

### MOTIVATOR 1

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MSAA

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

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

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# Up Front



Douglas G. Franklin

he recent months have been busy at MSAA, starting with an excellent fundraising event with Riley Cote, professional hockey player for the

Philadelphia Flyers. Riley shares a special connection with the multiple sclerosis community – his sister Jaime has MS. With a genuine desire to help and raise awareness for those with MS, Riley and his wife Holly hosted the First Annual Cote Carnival this past August at Swanky Bubbles, a Philadelphia-area restaurant. This event received overwhelming support from both the local community and the Flyers' family. Countless items were donated for raffles and auctions and more than 300 people attended, generating \$18,000 for MSAA's programs and services. Fundraisers like this one are important in helping to support MSAA's mission.

The end of September saw our Board meetings coincide with a President's Circle reception honoring donors at the National Constitution Center in Philadelphia. More than 60 people were in attendance to receive recognition for their financial support of MSAA. Numerous local volunteers were also honored at this event for their time and dedication spent helping MSAA to fulfill its mission. This Board meeting was the last for Paul Favorite, who completed his final term as a member (nine years total). Paul has been a

wonderful source of support for MSAA over the years and his strong focus on supporting programs and services was wonderful to see. He will be missed.

After considerable revisions and a new design, our MSAA programs and services booklet, *Solutions for Wellness* is now available for distribution. Readers may discover all MSAA does to help improve the quality of life for everyone affected by multiple sclerosis. In other public education news, MSAA received two APEX Awards (one for *The Motivator* and one for our web video series *A Closer Look*) as well as three National Health Information Awards for *The Motivator*. All of MSAA's publications and educational videos can be found on our website at www.msassociation.org.

Good news continues from the MS
Coalition (MSC) as we received word from
the Public Policy Office of the National
Multiple Sclerosis Society (NMSS) that the
area of research for multiple sclerosis has been
awarded \$5 million within the Congressionally
Directed Medical Research Programs (CDMRP).
This highlights the power of advocacy and
the influence of a collaborative grass roots
campaign. MSAA will again represent the
MSC at the Federal Activism Council
meetings in November.

Finally as we enter into the year's end, we thank everyone who has helped in so many ways to make MSAA what it is today. It is truly a team effort, and the many partnerships we enjoy are just a blessing in every sense of the word. Thank you so much!

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.

### Meet MSAA Board Member William Saunders

William "Bill" Saunders is not new to MSAA, but he is the most recent member on our Board of Directors, starting his term this past June. He has served for two years as a member of MSAA's Corporate Advisory Council (CAC).

"When I first came aboard as a member of the CAC," Bill explains, "I sat with some of the Helpline staff and was able to learn about programs such as Cooling and the MRI Institute. I was truly amazed by the staff and the fact that everything MSAA

offers is free. I also attended the Northeast Region's public education event in New York City," continues Bill. "I sat with a couple who were there for their daughter, who has MS and could not make the program. They told me it was the best seminar they have ever attended."

"I want to help MSAA reach out to new foundations and new corporations to let them know about all of the good work that MSAA provides," says Bill. "A great deal of promise is on the horizon. We have many

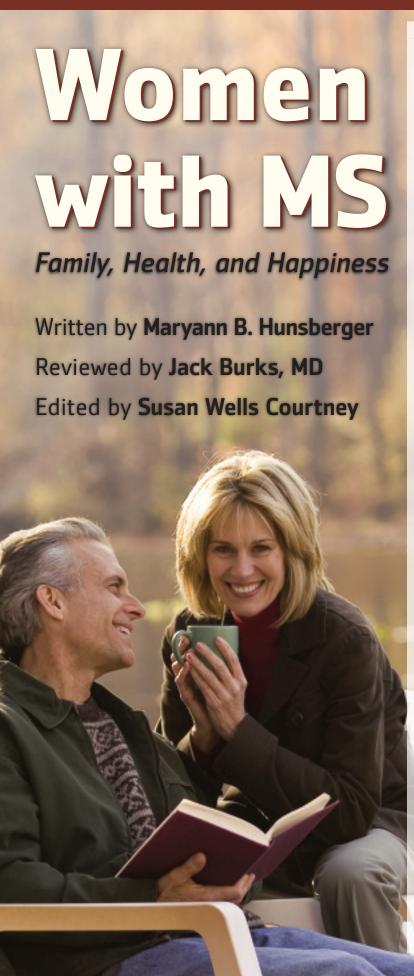


Bill Saunders (middle) receives an award from MSAA Board Chair Eric Simons (left) and MSAA former Board Chair and current National Chairman of MSAA's President's Circle Ross Maclean.

avenues to explore and hopefully I can help."

An avid outdoorsman, Bill has a passion for fly-fishing and backpacking, one he shares with his wife Sally and two sons. Bill resides in Bryn Mawr, Pennsylvania where he works in the financial sector. In addition to his continued work on the CAC, Bill is a very active Board member who also serves on the Audit Committee.

— Amanda Bednar



Trost experienced her first MS symptom, she and her husband Bob Trost had built their dream house. With six-year-old triplets, the family needed the space a new home could offer (please see page 18 for family photo). Her job as a microbiologist gave Gomez-Trost the financial security to feel that the time was right for a move. Later that year (in 2004), Gomez-Trost couldn't move her right leg or lift her right foot. "I thought I pinched a nerve," she says.

When Gomez-Trost's neurologist told her she had multiple sclerosis, she immediately thought about her family and career. Would she be able to keep the house clean, provide clean clothes, prepare hot meals, and help the children with their homework? And how might this affect her ability to continue a full-time job?

"I worried about how I'd keep up with everything," says Gomez-Trost. "For parents with MS, we have the added responsibilities of raising the children, cleaning the house, and helping with the homework."

According to Connie Easterling, a nurse practitioner who serves as clinical coordinator of the MS Care Center, Neurological Services of Orlando, MS can affect women differently. "MS is two-to-three times more common in women. Some experts believe the ratio may be as high as four-to-one. The emotional impact of dealing with the diagnosis can be overwhelming for some women. They may take the whole rhythm of the family,

along with keeping the family balance in place, more personally. When MS is diagnosed, there may be guilt due to the possible impact on the family."

MS affects women differently in other ways as well. Not only are women's nervous and immune systems different from men's, but women have reproductive issues to consider. Side effects from drugs may also vary between the genders, as a result of these differences.

Similar to Gomez-Trost, women diagnosed with MS have many questions about how their disability will affect them throughout their life. They want to know how they will manage as women and in the different roles they fill, such as girlfriends, employees, wives, and mothers.

