Exercise* won an APEX Award in the category of Education & Training – Electronic and Video Publications.

MSAA's educational video series, *A Closer Look at Multiple Sclerosis*, won a Stevie Award (presented by The American Business Awards) for Public Information Production of the Year.

"MS Research Update 2008" featured in *The Motivator* (Summer 2008 issue) received a Gold National Health Information Award for Patient Education Information in the category of Magazine/Newspaper/Newsletter Article.



"Partners in Wellness – The Importance of a Positive Doctor-Patient Relationship" featured in *The Motivator* (Spring 2008 issue) received a Merit National Health Information Award for Health Promotion/Disease and Injury Prevention Information in the category of Magazine/Newspaper/Newsletter Article.

MSAA's home page may be viewed at www.msassociation.org, and while visiting the website, viewers may go to the lower right side of the home page and click on "Multiple Sclerosis information (MSi)," to go to MSAA's online educational videos. MSAA's publications are currently available by selecting "Publications" from the top menu of MSAA's home page, or by calling MSAA at (800) 532-7667.

Extavia Receives FDA Approval for Treatment of MS

On August 14, 2009, the United States Food and Drug Administration (FDA) approved Extavia® (interferon beta-1b) for the treatment of relapsing forms of multiple sclerosis (MS). Extavia is also approved for individuals who have had a clinically isolated syndrome (CIS), which refers to those who experience a single attack of one or more symptoms characteristic of MS, with a high risk of developing clinically definite MS (CDMS). Marketed by Novartis Pharmaceuticals Corporation, Extavia is the same medicinal interferon beta-1b product as Betaseron®. No changes will occur in the marketing of Betaseron, which will continue to be available by prescription to MS patients. Extavia became available by prescription in the United States in October 2009.

Novartis offers nursing support and education to individuals who may be prescribed Extavia. A telephone helpline as well as one-on-one training with injection procedures are among the services provided. Extavia is given at the same dose and frequency as Betaseron: 250 micrograms administered via subcutaneous (under the skin) injection every other day. Patients may choose between traditional injections or using an autoinjector. Support services will include insurance advocacy and a reimbursement program for those who qualify.

Extavia will be joining six other disease-modifying therapies (DMTs) in the marketplace, all of which have been previously approved by the FDA for the

treatment of MS. In addition to Betaseron, these include: Avonex® and Rebif® (interferon beta-1a); Copaxone® (glatiramer acetate); Novantrone® (mitoxantrone); and Tysabri® (natalizumab). Betaseron has been used in the United States for more than 16 years. For individuals with relapsing forms of MS, it has been shown to reduce relapse rates by 34 percent, and may slow disease progression. For individuals with CIS, almost 75 percent did not progress to CDMS (as indicated by having a second relapse) following two years of treatment.

Flu-like symptoms and injection site reactions are among the commonly reported side effects with interferon beta-1b. These can often be minimized by gradual dose titration (starting with a low dose and increasing the dose slowly) and closely following injection instructions, along with the prophylactic use of analgesics during treatment initiation. Allergic reactions are among the rare complications of interferon use.

Self-injection techniques should be re-evaluated periodically to ensure that proper procedures are being followed. As with other injectable treatments for MS, rotating the injection sites is important, although the specific rotation recommended for Extavia may differ slightly from that of Betaseron. Blood monitoring and liver function tests are also recommended at regular intervals. Additionally, female patients considering Extavia should be warned about the potential risks of interferon use with pregnancy. This

drug should be used with caution in patients who also experience depression.

Novartis was given the rights to seek approval for its own branded version of interferon beta-1b through an agreement with Bayer Schering, the company which markets Betaseron. Outside of the United States, Extavia is presently available in 12 European countries for the treatment of MS. Betaseron is also available outside of the United States and is marketed as Betaferon®.

Novartis has information lines for anyone who has questions about Extavia. Members of

the MS community may call (866) 925-2333 for more information. Healthcare professionals with product-specific questions may call 866-EXTAVIA, or (866) 398-2842. Information is also available on Extavia's website at www.extavia.com.

Please note that this article also appears on MSAA's website at www.msassociation.org under "Recent News." To speak with a Helpline consultant about MS, its treatments, and MSAA's programs and services, or for additional support, individuals may call MSAA's Helpline at (800) 532-7667. ♦

FDA Reviews Fampridine-SR Study Data

The United States' Food and Drug Administration (FDA) is presently reviewing the New Drug Application (NDA) for 10 mg daily doses of oral Fampridine-SR, an investigational drug that improves the conduction of impulses between damaged nerves. This increase in communication between damaged nerves could increase neurological function, such as strength and endurance.