### Good News about Pregnancy and Raising Children

Not long ago, many physicians discouraged women with MS from becoming parents. Cheryl Faber, MD, a St. Louis, Missouri-based neurologist who treats women with MS, explains, "Physicians feared that MS would flare up following pregnancy, preventing women from parenting. They also thought that progressive disability would cause difficulty in raising a family. Doctors thought avoiding pregnancy would be an answer.

"We now have better treatment options for women with MS. Newly diagnosed patients using appropriate treatments can often go on to live a full life without disability, if their disease course isn't very aggressive. With the improved outcomes that we now have for MS, most patients can live decades without incurring a lot of disability. Most people find that giving up parenthood isn't a tradeoff, since women with MS can raise children."

Easterling explains that MS does not impair fertility or lead to miscarriage. "Pregnancy has a positive effect on MS. It's a natural immunosuppressant. Higher levels of natural corticosteroids and estrogen are present during pregnancy, so relapses decrease by about 70 percent during the second and third trimesters."

After childbirth, however, problems can develop, since exacerbations increase 40 percent in the first six months after delivery. Despite this risk, studies show that this does not impact one's long-term prognosis. "As hormonal levels normalize, women are at greater risk for exacerbation. Therefore, good postpartum care with both a gynecologist and a neurologist is important. Neurologists often recommend that women go back on disease-modifying treatment to prevent exacerbations. Since women should not breastfeed while taking these medications, they must make personal choices in deciding what is best for them."

Faber explains that raising children could benefit women with MS. "For people who do want a child, I tell them not to let this disease rob them. Most people find that having children is an integral part of life, so they are willing to do the extra work to raise children and keep their family together. Being a mom is tough even for able-bodied women, so it becomes harder with a disability. Yet, the rewards are there. It's an obvious

added stress, but a blessing in many ways."

Women who use wheelchairs due to MS can parent with some added challenges, asserts Faber. "Mothers in wheelchairs are still moms who can do mom stuff. They just have some added work involved. I have a friend who uses a wheelchair and is adopting. She is cutting back on her work hours to focus more on being a mom. None of us can do everything all the time. Being disabled makes things more difficult, but it is doable."

Easterling stresses that women with MS should have adequate levels of support in the home when a baby arrives. New mothers might ask family, friends, or church members to assist. Some might hire part-time help. When a woman develops MS after having children, some might use part-time daycare services. Other women, such as



Gomez-Trost, have extended family members who can help with childcare.

Either way, Faber continues, "Most patients who choose to have children are proud and satisfied that they decided to have families. MS shouldn't stop women from having a full life."

### Improved Quality of Life

MSAA's Chief Medical Officer Jack Burks, MD, explains that MS can create enormous challenges for women. MS is typically diagnosed in the "prime" of life, when young people are preparing for their futures in terms of education, career, and family. This can be a very emotional time for a woman, and so much depends on her physical and mental health, as well as social and professional activities.

"The number-one advancement to help women with MS has been the development of disease-modifying therapies within the past 15 years," states Dr. Burks. "These medications are improving quality of life tremendously, and the future looks brighter than ever before for individuals with MS. More people are now able to continue working while raising families, and this just was not possible for many individuals 15 years ago, when these long-term treatments were not yet available."

The management of symptoms and side effects has also been greatly improved in recent years. "This is not limited to taking medications," explains Dr. Burks. "For example, individuals with MS fight fatigue by learning ways to avoid becoming overheated, along with strategies for conserving

energy. Healthcare professionals now know the value of exercise and rehabilitation for optimal range of motion and strength, improving activities of daily living, as well as cardiovascular and other benefits. Certain alternative and complementary therapies (such as tai chi, yoga, guided imagery, self-hypnosis, biofeedback, and massage) are yet another avenue of treatment that many MS patients are finding useful in helping to manage their symptoms and improve their outlook."

In summary, the advancements in the medical treatment of MS and its symptoms have changed the future for individuals with MS. Women today may look forward to a far better long-term prognosis. This means that while many challenges may still exist, their dreams and goals in terms of education, career, and family, are no longer beyond reach for many women with MS.

Enjoying optimal health, and continuing with daily activities, requires more than just treating a woman's MS. She also needs to keep up with regularly scheduled health examinations and testing, along with eating right, exercising, and getting a good night's rest. In the sections to follow, these vital health-related issues are explained – along with helpful strategies for staying well.

### **General Healthcare** for Women with MS

As with all women, those with MS need to maintain their health. Women can take an active part in this by keeping up with routine blood tests for blood sugar, thyroid, and cholesterol, as well as screenings for

high blood pressure.

Easterling points out that individuals with MS have the same rate of high blood pressure, diabetes, and high cholesterol as anyone else, so checkups are important. "Women with MS must address and treat these conditions the same way a person without MS addresses and treats them."

While these tests and exams are just as significant for men, some tests and exams are specific to women. Easterling stresses that the following tests are important for women with MS:

- Clinical breast exam: Annually
- Self-breast exam: Monthly
- Pap Smear: Start at age 21 (earlier if sexually active), and then every one to three years if sexually active.
- HPV Vaccine: Adolescent girls (approved by the FDA in 2006, the Centers for Disease Control and Prevention [CDC] recommends that adolescent girls [ages 11 and 12] be routinely vaccinated; girls and young women [ages 13 to 26] may receive "catch-up" vaccinations. Interested individuals and/or their guardians should consult their physician for more information.)
- Bone Density Scan: Start before age 60 if at risk; risk factors include steroid use, family history, lack of exercise, alcohol use, thin body, and smoking.
- Mammogram: Every one to two years, starting at age 40; annually after age 50.

Since the Americans with Disabilities Act (ADA) requires accessible construction on only new buildings, older medical offices



are often inaccessible. Most women with mobility impairments are familiar with the difficulties of getting healthcare. Many women are not able to climb steps, push their wheelchair up ramps with broken slats, or fit through too-narrow doorways.

Inaccessible exam tables often present an obstacle. Despite the availability of hydraulic exam tables that lower and rise, most physicians do not purchase these tables. If a medical practice is not comfortable helping a patient onto the table, a woman may go home without receiving treatment.

"In gynecology offices, women with physical disabilities often can't get into the office or are turned away. The practices frequently aren't open to seeing women with lower extremity spasticity or weakness, since the office may not have enough support to help with the examination. They don't want to be responsible for transferring the patient onto a table," explains Easterling. She recommends contacting a local MS support group to find names of physicians who are open to helping patients. Some women call doctors' offices in advance to alert the staff of their need for assistance. Others choose to bring a friend or relative to help them with these barriers.

Chronic health conditions can be confusing to manage. Marie Savard, MD, an internist and author of *How to Save Your Own Life*, suggests writing questions before a doctor visit and maintaining a health journal to track symptoms, weight changes, complaints, and medication side effects.

A journal can also include the names and phone numbers of all doctors, dates of doctor visits, and information about allergies, current medications, and surgeries. *Health* magazine's October 2008 issue reports that the average patient has 22 seconds to speak before her doctor interrupts her. Therefore, assuring that patient and doctor have discussed all questions before leaving is important.

Easterling tells new patients to learn as much as possible about MS. She advises them to take advantage of counseling to cope with changes in their lives. She also recommends that women do the following to maintain general good health:

- Exercise regularly
- Eat a well-balanced diet
- Drink fluids
- Maintain a healthy weight
- Consume adequate calcium and vitamin D

- Folic acid daily for women of child-bearing age
- Limit alcohol consumption
- Don't smoke
- Use complementary and alternative treatments cautiously
- Use protection against sexually transmitted diseases

### Medical Issues for Women with MS

According to P.K. Coyle, MD, females differ neurologically from males, in areas such as spatial and language skills. They also differ regarding autoimmune response, since more females have autoimmune disorders, including myasthenia gravis and systemic lupus erythematosus (commonly referred to as "lupus"), and others.

MS is also more dominant in females. Sex hormones are partly responsible for this gender preference, since these hormones affect both the autoimmune and nervous systems in various ways. These hormones, which fluctuate constantly in females, can also affect cognitive function and coordinated movements.

Medications used to treat MS can bring unique concerns regarding women's reproductive health, and some should not be used if planning a family. Therefore, women with MS are in the unenviable position of having to decide whether to discontinue disease-modifying medications while pregnant or trying to become pregnant, or to give up breastfeeding to receive treatment, for example.

Other medications include tricyclic antidepressants. Used to treat pain and depression, these types of drugs can excrete into breast milk. Certain pharmaceuticals for fatigue, such as Symmetrel® (amantadine), also excrete into breast milk. Women with MS should speak with their doctor about their present medications, and before taking any new medication, to find out about possible side effects – including any risks while pregnant or breastfeeding, along with any drug interactions.

Glucocorticoids, such as methylprednisolone, speed up recovery from MS exacerbations, yet can cause loss of bone density. This is an important issue and physicians need to monitor and potentially treat patients for this risk of thinning bones. High-dose interferon-beta therapy can affect menstruation by causing spotting, clotting, or delayed menses. It may also have the potential to cause a miscarriage.

According to Easterling, 50 percent of women with MS report that symptoms worsen the week of and before menstruation. These symptoms can include increased fatigue, poor endurance, depression, bladder dysfunction, spasticity, dyscoordination, weakness, and visual changes. One option for symptom management is oral contraceptives. This, again, requires a balancing act for women taking medications that might interfere with oral contraceptive use.

A variety of medications, including a simple antibiotic, may potentially decrease the effectiveness of oral contraceptives. With this in mind, women with MS should consult their gynecologist and neurologist on any potential drug interactions. Having these two medical specialists working closely with a patient's treatment is important.

Faber explains that the FDA divides MS medications into three categories: B, C, and X, based on their level of danger to pregnant women and fetuses. While some medications cause fewer complications, some are highly toxic.

In general, for pregnancy category B: animal reproduction studies have failed to demonstrate a risk to the fetus and there are no adequate and well-controlled studies in pregnant women; or, animal reproduction studies have shown an adverse effect (other than decrease in fertility), but adequate and well-controlled studies in pregnant women have failed to demonstrate a risk to the fetus during the first trimester of pregnancy (and there is no evidence of a risk in later trimesters). Copaxone® (glatiramer acetate) is in this category.

In general, for pregnancy category C: animal reproduction studies have shown an adverse effect on the fetus, there are no adequate and well-controlled studies in humans, and the benefits from the use of the drug in pregnant women must be weighed against its potential risks; or, there are no animal reproduction studies and no adequate and well-controlled studies in humans. The interferons (Betaseron®, Avonex®, and Rebif®) as well as Tysabri® (natalizumab), are in this category.

In general, for pregnancy category X: studies in animals or humans have demonstrated fetal abnormalities; or, there is positive evidence of fetal risk based on adverse reaction reports from investigational or marketing experience; or both. Novantrone® (mitoxantrone) is in this category. Women

of child-bearing years should discuss the risks and benefits of Novantrone with their physician, giving specific attention to the effects on fertility and pregnancy.

Please note that detailed and specific package labeling on medications must follow the exact wording for each category.

"Doctors typically advise women to avoid taking any of these medications while pregnant or breastfeeding, to reduce risk," says Marijean Buhse, PhD, a nurse practitioner at the MS Center at North Shore University Hospital and a professor of nursing at Stony Brook University.

### **Depression**

About 70 percent of women with MS experience depression. Buhse says depression could come from lesions on the brain, from medication side effects, or from the challenges of living with a disability. Physicians treat this symptom with antidepressants and counseling, but Buhse also recommends exercise to alleviate depression. The type of exercise depends on the individual's limitations.

Buhse explains, "Exercise increases endorphins in the brain and decreases how quickly disability progresses. Literature shows that a person who steadily exercises may help to slow her rate of disability. Some people might take a walk or use a treadmill. Others might like to take a bike ride or use a stationary bike."

Noting that counseling, medication, and exercise work more effectively together, Easterling also recommends the following ways of reducing depression:

- Stay involved
- Be realistic about what you can and cannot do
- Maintain strong bonds with family and friends
- Think positively about your health
- Set goals
- Talk about your feelings
- Take part in fun activities and relaxation
- Maintain a sense of hope

MSAA offers a free informational booklet titled *Understanding and Treating Depression in Multiple Sclerosis*. Copies may be viewed or downloaded by going to www.msassociation.org/publications/depression. Copies may also be ordered by calling MSAA's Helpline at (800) 532-7667.

### **Cognitive Changes**

According to Rosalind C. Kalb, PhD, a psychologist and author of *Multiple Sclerosis: A Guide for Families*, about 50 percent of women with MS have cognitive changes caused by damage to nerve fibers in the brain and spinal cord. Buhse points out fatigue can also affect cognition. "If you're too tired, you can't think." Cognitive changes can affect the following functions:

- Memory: Short-term memory is most affected, which requires one to spend more time learning new information. Memory loss can lead to problems at home or at work.
- Attention and concentration: Focusing on details and multi-tasking may be difficult at times, since these require uninterrupted attention.



- Word-finding: This deficit can disrupt conversation as the person speaking has difficulty recalling the right words, which can also lead to frustration.
- Slowed information processing: A slowing of thought processes and response time can cause difficulty when quick processing skills are necessary.
- Reasoning, problem solving, judgement: When one has trouble making the correct decisions, this can affect performance at work and create issues at home.
- Visual-spatial abilities: Among other things, this can affect safe driving because it may cause someone to forget which pedal to step on or which way to turn.
- Executive functioning: Planning, prioritizing, and scheduling become difficult.