Individuals with relapsing forms of MS, as well as individuals with progressive forms of MS, were included in the trials. Results from the Phase II and Phase III studies showed that a significantly greater number of "Timed Walk Responders" were in the treated group versus the placebo group. A "Timed Walk Responder" refers to someone who experienced a consistent improvement in walking speed when taking the drug, versus his or her timed walking speed when not

taking the drug.

Developed by Acorda Therapeutics and manufactured by Elan Corporation, Fampridine-SR is a sustained-release version of 4-aminopyridine (4AP). In earlier studies, larger doses of the drug were given; however, the risk of seizures with this drug became a concern. With the sustained-release version, the risk of seizures did not differ from the placebo group. The most common adverse events included urinary tract infection, insomnia, dizziness, headache, nausea, asthenia, and back pain.

The FDA's Advisory Committee voted in early October 2009 to recommend approval. The FDA's decision-making body has extended its deadline for completing its review of Fampridine-SR's study data to January 22, 2010. The FDA could potentially approve this drug for individuals with MS at that time. ♦

Application Submitted to FDA for Oral Cladribine Tablets

On September 30, 2009, EMD Serono announced that a New Drug Application (NDA) had been submitted to the FDA for the investigational, oral form of cladribine for the treatment of relapsing forms of MS. This drug has been designated by the FDA as a Fast Track product, for an expedited review.

The CLARITY study was a two-year Phase III trial of two dose levels of cladribine tablets versus placebo in 1,326 randomized relapsing-remitting patients. Tablets were given in two or four treatment courses per year, with four to five consecutive once-daily doses per treatment course.

All primary and secondary endpoints were reached in this trial, including a 55 to 58-percent reduction in annual relapse rates,

as well as a reduction in gadolinium-enhanced lesions as seen by magnetic resonance imaging (MRI) scans. Most common side effects, such as headache and nausea, were similar between all three groups. Lymphopenia (low level of lymphocytes in the blood) and herpes zoster infection occurred more often in the treated groups; four individuals taking cladribine developed malignancies.

A safety registry for cladribine is being planned and will help to determine the long-term safety of this drug. If approved in the coming months, cladribine tablets could be the first oral disease-modifying therapy (DMT) available for individuals with relapsing forms of MS. ♦



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Copaxone Approved for Treatment of Early MS

Copaxone® (glatiramer acetate) is one of the seven approved DMTs for the long-term treatment of relapsing forms of MS. Teva Neuroscience markets this drug, which is given via daily subcutaneous injections.

Earlier this year, the results of the PreCISe Phase III study were presented to the FDA. This study found that individuals who initially experience a single neurological event suggestive of MS (known as a clinically isolated syndrome or “CIS”), were 45 percent less likely to develop clinically definite MS

during the study period when given Copaxone, compared to those in the placebo group. In 25 percent of the treated patients, conversion to clinically definite MS was delayed by 115 percent (from 336 days for placebo to 772 days for Copaxone).

From these findings, the FDA expanded its approval of Copaxone in March 2009, for the early treatment of patients who have experienced a CIS and have MRI features consistent with MS. The results of this trial were published in the October 6, 2009 issue of *Lancet*. ♦

New Cases of PML with Tysabri

Tysabri® (natalizumab) is also one of the seven approved DMTs for the long-term treatment of relapsing forms of MS. It is administered via intravenous infusion every four weeks and is generally recommended for patients who have not responded adequately to, or who cannot tolerate, another treatment for MS. Tysabri is marketed by Biogen Idec and Elan Pharmaceuticals, Inc.

Patients taking this drug are at an increased risk of developing Progressive Multifocal Leukoencephalopathy (PML), a sometimes fatal viral infection of the brain. All patients now receive the drug through safety monitoring programs such as the Tysabri Outreach: Unified Commitment to Health (TOUCH™) Prescribing Program and registered infusion centers and pharmacies in the United States; and the international Tysabri Global Observation Program In Safety (TYGRIS). As of October 2009, more than 60,000 patients had been treated with the drug worldwide. The reported cases of PML

are now at 24, since its re-release in 2006 after a temporary suspension due to the discovery of PML in patients taking Tysabri.

The European Medicines Agency (EMA) is conducting a risk-benefit evaluation of Tysabri to see if any additional steps may be necessary to ensure the safety of patients taking the drug. Presently, the TOUCH program in the United States is able to monitor patients more closely than through the international program. Studies are ongoing to see if it is possible to predict which individuals may be at risk for this condition. If PML is suspected or diagnosed, the Tysabri treatment is immediately discontinued; the patient then undergoes plasmapheresis (also known as plasma exchange or “PE”), to help clear the drug from the patient’s blood system. Sometimes this procedure of rapidly clearing Tysabri from the blood can precipitate an Immune Reconstitution Inflammatory Syndrome (IRIS), which can cause additional symptoms. ♦

Initial Phase III Study Results Reported for Fingolimod

Fingolimod (FTY720) is an investigational, oral medication taken daily for the long-term treatment of MS. Studies are now being conducted with relapsing-remitting as well as primary-progressive types of MS. Its parent company is Novartis Pharmaceuticals Corporation.