Current treatment for cognitive changes includes cognitive rehabilitation and medications, such as disease-modifying therapies, which may possibly help with cognition. Drugs to treat Alzheimer's disease are sometimes used, but so far, study results with these drugs and MS have been mixed.

### Social Issues

MS can also cause difficulties socially. According to Coyle, women with MS are more likely to have a poor quality of life from being socially isolated, since they are less likely to be involved in homemaking, educational, or vocational activities.

Peggy Walsh, a psychotherapist in private practice in Pennsylvania, believes women with MS must work at creating social opportunities. "When

people become socially isolated, they can become depressed. They need to protect themselves by building up a social structure and staying in contact with other people in the social world."

When a woman feels well enough, she should set up a lunch date or take a yoga class. "Even getting out to physical therapy keeps women in touch with other people and gets them out of the house. Participate in MS support groups and workshops, or take part

in religious activities. Without social structure, it's too easy to become isolated. People with MS have to be proactive to pull themselves into the world again," says Walsh.

### **Regaining Self-Esteem**

As women with MS develop neurological

deficits, gain or lose weight, or require the use of orthopedic aids, their self-esteem might suffer.

"Patients with MS might walk differently, use a cane, or eventually use a wheelchair. Some become ataxic, which means they have a wide-based walk and appear drunk. This affects how women feel about themselves and how people look at them," notes Buhse.

Women with MS sometimes find it too difficult to apply makeup, fix their hair, or shower. Buhse points out that this

can have tremendous impact. "MS strikes when women are young and typically energetic. Yet it is common for women with MS, even at a young age, to become exhausted. While they want to take care of themselves in terms of appearance, a woman may sometimes be too tired to do this."

Walsh feels that this inability to care for one's appearance can affect women more profoundly than men. "People judge women's looks more harshly, so women deal



with this more than men. Women tend to be caretakers, so it's hard to ask others to help by dyeing or blow-drying their hair. Women should ask their partners and friends how they see them to build their self-esteem."

According to Buhse, women with MS should talk with their healthcare provider about these issues. "Body image doesn't often come up in medical conversation. But symptoms relating to body image – such as weight gain – can come up. If a woman gains weight, we talk about what she is eating and ask her to make a food diary. We look at medications and perhaps change them. Some antidepressants cause weight gain, so maybe we can change them."

Buhse explains that medical treatment can also help with debilitating exhaustion. "After ruling out depression, we look at how to help the fatigue. Sometimes, we use physical therapy. We can use amantadine, an antiviral that works in 30 to 40 percent of MS patients. We sometimes use Ritalin because it stimulates people with fatigue."

Ritalin® (methylphenidate), however, can be addictive, so physicians prescribing this medication are careful to keep a close watch on patients taking this drug. Another useful treatment for fatigue is Provigil® (modafanil). Women with MS need to discuss the potential side effects and benefits of these drugs with their doctors, to determine their most appropriate treatment options.

### **Dating**

Even if a woman with MS feels well enough to take care of her physical appearance, other social issues might occur. Easterling says her patients may feel that they can't date because they have MS. "Many women with MS don't know how to meet someone who will accept them. I tell them to go through old friends to find people to date. If doing internet dating, I advise using caution and bringing a friend along on a first date."

Before a date, stress-reduction activities such as taking a relaxing bath can help alleviate anxiety. Heat-sensitive individuals may want to use tepid water. Easterling says using strategy in taking medication is important when dating. "A woman with spasticity problems should schedule medications so that they will be most effective on the date."

When planning a date, women should engage in activities that build confidence and self-esteem. "If you have imbalance issues, don't go bowling on the first date."

Easterling says many women may fear telling their dates that they have MS. "They don't need to disclose anything right away, especially on a first date. Women should discuss MS only when they are comfortable, but remember that if a relationship is worth pursuing, it's worth telling."

### Marriage and Sexual Issues

Approximately 75 percent of MS patients are married. Easterling cites studies showing that marriage is associated with better health for people with disabilities.

However, according to the Center for Research on Women with Disabilities, studies reveal that women with disabilities marry at a lower rate than women without disabilities. Women who develop a disability after

marriage are also more likely to divorce than men with disabilities.

Sadly, the rate of abuse among women with disabilities is higher than in women without disabilities, although exact numbers vary. This abuse can occur in marriages for reasons that include increased vulnerability, social isolation, and immobility. Shelters for abused women are generally not accessible to women in wheelchairs and cannot offer personal assistance services, causing some women to remain in abusive marriages. Anyone in an abusive relationship should see a professional for assistance. If a woman's safety or wellbeing is at risk, she should immediately call for emergency help.

Despite these statistics, many women with MS enjoy happy marriages. Individuals in a relationship, especially where a disability is involved, should work to promote open communication and mutual understanding.

The physical side of a relationship is important as well, and sexual dysfunction can occur for many individuals – with or without MS – for a variety of reasons. The majority of women with MS have primary sexual dysfunction, so sexuality can be a big issue for these women and their partners.

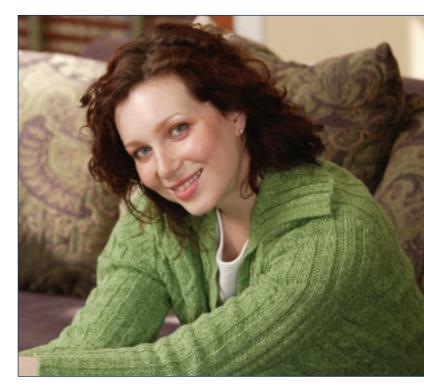
In MS, primary sexual dysfunction refers to changes in sexual response caused directly by neurologic impairments. Women with MS who are experiencing primary sexual dysfunction can experience one or more of the following symptoms: decreased or absent libido; altered genital sensations; decreased vaginal lubrication; and decreased frequency of orgasm.

In MS, secondary sexual dysfunction

refers to changes in sexual response caused indirectly by certain symptoms or complications of MS, such as: bladder or bowel dysfunction; fatigue; spasticity; pain; depression; and anxiety.

Walsh points out that decreased libido can also occur from the low self-esteem that living with MS can cause. A doctor can determine the reason for sexual dysfunction and the way to treat it. "Women need to talk to care providers about sex, as their quality of life can be better when sexuality is a normal outcome of a healthy life. I also encourage women to address this with their partners and find ways to make sexuality a part of their lives again to feel like vital sexual beings."

Easterling agrees on the importance of women developing good communication skills about sexual issues. "Silence can be misunderstood. Nobody should assume that she knows what her sexual partner is think-



# Appreciating Life Much More

When a neurologist diagnosed Debbie Gomez-Trost with MS in 2004, she and her husband were living in a new home with their seven-year-old triplets. Gomez-Trost had a career as a microbiologist, spending her days working in a lab. One year later, she decided to leave her job under the advice of her physician.