Previously, a 36-month Phase II study showed that 60 percent of relapsing-remitting MS patients remained relapse-free and had a low rate of disease activity as observed on MRI. An extension study, FREEDOMS II, is evaluating long-term safety, tolerability, and efficacy; all participants are receiving fingolimod. There have been two deaths from Herpes virus infection in the FREEDOMS trials.

On September 30, 2009, initial results from the FREEDOMS Phase III studies of low-dose and high-dose fingolimod versus placebo were announced. According to a press release from Novartis, fingolimod reduced relapse rates by 54 to 60 percent compared to those taking a placebo. Disability progression was reduced by 30 to 32 percent.

Fingolimod was generally well tolerated and had fewer adverse events with the lower dose than the higher dose. In the TRANSFORMS trial of fingolimod versus Avonex, fingolimod patients had fewer relapses. Novartis is planning to submit fingolimod's study results to the FDA (as well as to European agencies) at the end of 2009, for possible approval. ♦

Plans to Submit Study Data for Zenvia

One of the lesser-known symptoms of MS is pseudobulbar affect (PBA), a neurologic condition characterized by uncontrolled, inappropriate, and/or exaggerated episodes of crying, laughing, or other emotional display, occurring with only minimal or no stimulation to invoke such a response. Presently, no FDA-approved drugs are available to treat PBA.

Avanir Pharmaceuticals has been conducting trials with their investigational drug, Zenvia™ (dextromethorphan/quinidine), for the treatment of PBA. On August 11, 2009, Avanir announced that Zenvia had met its primary endpoint of effectiveness in treating PBA, in the confirmatory Phase III STAR trial. Two dose levels and a placebo were compared in this 12-week study. The two doses were both lower-dose formulations

than those used in previous studies, and have an improved safety and tolerability profile.

A 47.2 percent incremental reduction in the rate of episodes was experienced by the higher-dose group, compared to the placebo group. The lower-dose group also had an incremental reduction in episodes compared to placebo, and the higher-dose group reported an 88-percent mean reduction of episodes compared to their rates at baseline (prior to taking the drug).

Avanir plans to submit study data to the FDA in the first half of 2010. To learn more about PBA, please call Avanir at (888) 805-8852 or visit www.pbainfo.org. Readers may also visit www.msassociation.org or call MSA's Helpline at (800) 532-7667 for more information. ♦

Program Notes

Volunteer Initiative Aims to Reach More People

The need for volunteers to help MSAA has never been greater. Given the nation's economic downswing, donations to virtually all charities have been greatly reduced. For this reason, we look to dedicated individuals from across the country to help us meet the demand for MSAA's urgent programs and services, all aimed at enriching the quality of life for everyone affected by MS.

In July, MSAA launched a major initiative designed to fulfill the needs of people affected by MS, and to reach more people in more locations. The staff at our regional offices has begun to actively recruit and train individuals as well as groups of committed volunteers to help MSAA achieve three specific objectives:

- Assist in organizing local patient education programs and events
- Spread the word about MS and MSAA's services
- Assist in raising much needed funds for MSAA's programs and services

MSAA's regional staff members will work closely with these individuals and groups to achieve one or more of the objectives mentioned. MSAA President and CEO Doug Franklin talks about some of the recent achievements of our dedicated volunteers in the "Up Front" column on page 2 of this issue.

Volunteers do not need to have any special skills or training; just some time and a strong desire to improve the lives of people who are coping with this disease. Some of our most successful volunteer initiatives are led by people who have MS and remarkably, still find the time and energy to help others.

You can help make a real difference in the lives of individuals affected by MS. Please call MSAA at (800) 532-7667 or email supportms@msassociation.org and let us know about your fundraising ideas. Please contact MSAA today! ♦



Cote Carnival for MSAA

The Second Annual Cote Carnival held at Swanky Bubbles Restaurant in Cherry Hill, NJ raised over \$27,000 for MSAA. Left to right: Vince Frankowski of Swanky Bubbles; Philadelphia Flyers forward Riley Cote; MSAA President & CEO Doug Franklin; and Ira Zipper of Swanky Bubbles.

Live Webcasts Now Join MSAA's On-Demand Educational Videos

As a way to reach more clients in more locations, the MSi ("Multiple Sclerosis information") section of MSAA's website now includes live video webcasts. Over the past few years, we have produced and posted nearly two dozen, quality on-demand educational videos on multiple sclerosis, its symptoms, its treatments, and strategies to improve one's quality of life. Now complementing these videos are live webcasts, beginning with a four-part series on mobility and multiple sclerosis.