The 43-year-old mother of three 11-y has now adapted to having a disability by making changes in her life. One difference was learning that her house didn't need to be perfect. She also found that she had to make time for her own needs.

Gomez-Trost explains, "I have to cope with school, Scouts, basketball, and homework for three kids while my husband works shift work. Taking time to unwind helps. Last night, I went fishing for an hour and it was great. Relaxing is important for survival, and this sometimes means using babysitters or asking family members to help, so we can have time for ourselves."

Gomez-Trost feels empowerment is the most important step in living with MS. "Empowerment happened in stages. As the disease progressed, I realized I had to make the best out of life, since a positive attitude is best for anyone. To keep active for my children, I began using mobility aids and continued taking my prescription



Debbie Gomez-Trost and husband Bob with their 11-year old triplets, Mackenzie, Cole, and Jacob.

medications. This way, I am not so tired. You must be proactive against MS.

"Having triplets as well as MS means looking at my week, figuring out which days I need to be active, and resting on the other days. I tell others to give their kids all the love they can. Talk things out with them. Let them know what's going on, if they are old enough to understand."

The stay-at-home mom feels that having MS has brought her family closer. She believes her children are better people because of this experience. "From having a mother with a disability, they are more compassionate, loving, and tolerant people. They are the first to hold a door for another person or to pick up whatever someone drops. Some days, they thank me just for all I do despite my disability. This really helps me to appreciate life so much more."

- Maryann B. Hunsberger

ing. Women have to discuss their concerns and their needs as a sexual human being."

She stresses that women should prepare for intimacy. "With MS, intimate moments should be planned, if possible. Soak in a cool or tepid bath first to reduce symptoms. Use the bathroom in advance, and time bladder dysfunction medications carefully to avoid having an accident during intimacy. Do stretching exercises to reduce spasticity during sex. Don't always think about being

intimate in the evening when it's natural to be tired. Mornings may be better."

### **As Women** become Older

As women with MS age, they face issues of menopause, just like all women. MS symptoms may slightly worsen while going through menopause.

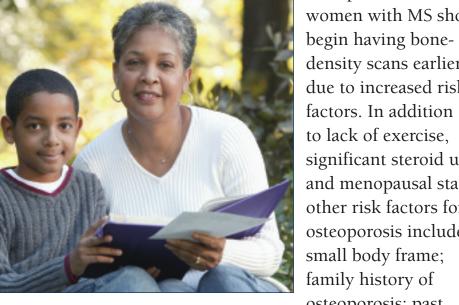
Although hormone-replacement therapy (HRT) helps manage symptoms, 80 percent of menopausal women choose against HRT because of the risks of cancer and stroke. Some women with MS use antidepressant therapy or stress management techniques instead. Others use alternative therapies, such as topical hormone creams found in compounding pharmacies or health food stores, according to Easterling.

Women with MS have no increased risk for breast or cervical cancer, but can be more at risk for osteoporosis because of

steroid use and lack of weight-bearing exercise. "Menopause is a bigger issue for women with MS. Walking prevents or minimizes osteoporosis, so women who use wheelchairs are more at risk. For women who can exercise, even walking leisurely for one-half hour each day will be beneficial. They don't have to run or lift weights, but they need to exercise."

Although physicians should routinely screen all women aged 65 and older for

> osteoporosis, Faber says women with MS should begin having bonedensity scans earlier due to increased risk factors. In addition to lack of exercise, significant steroid use and menopausal state, other risk factors for osteoporosis include: small body frame; family history of osteoporosis; past



or present smoking; caucasian; concurrent thyroid disease; and low calcium intake.

### Taking a Proactive Approach

"MS has a great impact on dating, family life, working, and whether to have children," says Buhse. "I try to empower patients to take as much control over the disease as they can by taking medications regularly, exercising, and talking about their symptoms to other people. A lot of patients say, 'I have MS, but MS does not have me."

Dr. Burks emphasizes that women today

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can take a proactive approach to minimizing the effects of MS. Some of the best ways to do so include:

- Positive mental attitude
- Proper nutrition and weight control
- Medical management of MS and its symptoms
- Exercise and staying active
- Conserving energy by pacing activities
- Stress management
- Asking for help when needed
- Cognitive rehabilitation, if needed
- Accommodations at work and at home

Even for women without MS, the demands can be great as they balance career, family, and relationships. For women with MS, this may mean even greater challenges. But now that medical treatments are available to slow the effects of MS, and with the help of family, friends, and outside services such as MSAA, these women are making strides in their careers while enjoying a rewarding family life. Although things may not always be easy, many women with MS are able to take the challenge and continue to fulfill their professional and personal hopes and dreams.

### **Helpful Resources**

### Center for Research on Women with Disabilities

www.bcm.tmc.edu/crowd or (800) 442-7693

### **Chronic Illness Coach**

www.cicoach.com or (617) 969-1930

### **Dating 4 Disabled**

www.dating4disabled.com or (201) 984-9230

#### **Dress for Success**

www.dressforsuccess.org or (212) 532-1922 (Provides professional attire, support, and career development to disadvantaged women)

### **Ethel Louise Armstrong Foundation**

www.ela.org or (805) 252-7983 (Promotes women with disabilities through grants and scholarships)

### **National Domestic Violence Hotline**

www.ndvh.org or (800) 799-SAFE (7233)

#### National Women's

#### **Health Information Center**

www.4woman.gov/wwd or (800) 994-9662

### Society for Women's Health Research

www.womenshealthresearch.org or (202) 223-8224

### Some Things Only a Woman Can Do

www.womancando.org or (877) 332-2636

### The Family Village

www.familyvillage.wisc.edu

For additional resources, please speak with an MSAA Helpline Consultant at (800) 532-7667. ◆

## Ask the Doctor

By Dr. Jack Burks Chief Medical Officer for MSAA



Dr. Jack Burks

Q: I was diagnosed with relapsing-remitting multiple sclerosis (RRMS) in 1991. Following a three-day course of intravenous (IV) Solu-Medrol® (IV methylprednisolone) for an MS attack

(causing weakening on my right side), I experienced debilitating sharp, stabbing pains several times daily. Only on the left side, these radiated from my jaw, neck, upper chest wall, and shoulder. During that time, I saw nine doctors, tried countless medications (including Neurontin® [gabapentin], Topamax® [topiramate], and Lyrica® [pregabalin]), had several diagnostic exams, and spent a lot of money. Have you heard of similar adverse reactions to Solu-Medrol?

A: While I cannot make a specific conclusion about your pain, I will share my general thoughts on Solu-Medrol and MS pain. Solu-Medrol is an intravenous steroid used to treat an acute attack (relapse) of MS. The pain that you describe may be related to your MS and not from the Solu-Medrol. To answer your question specifically, I am not aware of Solu-Medrol causing symptoms such as your pain. Sometimes, I have used Solu-Medrol successfully as treatment for intermittent pain from an acute MS attack.

In addition to the treatments you have received, some pain in MS patients is helped by tricyclic antidepressants such as Elavil®

(amitriptyline), which was not on your list of treatments. Also, Cymbalta® (duloxetine), another type of antidepressant, has been shown to help neurogenic pain. Narcotics are usually not helpful in this type of pain. If your pain symptoms are severe and continue over a long period of time in spite of medication, a pain specialist may be helpful.

Q: I have been having a bad case of diarrhea for three months. I have had several bowel tests and results have all been negative. Could this be my MS?

A: Short questions are often the most complex to answer. Diarrhea as a direct result of MS is unusual. Constipation is much more common. Therefore, I try to find other causes for diarrhea in people with MS. For example, some medications or other medical conditions may be responsible. Irritable bowel syndrome (IBS), colitis, infections, coffee, alcohol, and intolerance to food such as dairy (lactose) and spicy foods are examples. An internal medicine physician or gastroenterologist may be helpful in sorting out the diarrhea problem.

If it is determined the diarrhea is directly related to MS, the therapeutic approach can be complex. Bulk-forming agents such as Metamucil®, Benefiber®, or Perdiem Plain® may be helpful. These agents are also used for constipation. However, with diarrhea, bulking agents are taken without additional fluids. Balancing fluid intake is tricky, because people with bowel issues may have bladder problems as well.

Another treatment approach involves the use of anticholinergic medicine, such as Ditropan® (oxybutynin), which can help with diarrhea. However, bladder function must be monitored during this therapy. A nurse with bowel and bladder expertise can help to get bladder and bowel functioning under control. In addition, a short course of anti-diarrhea medication such as Lomotil® (diphenoxylate) can reduce the diarrhea, especially if incontinence is present.

As you can see, bowel function in MS patients is complex and requires careful management. To add to the complexity, bladder and sexual dysfunction may accompany bowel problems and the treatments need to be balanced. Bowel-management experts are invaluable.

Q: I was diagnosed with MS in 2002 and started on Betaseron® (interferon beta-1b) after an MRI showed lesions on my brain. I continued on this for three years without any new lesions, and seemed to tolerate it very well. However, I had two triple bypasses and a stent put in following a heart attack. My cardiologist thought it may be due to the Betaseron causing my arteries to close. My neurologist mentioned it could increase cholesterol levels. I switched to Copaxone® (glatiramer acetate). After three years, I'm still developing knots and pain at the injection sites that can last for up to a week (or more). I've also developed two new lesions, but I've had no artery problems.

Do you know if Betaseron causes heart problems or arteries to close? Also, what is



### Have you been diagnosed with

### Multiple Sclerosis?

A clinical study is under way to determine the safety and effectiveness of a new investigational **oral medication** for Relapsing-Remitting MS.

Coordinators of the RRMS study seek participants who:

- Are 18 to 55 years old
- Have a confirmed diagnosis of Relapsing-Remitting Multiple Sclerosis
- Have had one relapse in the past 12 months

For more information, visit:

www.msclinicalstudies.com

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the difference between the two interferons (1a and 1b) and are there any other treatments I should ask my neurologist about?

**A:** To my knowledge, Betaseron is <u>not associated</u> with "causing arteries to close." On the contrary, Betaseron has been shown to decrease cholesterol levels. A major source of medical information, the *Physicians' Desk Reference* (PDR) book, does not link hardening of the arteries (atherosclerosis) to Betaseron.

Your second question asked about the difference between the interferons. The interferon beta-la (Avonex® and Rebif®) and interferon beta-lb (Betaseron) are very similar but do have structural differences. Interferon beta-la has the structure of naturally occurring human interferon beta, while interferon beta-lb has a structure that differs slightly.

Interferon beta is a protein found in the body that works by modifying the immune system. In the treatment of MS, interferon beta has been shown to reduce attacks and the progression of disability.

The dose and frequency of interferon beta-

### 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.

1a and 1b also vary. Avonex is a "low-dose" interferon, given once weekly, and more deeply into the muscle (via intramuscular injection). Rebif is administered just under the skin (via "subcutaneous" injection) three times per week. Betaseron is given subcutaneously as well, but it is administered every other day. Betaseron and Rebif are considered "high-dose" interferons.

Your third question asks about other MS treatments. Six medications have the United States Food and Drug Administration (FDA) approval for the treatment of MS. You are taking Copaxone and I have discussed Betaseron, Avonex, and Rebif. The two other treatments are Novantrone® (mitoxantrone) and Tysabri® (natalizumab). These drugs are usually reserved for patients who have had a less-than-optimal response to an alternate therapy mentioned above, or for those who have not been able to tolerate an alternate therapy. Your neurologist can be more specific and provide additional information.

Q: I was diagnosed with MS in 1998 and had a horrendous attack in 2000. I flew to England to see a homeopathic microbiologist, who said I had shingles in my right eye, which also spread to my brain. Does that make any sense to you?

A: Both shingles (herpes zoster viral infection) and MS can have eye symptoms and brain symptoms. The similarities usually stop there. The shingles virus is the same virus that causes chicken pox. Shingles is usually easy to identify because it is associated with blisters on the skin. The herpes

#### Ask the Doctor

zoster virus encephalitis occurs when the virus affects the brain. This is uncommon and can cause severe headaches and mental confusion. MS has recurrent symptoms (exacerbations) usually without severe headaches or mental confusion. Eye problems with MS are different. A spinal-fluid evaluation can also help distinguish the two.

If the homeopathic microbiologist was referring to shingles in addition to your MS (versus instead of), this is also possible. MS patients may develop shingles just as often as someone without MS, and steroids can make an individual more susceptible to the virus. Shingles in most cases is temporary, causing acute pain and a rash, which eventually go away. For some patients, the pain can linger.

Q: I was diagnosed with MS in 2000 and my hands have been numb since 2005. I am on Copaxone which is working well. For the last few months, my legs between my knees and ankles have felt inwardly cold. I had a doppler ultrasound and all pulses were good. My neurologist said that what I am experiencing might be due to the MS, but I was wondering if you had heard of anyone else with this type of symptom.

A: Your doctor is correct. Your symptom might well be MS-related. Experiencing cold or heat (or discoloration of the skin) in the arms and/or legs is fairly common in MS patients. Nonetheless, I am pleased you were evaluated for other causes of coldness in your legs, because MS patients can have different conditions which may mimic MS symptoms.