Sponsored by grants from Acorda Therapeutics and Eli Lilly and Company, *Staying One Step Ahead* made its live debut on October 15, 2009. With the focus on communicating issues of mobility to healthcare providers and family members, this one-hour program featured Dr. Kathleen Zackowski. During this webcast, Dr. Zackowski explored our understanding of mobility, explaining the importance of occupational therapy, and giving a PowerPoint slide presentation on safety

and adaptive equipment. She included a video tour of her unique Motion Analysis Laboratory at the Kennedy Krieger Institute in Baltimore, Maryland.

Because the program was live, online viewers had the opportunity to submit email questions directly to the presenter and have her respond during the program. As an extra benefit, all live webcasts will be archived as on-demand video programs for 12 months following their broadcast. You can view this program now at www.msassociation.org.

The second live video webcast, which is part two of this series, is titled *Exercise and Multiple Sclerosis*. This is scheduled for **Thursday, January 21, 2010 at 8:00 pm eastern time**. Registration for this program will soon be available on MSAA's website at www.msassociation.org, and e-vites will be sent to our members once the link is posted. We invite you to join us for these exciting new webcasts and to use this live format to present your questions to our experts. As always, happy viewing! ♦

Cranial MRIs Available through MSAA's MRI Institute

As the number of people with inadequate health insurance or no insurance continues to grow, MSAA has expanded its ability to serve more people through its MRI Institute. This program works to secure vital MRI scans of the brain so doctors and their patients can monitor the ever-changing course of their MS.

With the generous support of EMD Serono, Inc. and Pfizer Inc, MSAA's MRI Institute will be able to serve an additional 300 new clients in 2010. If you and your doctor are having difficulty securing a cranial MRI because of finances or lack of adequate insurance coverage, and have not received assistance through MSAA for an MRI in the past two years, please call the MRI Institute at (800) 532-7667, extension 120 or email MRIIInstitute@msassociation.org. ♦

Priceless but Free



Bruce Makous

My wife Bobbie, who has been coping with the symptoms of MS for many years, recently went through a very difficult time due to complications of her disease. During this six-month ordeal, the information I re-

ceived through MSAA's programs and services proved priceless.

My awareness of the risks of a high body temperature for many people with MS, and understanding how to manage this serious problem, was something I learned through MSAA. This was extremely helpful when Bobbie was running a very high fever at one point. A little while after her physical crisis, when she was ready to work on rebuilding her mobility, her neurologist said she needed MS-specific rehabilitation. My colleagues in MSAA's Resource Detectives Program provided a list of recommended facilities in the area – something that our Helpline consultants are able to do for anyone who contacts MSAA.

As my wife became stronger and was ready to come home from rehab, my colleagues also recommended home-care programs, which have turned out to be critical resources in this transition. I also took advantage of MSAA's MSi online educational videos, articles in *The Motivator*, and other information from MSAA. All of these resources helped me to better understand

state-of-the-art rehabilitation, physical and occupational therapy, and everything Bobbie would be going through during this crisis and her recovery.

This experience has emphasized the great value of MSAA's programs, services, and publications for people living with MS and their care partners. Our needs-based programs provide people with priceless but free improvements to their quality of life. Our information-based programs provide educational materials and assistance – all of which are extremely helpful in day-to-day activities, in symptom management, and in learning about treatments that may improve the course of one's disease.

These MSAA activities that help people living with MS would not be possible without the generous support from you, our donors. Many of you support MSAA because you know first-hand the impact MS has had on your life or the lives of people you know or love, and you certainly can understand and appreciate mine and Bobbie's recent experiences. Others simply recognize the great value of MSAA in helping those in need.

On behalf of people living with MS, their care partners, and those affiliated with MSAA, I would like to say thank you to everyone for your generous support!

Sincerely,
Bruce Makous
Vice President of Development

President's Circle Reception at the Independence Seaport Museum

MSAA was pleased to hold a special reception in October for its top supporters residing in the northeast. The event was held at the Independence Seaport Museum in Philadelphia. MSAA President and CEO Douglas Franklin, along with our Board of Directors, had the opportunity to personally thank MSAA's donors and volunteers in the region.

More than 400 individuals from across the country currently support MSAA at the generous President's Circle level. Please visit support.msassociation.org/presidentscircle for more information.

MSAA expresses appreciation to supporter Karen Lynch and receives a President's Circle award from Board Chair Eric Simons (right), and Board member Joe King during the President's Circle reception at Philadelphia's Independence Seaport Museum in October.



MSAA supporter Ayesha Fatin Browning (rear left) and friend Tina Elliott enjoy the fascinating Independence Seaport Museum setting, along with 2009 President's Volunteer Award-winner James Shoch and his wife Valerie.

Year-End Charitable Planning

As this tax year comes to a close, you may want to consider these two particularly interesting methods of supporting MSAA.

Charitable IRA Rollover

Through December 31, 2009, individuals can make outright gifts using IRA funds without tax implications. While you cannot claim a charitable deduction for the IRA gifts, you will not pay income tax on the amount. You may contribute funds this way if you are 70½ or older, as long as you transfer funds from your IRA directly to one or more public charities, like MSAA. The gift generates neither taxable income nor a tax deduction, so even those who do not itemize their tax returns receive the benefit.

A Gift Annuity

A gift annuity provides a contractual amount paid by MSAA to you throughout your life, in return for your contribution. The creation of a gift annuity is an excellent strategy to establish a contracted quarterly income payment for you that is not affected by the financial markets. For this reason, a gift annuity is an ideal way to help diversify your retirement portfolio.

The payout rates for annuities today are better than many other options for increasing income in your portfolio. A gift annuity provides income to the donor or couple for a lifetime, at a rate based on age at the time of creation of the annuity. (Please see the gift annuity rate chart at right.) Some of the income is received tax-free, thus also diversifying against future changes in taxation.

For example, if a couple (both age 75) gives MSAA \$10,000, they will receive 5.6 percent, or \$560, per year for life. And they will qualify for a federal income tax deduction of approximately \$3,656, which will save them \$1,024 in taxes in the 28-percent marginal tax bracket. In addition, \$387 of each year's payments will be tax-free for the first 16 years. Finally, the residuary of the gift, usually more than half of its original value, creates a generous fund within their favorite charity, MSAA.

GIFT ANNUITY RATES

| Age | Single | Couple* |
|-----|--------|---------|
| 60 | 5.0% | 4.6% |
| 65 | 5.3 | 4.9 |
| 70 | 5.7 | 5.2 |
| 75 | 6.3 | 5.6 |
| 80 | 7.1 | 6.1 |
| 85 | 8.1 | 7.0 |
| 90 | 9.5 | 8.3 |

*same age

Gift annuities are not available in California

“I had been supporting MSAA through annual contributions, and decided I wanted to establish a legacy gift, too,” said Herbert Weisz of Deerfield Beach, Florida. Herb and his wife created a significant gift annuity with MSAA and will receive income from this gift throughout their lifetime. The balance will provide general support for MSAA. ♦

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

Symptom Awareness

Facts and Tips for a Better Night's Sleep

Many individuals with MS experience trouble sleeping, which often leads to fatigue, a common and disabling symptom of MS. MS patients are not alone in having trouble sleeping. A 2005 survey of the general population found that 75 percent of adults had at least one sleep problem during the preceding year. With busy lifestyles and access to media 24-hours a day, Americans average less than seven hours of sleep per night – and some people get by with six or less hours a night. Research shows that at least seven-and-a-half or eight hours are needed each night for proper repair and restoration of the body and mind.

The benefits of a good night's sleep include increased alertness, a quicker reaction time, and better performance with tasks at work and at home. One's memory, concentration, and creativity are also improved. When well-rested, people are more motivated to get things done and they are more efficient at what they do. In general, a good night's sleep helps someone to feel good throughout the day, and ultimately, sleep may improve one's overall health.

Insomnia can occur for a number of reasons, including “over-activation,” where someone has too much on his or her mind to drift off to sleep. Specific or general worries, or an upsetting event, can often keep someone awake, and the worry of not falling asleep only worsens the problem. In addition to anxiety, depression can impact one's ability to sleep as well. Naps can be helpful to re-energize people

during the day, but too much napping will also contribute to nighttime insomnia.

Another issue is when a person's biological clock and “circadian rhythm,” which normally promote sleepiness during the dark of evening and wakefulness during the light of day, are not working properly. These can get off balance by not staying on a schedule, or from late-night activities, including shift work. Sensory disruptions of noise or light during the night can interrupt one's sleep schedule as well, and taking steps to minimize these disturbances during times of sleep can be of help. Examples of such steps include closing windows, installing shades or curtains that block outside light, turning down the phone, and dimming or blocking inside light. Some people sleep better with the constant sounds of “white noise,” from a room fan or a CD designed for that purpose.

Restless legs syndrome is a sleep disorder experienced by some individuals with MS. When relaxed in a chair or bed during the evening, people with this disorder will feel uncomfortable and have the constant urge to move their legs. For restless legs syndrome, experts advise staying away from alcohol, caffeine, and nicotine. Certain medications can also cause restless legs syndrome as a side effect, and individuals should check with their physician about the medicines they are taking. Other conditions, including anemia, diabetes, nutritional deficiencies, kidney disease, thyroid disease, and varicose veins could be

involved, so individuals should be screened for these conditions.