If this sensation is not painful, you may try different conventional ways to feel warmer. Some people will try extra layers of clothing, massage, or a warm bath. If the sensation becomes painful, your doctor may choose to prescribe pain medication to help. •

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

### Have you registered at msassociation.org?

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- Get invites to local educational and special events
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- Share your stories and feedback on important topics in MS
- Interact online with others in the MS community

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## Research News

# World Congress on Treatment and Research in Multiple Sclerosis

Written by Susan Wells Courtney Reviewed and information provided by Jack Burks, MD

More than 5,000 medical professionals attended this year's first World Congress on Treatment and Research in Multiple Sclerosis, held in Montreal, Canada this past September. MSAA's Chief Medical Officer Jack Burks, MD, not only attended the meeting, but also reviewed approximately 1,000 poster presentations – specifically about the latest in MS news and research.

From this vast amount of information, cutting-edge studies, and exciting drugs in development, Dr. Burks selected those posters which he found to be of greatest interest, and summarized them in a presentation to MSAA staff. To follow are some highlights from Dr. Burks' presentation.

### **General MS Information**

An estimated two and a half million people worldwide are now thought to have MS. Most individuals with MS are diagnosed between the ages of 15 and 45. Four times as many women are diagnosed than men, and 85 percent of those diagnosed begin with the relapsing-remitting form of MS (RRMS). Without treatment, half of these patients will advance to secondary-progressive MS (SPMS) within 10 years, where symptoms usually do not remit, and patients are more likely to develop greater disability.

Years ago, MS in children was considered to be extremely rare. Presently, up to five percent of the MS population is under the age of 18 (pediatric MS), and pediatric MS centers have been setup to address the special needs of this age group.

While adult MS has a much greater female population, pediatric MS is more evenly divided between the genders. Among common symptoms experienced, approximately 70 percent have mental health issues – such as depression and attention deficit hyperactive disorder (ADHD). Fatigue is another symptom seen frequently in pediatric MS, which can greatly impact daily activities.

Approximately 25 percent of children with MS have cognitive problems. For adults and children, cognitive dysfunction can also impact many aspects of one's life, affecting memory, concentration, and mental quickness. Cognitive rehabilitation and cognitive functioning are getting more attention from researchers. While much is not known about the evaluation and treatment of this symptom, the development of cognitive retraining at some MS centers has had some exciting results.

Although fewer **African-Americans** develop MS, this subset of the MS community tends to have a more aggressive disease

course. The B cells in the immune system may be a factor, versus the immune system's T cells. These T cells have traditionally been believed to be the primary source of inflammation. These findings may lead to new research into different types of treatment for specific groups of individuals.

Neuromyelitis optica (NMO), also known as Devic's disease, is a disorder that can appear to be very similar to MS, affecting the spinal cord and optic nerve. Although this is not a progressive disease, it can be recurrent with severe symptoms. A new test has been developed to help doctors differentiate some NMO patients from MS patients. New treatments for NMO are being studied. Rituxan® (rituximab) is one example.

### **Research from Many Directions**

Research into the **cause** of MS is focusing on four areas:

- Immunologic/autoimmune (problems with the immune system)
- Microbial (pointing to infection, possibly viral; popular suspects include Epstein-Barr Virus [EBV] and Chlamydia)
- Genetic (another area of investigation; genes possibly linked to EBV with MS)
- Environmental (industrial waste and pollution may play a role; or vitamin D and sunshine, for example)

Damage from MS occurs in two different ways: **inflammation and degeneration**. Early in the disease, inflammation occurs as the body's immune system attacks the brain. Anti-inflammatory drugs, such as the current disease-modifying therapies (DMTs) for MS,

minimize the damage from inflammation and reduce the attacks.

Cells can be damaged and then recover, but may be destined to not live as long – because they have been previously damaged. This could be a link to the second component in the disease process: cell degeneration.

The degeneration is more pronounced later in the disease, and is characterized by loss of axons and nerve cells, as well as myelin. This damage occurs without the intense inflammation to the axons (nerve fibers) and the neurons (the grey matter in the brain). This grey matter in the brain can also be damaged, which may affect cognition.

If later degeneration is related to earlier inflammation, early treatment might stop or at least slow this damage. With this in mind, how can MS be diagnosed and treated sooner? MRI findings can lead to treating patients after their first attack.

Researchers are searching for the causes of the degeneration. A number of theories exist; some say that this latter degenerative phase is independent of inflammation, but others believe that the two phases are linked.

Does brain atrophy (shrinkage) occur only late in the disease? Researchers have shown that brain atrophy starts early in the disorder. One study found reductions in brain volume to be similar in early and late stages of the disease.

The good news is that the body's natural process of making **new myelin** – while not as efficient in the white matter of the brain – is much more efficient in the grey matter of the brain. As mentioned earlier, damage to the grey matter can affect cognition, and this is because it is the "thinking" area of the brain.

One possibility for the lack of new myelin production in the white matter is interference from the inflammatory cells. A study in Tokyo found that a molecule called "TIP30" may inhibit the cells that normally repair nerves.

With MS, a protein called "fetuin-A" has been found to be increased in the spinal fluid and the brain, especially around lesions. These and other new biomarkers for MS could possibly be measured to help researchers discover more about the disease, in terms of diagnosis and disease course.

Gene expression changes dramatically with different disorders. Researchers can now map changes when a patient is sick and prescribe drugs that change specific gene expression. These are referred to as "boutique therapies." Using the Human Genome Map, this type of treatment may one day be developed for individuals with MS.

**Risk factors for MS** continue to be investigated. These include:

- New genes have been identified with MS
- Vitamin D (naturally derived from sunshine) could play a role; 65 percent of children with MS in Canada have a vitamin D deficiency
- Smoking increases the risk of autoimmune disease; smoking also increases the risk of MS in association with EBV infection
- Human Herpesvirus 6 (HHV6) virus, which first appears as a rash in childhood, has a molecular structure that is similar to myelin basic protein (MBP); this could implicate "molecular mimicry," where the immune system believes it is attacking a foreign protein, but is actually attacking its own myelin

Osteoporosis is another concern for individuals with MS. Patients are at a higher risk, partly from steroid treatment, which reduces calcium in the body. In addition, while pulse steroids may seem like a good idea, they can destroy joints, a process known as "osteonecrosis." One group of MS scientists reported that approximately seven percent of individuals treated with pulse steroids develop this disorder.

A growing number of patients (with no MS-type of symptoms) are being diagnosed with "Radiologic Isolated Syndrome." This is where a patient undergoes an MRI for some unrelated reason, and MS-type lesions are found. Researchers are seeing more of asymptomatic patients. Of those patients followed, 80 percent later developed new lesions, and 21 percent went on to have a neurological attack.