Other helpful strategies for restless legs syndrome include stretching, taking warm or cool baths, whirlpool baths, applying hot or cold packs to the affected area, limb massage, or vibratory or electrical stimulation of the feet and toes before bedtime. (Individuals who are heat sensitive should not take a warm bath.) Exercise and relaxation techniques may be helpful, and drug therapies may also be prescribed.

Sleep apnea is a serious disorder which occurs when a person's throat muscles relax too much and the airway is temporarily blocked. Overweight individuals are more prone to this

disorder, and snoring can sometimes be a sign of the condition. While people with sleep apnea usually do not have trouble falling asleep, their breathing is affected once asleep, and the sudden inability to take a breath wakes them repeatedly throughout the night, sometimes as often as every 30 seconds.

Sleep apnea can be particularly dangerous since it affects breathing. For a proper diagnosis of a sleep condition, a sleep study at a sleep center is often prescribed. Some overweight individuals even lose weight once they are able to get adequate sleep. This is due to a decrease in the production of a hormone that promotes appetite.

Other sleep problems can include sleepwalking, sleep terrors and nightmares, acting out physically while dreaming, waking up confused, and even overeating while asleep. Medical conditions, including frequent nighttime trips to the bathroom (common with bladder problems in MS), also interfere with one's quality of sleep and should be addressed. Grinding of teeth and/or snoring can have health implications and are disruptive to a partner's sleep. Any underlying medical conditions which may affect sleep need to be investigated, diagnosed, and treated.

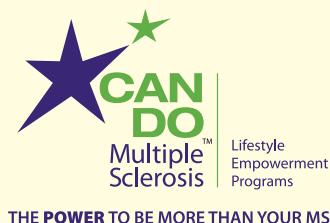
Some individuals need medication to help them get the sleep they need. Many sleep aids are available, but these have side effects, and most require a prescription. Individuals should always consult their physician about what medication might be the most appropriate for them.

To encourage a good sleep regimen, experts recommend practicing a healthy

The Heuga Center for Multiple Sclerosis changes name to Can Do Multiple Sclerosis

Can Do Multiple Sclerosis (formerly known as **The Heuga Center for Multiple Sclerosis**) is a national nonprofit organization based in Edwards, Colorado and focuses on empowering people with MS and their support partners to transform and improve their quality of life. According to Can Do MS CEO Kim Sharkey, "Our new name and brand reflect our growing role as a unique educator that uses health, wellness and lifestyle principles to empower people with the knowledge, skills, tools and confidence to realize their power to create well-being and transform their lives."

For more information on Can Do Multiple Sclerosis, please visit www.mscondo.org or call (800) 367-3101.



lifestyle, which includes daily exercise, a healthy diet, limiting one's alcohol and caffeine intake, and not smoking. Staying on a good sleep and waking schedule is important, as is preparing for sleep. For the latter, time should be allowed to finish household chores or take care of any loose ends before going to bed. Writing down any concerns is a good way to put them aside until the next morning. And taking time to unwind and relax – by drinking herbal tea, taking a warm bath (if not heat sensitive), or reading a book, can assist with falling asleep more naturally. Some individuals may find relaxation techniques, such as guided imagery, meditation, or biofeedback, to be of great help. ♦

Resources: WebMD at www.webmd.com and *The Harvard Medical School Guide to: A Good Night's Sleep*, written by Lawrence J. Epstein, MD, (McGraw Hill, 2007).

This book is highlighted in “Spread the Word” on page 48 of this issue, and may be borrowed at no charge from MSAAs Lending Library. Other books dealing with sleep disorders are also available from the Lending Library.

PLEASE NOTE: MSAA does not endorse or recommend any specific drug or treatment. Readers are strongly urged to consult a medical professional before making any changes to their medications, diet, or activities.

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Flu Vaccines

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

Two flu vaccines, the seasonal flu and the H1N1 (“swine flu”) vaccines, are available for the 2009/2010 flu season. The seasonal flu vaccine protects individuals from three common types of flu. The H1N1 flu vaccine protects individuals from this fourth and newest type of flu, which was first detected in people living in the United States in April 2009.

Each of the flu vaccines are available in two forms: injected and intranasal. The injected type of flu vaccine uses the inactivated (or killed) viruses and is considered safe for individuals with MS. The intranasal vaccine, given by nose with a mist, contains live viruses and is not recommended for individuals with MS.

The new H1N1 vaccine is manufactured using the same processes as the seasonal flu vaccine. In previous studies, seasonal flu vaccines (with inactivated viruses given via injection) have been shown to be safe for individuals with MS. These vaccines did not cause one’s MS to worsen, nor did they cause an increase in exacerbations (symptom flare-ups). People cannot develop the flu from the injected vaccines, since these contain non-infectious particles.

In studies, the most commonly reported side effects of the vaccine are injection-site tenderness and pain, muscle aches, and systemic symptoms such as headache. Protection from the flu is likely to be established within two weeks.

As a group with a chronic health condition, individuals with MS qualify to get priority for receiving a flu shot. Other individuals who get priority include: pregnant women; household contacts or caregivers for infants younger than 6 months; medical services personnel; children and young adults 6 months to 24 years of age; and persons aged 25 to 64 years who are at greater risk of influenza-related complications because of underlying medical conditions.

Although initial supplies may be limited, shortages for the season are not expected. Both vaccines are given in one dose each (via individual injections), and may be given at the same time, provided the injections are made at different locations on the body. People who have an allergy to eggs or other ingredients in the vaccines, or who have had a reaction to a vaccine in the past, should not get the flu vaccines. The two intranasal vaccines, which use live viruses, may not be given at the same time – and again, these are not recommended for individuals with MS.

Most flu vaccines contain the preservative, thimerosal, which contains ethylmercury. Despite concerns, according to the Centers for Disease Control and Prevention (CDC), no evidence of harm has been confirmed when using this preservative in small amounts. For more information, readers may visit www.cdc.gov/FLU/ABOUT/QA/thimerosal.htm or call the CDC at (800) 232-4636.

Flu Vaccinations for Individuals with MS

MSAA's Chief Medical Officer Jack Burks, MD, recommends the injected flu vaccines for almost all of his patients with MS. He stresses that individuals with MS should first consult their physician about whether or not to get the vaccinations.

Dr. Burks explains, "The decision is up to one's doctor regarding flu vaccinations. Except in instances where the vaccines may aggravate another condition, I view flu shots as a high priority for my patients with MS. According to the American Academy of Neurology (AAN), earlier flu vaccines have not been found to increase the risk of an MS attack. These earlier flu vaccines were manufactured using the same process as the newest vaccines given today, including the H1N1 "swine flu" vaccine. The flu vaccines are the best defense against catching the flu, which poses a much greater threat to a person's health when he or she has MS.

"The reason why the flu is more difficult and potentially damaging to individuals with MS is three-fold. First, if individuals with MS get the flu, they must endure the associated aches and pains in addition to their normal MS symptoms. Second, high fever accompanies the flu, and an elevated temperature may increase MS symptoms, affecting one's overall wellbeing. And third, the body responds to the flu with an outpouring of gamma interferon, a chemical that increases the risk of an MS exacerbation. For this reason, individuals with MS who catch the flu have a greater chance of experiencing an MS attack within several weeks following their influenza (flu) illness."

Dr. Burks concludes, "While the benefits of flu vaccines are clear, individuals with MS should still consult with their physician before getting vaccinated. For those who are vaccinated, they may experience a mild temperature and a slight increase in MS symptoms for a day or two following the injection. Anyone experiencing more severe or longer-lasting side effects from the flu vaccines should contact their doctor."

The 2009 H1N1 Influenza Virus

This particular flu virus was first seen in individuals in the United States in April 2009. It was originally referred to as "swine flu," because in the laboratory under a microscope, the genes in this virus appeared similar in form to flu viruses sometimes found in pigs of North America. Later observation found that these viruses were actually from those found in pigs in Europe and Asia, as well as in birds and humans. The term "swine flu" has since been replaced by the virus name of H1N1.

The H1N1 virus is believed to be spread mainly through coughing, sneezing, or speaking when close to others, similar to other types of flu viruses. The flu virus may become airborne and tiny droplets of flu particles may be inhaled by another person nearby, and the virus then grows in the upper and lower respiratory tracts. In addition to being close to someone with the flu, touching a surface (such as a door knob, shopping-cart handle, or counter, etc.), which has droplets of the virus from an infected person who may have coughed or sneezed nearby, and then

touching one's own nose, eyes, or mouth, is a common way to catch the virus.

To reduce the risk of catching the flu, the Centers for Disease Control and Prevention (CDC) advise that people wash their hands often and use an alcohol-based hand rub when soap and water are not available. People should avoid touching their nose, eyes, or mouth when out, and to avoid close contact with others who are sick.

The seasonal and H1N1 flu viruses may be spread beginning the day before someone gets symptoms, and then for five to seven days afterward. Studies show that the virus may remain present for up to 12 days in a small percentage of individuals, but it is not yet known if the virus is still contagious at that point. The CDC also recommends that anyone who has been sick, should stay away from others and remain home for at least 24 hours after the fever is gone (specifically, the fever must be gone for 24 hours without the use of fever-reducing medicine). If someone is sick and must go out, Dr. Burks strongly advises that he or she wears a face mask (covering the nose and mouth) to avoid spreading the virus to others.

Please note that the H1N1 virus is not spread through eating pork or any other food. It is unlikely that the virus may be transmitted through drinking water, as influenza viruses are normally inactivated through water treatment in tap water. These flu viruses are also not transmitted through swimming pools, hot tubs, and other water used recreationally, as the disinfectant levels inactivate flu viruses.

The symptoms of the H1N1 flu are similar

to those of other flu strains. These symptoms include:

- fever
- cough
- sore throat
- body/muscle aches
- headache
- chills
- tiredness/fatigue
- feeling badly all over
- in some cases, vomiting and diarrhea

With the H1N1 flu, some patients have experienced respiratory symptoms without a fever. Additionally, this virus may cause severe illness (such as pneumonia and respiratory failure) in some individuals, and some patients with the H1N1 virus have died. So far, most of the patients with H1N1 flu have experienced only mild symptoms.

The symptoms of the H1N1 flu can range from mild to severe, but individuals younger than 25 years of age appear to be at risk of the most serious disease burden. In general, those who are of greatest risk of complications from the flu are older people (over the age of 65), children under 5 years of age, pregnant women, and individuals with chronic conditions.

Anti-viral medications are available by prescription to treat the H1N1 flu. These include oseltamivir and zanamivir. If an individual develops an infection from the flu, he or she may also be prescribed an antibiotic. One's healthcare professional may advise using over-the-counter pain relievers or cold medicines, but individuals should always check with their doctor and read labels care-

fully before using these types of products.

When someone has the flu, the CDC lists the following warning signs that need urgent medical attention.

In children:

- Fast breathing or trouble breathing
- Bluish or gray skin color
- Not drinking enough fluids
- Severe or persistent vomiting
- Not waking up or not interacting
- Being so irritable that the child does not want to be held
- Flu-like symptoms improve but then return with fever and worse cough

In adults:

- Difficulty breathing or shortness of breath
- Pain or pressure in the chest or abdomen

- Sudden dizziness
- Confusion
- Severe or persistent vomiting
- Flu-like symptoms improve but then return with fever and worse cough

For More Information

For more information about the flu and flu vaccines, please visit www.cdc.gov/flu or www.flu.gov. The CDC also has a hotline at (800) CDC-INFO, or (800) 232-4636. To find local clinics, stores, or other facilities which are offering flu shots, please visit www.findaflushot.com. To speak with one of MSAAs Helpline consultants, please call (800) 532-7667. (Please note that this article also appears on MSAAs website at www.msassociation.org under “Recent News.”) ♦

THE PHILANTHROPY CIRCLE

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

CHAMPIONS (\$100,000 and up)

Acorda Therapeutics
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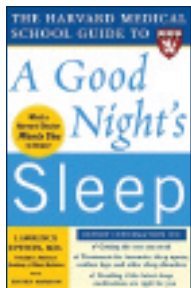
Written by Nancy Davis

Published by Fireside

MSAA Book #237



Author Nancy Davis was diagnosed with MS at the age of 33. From that time forward, she decided to take control through education, a healthy lifestyle, a positive outlook, and becoming her own health advocate. In her book, she tells her personal story and offers a step-by-step guide to empower others. Nancy is the founder of the Center Without Walls, a national medical research foundation, and to date, has assisted with raising \$22 million over 13 years for MS research.



The Harvard Medical School Guide to A Good Night's Sleep

Written by Lawrence J. Epstein,

MD with Steven Mardon

Published by McGraw-Hill

MSAA Book # 22

This valuable resource is one of a series of different books published under the Harvard Medical School name. It explains the importance of sleep, what happens to the mind and body during sleep, why problems may occur, and provides a six-step plan for getting a good night's sleep. Later chapters discuss sleep disorders such as breathing problems, restless legs, sleepwalking, and other challenging sleep situations.

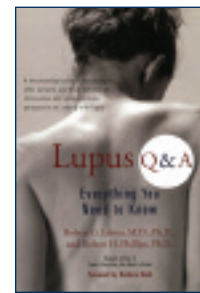
Lupus Q & A, Everything You Need to Know

Written by Robert G. Lahita, MD,

PhD and Robert H. Phillips, PhD

Published by Avery Trade

MSAA Book # 61



Written in an easy-to-read, question-and-answer format, this book touches on most every aspect of lupus. Topics range from diagnosis and treatments, to descriptions of medications and an explanation of how lupus can impact one's life. The authors of this book are a rheumatologist and a psychologist.

MSAA Lending Library

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

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