### The Success of Disease-Modifying Therapies

The approved disease-modifying therapies (DMTs) for MS can help to reduce the number of relapses, decrease the number of active lesions on MRI, and slow the progression of disability. Several also delay the onset of clinically definite MS (CDMS) following the first neurologic event, which is called a clinically isolated syndrome (CIS). In long-term follow-up studies of 15 years or more, patients taking DMTs frequently report a high quality of life and reduced disability. Many continue to remain ambulatory.

With the interferons, 15 years of data show that patients who stay on Avonex® (interferon beta-1a) continue to do well.

Most individuals taking Avonex long-term state that their health is excellent, and a significant percentage of these long-term users are able to walk unassisted.

When treating CIS with Betaseron® (interferon beta-1b), immediate treatment decreased disability by 40 percent at three years and by 24 percent at five years versus those whose treatment was delayed until the second attack or at two years. Betaseron users also report a high quality of life.

Rebif® (interferon beta-1a) has tested a reformulated product, which improved tolerability and reduced neutralizing antibodies. Also, a 16-week study showed fewer MRI lesions in treated patients versus patients on placebo. The new formulation is undergoing Food and

Drug Administration (FDA) review for possible approval in the United States.

Also, generic versions of DMTs are becoming available in foreign countries (Mexico, Argentina, Korea, and Iran). The similarity of these to brand-name drugs is being challenged. Some experts believe these biogenerics lack adequate safety and efficacy data.

Looking at Copaxone® (glatiramer acetate), those with a clinically isolated syndrome (CIS) were 45 percent less likely to be diagnosed with clinically definite MS (CDMS) within two years if taking Copaxone versus placebo. This drug may also offer protection of the axons (nerve fibers). A study showed that a higher dose did not offer any



benefits over the regular dose, although everyother-day dosing may be of equal benefit – but more studies are needed. Copaxone's long-term follow-up of 15 years shows an improvement in relapses and disability. More than 80 percent of patients were walking unaided.

Novantrone® (mitoxantrone) is used as a rescue therapy. A "rescue therapy" is used for patients with a suboptimal response to a DMT given as a first-line of treatment. Patients need to be monitored carefully as it may cause heart failure, loss of menstruation, and even leukemia. Treatment is limited to a maximum of two to three years and regular heart testing is recommended. A small study in Italy administered gonadotrophin releasing hormone (GnRH)-analogue treatment in conjunction with Novantrone, in an effort to avoid the premature loss of menstruation. At the time of this report, half of the women had completed their treatment with both medications, and these six women now have normal menstrual cycles.

Tysabri® (natalizumab) continues to be an effective DMT, but risks still exist. Two new cases of Progressive Multifocal Leukoencephalopathy (PML) occurred in July 2008, with two men in Europe. At last report, due to early diagnosis, both continue to be stable (PML is an often fatal viral infection of the brain). Other potential adverse events include low platelet count, as well as herpes virus encephalitis and meningitis. Tysabri has also been shown to be very effective in treating pediatric MS patients, whose MS is highly active.

**Rescue therapies** which are not FDA approved for MS include: pulse steroids;

Rituxan; Cellcept® (mycophenolate mofetil); and high-dose Cytoxan® (cyclophosphamide).

### **Emerging MS Therapies**

Campath® (alemtuzumab) shows much potential in the treatment of MS, with a significant reduction in annual relapse rates, disability, and MRI lesions. Toxicity with this drug is still an issue, with an increased risk of low platelets and Graves' disease. One successful study used Campath as a rescue therapy in RRMS.

Rituxan is a monoclonal antibody that reduces specific antibodies. Positive data in RRMS has been demonstrated. In primary-progressive MS (PPMS), overall results were negative, but patients under 55 with active MRI lesions showed a benefit in an analysis that was completed after the study. For other diseases treated with Rituxan, PML has been reported. As noted earlier, this drug is also showing positive effects in preliminary studies in NMO.

Oral cladbribine will be the first oral therapy to report phase III trial data to the FDA, with results available in 2009. It reduces certain T-lymphocytes, which may help in the treatment of MS.

In a Phase II RRMS trial, oral fingolomod (FTY720) demonstrated reductions in relative relapse rate and the development of new MRI lesions versus placebo. A phase III RRMS study with more than 3,000 participants is underway. Two patients in this study died from viral infections. While fingolomod has not been proven to have caused these deaths, the association cannot be ruled out at this time. A study with PPMS patients is

also underway (outside of the United States), with plans to begin United States' enrollment in January 2009.

Parasites are another interesting area of research in the treatment of MS. In general, countries with a high prevalence of parasite infections have low prevalence of MS. Parasites may help to regulate immune activity. One study involving parasites and MS is underway.

MBP8298 has been granted fast-track designation from the United States Food and Drug Administration (FDA) for SPMS. Fast-track designation can help in the development of drugs for serious or life-threatening conditions, as well as speed-up the review process. This treatment is being studied in RRMS and SPMS; it appears to be well tolerated. Other similar drugs are also being tested in MS. Their aim is to "tolerize" the immune system from attacking the myelin.

CDP323, an oral drug with action similar to Tysabri, is being studied. It has a shorter half-life than Tysabri, which means that it does not stay in the body as long. This may have a lower risk of PML, and is currently in phase II studies.

Stem cell studies are ongoing. Stem cells taken from bone marrow have shown some evidence of revitalizing brain tissue in RRMS.

An eight-week study with Low Dose Naltrexone (LDN) was found to increase quality of life. Specifically, mental health was improved, but physical measures were not affected. In animal studies, higher doses caused damaging effects in an MS-like disease.

Flavinoids, green tea, and red wine are showing some positive effects. These may possibly help to protect nerve fibers. Re-



searchers are also looking at the potential value of a diet rich in fish, as well as the benefits of olive oil.

Whether **vitamin D** supplements can help protect people from developing MS, or help reduce the effects of MS, is not yet known. More research is needed to determine the potential for treating with vitamin D. The appropriate doses also need to be identified.

Other emerging therapies for MS include: Zenapax® (dacilzumab); teriflunomide; BHT-3009; NM-166; intravenous immunoglobulin (IVIg); estriol, menocycline; doxycycline; Prozac (fluoxetine); laquinimod; BG 12 (fumarate); antisense oligonucleotide (ATL1102); bone-marrow transplant (BMT); oral IFN-Tau; Atacicept (ATAMS); PEGylation of IFN-B in EAE; Rilutek® (riluzole); ATX-MS1467 (4 MBP Peptides); RTL1000 (recombinant T-cell receptor ligand); glucosamine sulfate; semaphorins (guidance molecules for remyelination);

Tovaxin<sup>™</sup> (T-cell vaccination); and statins, among many others.

In summary, researchers now have a better understanding of MS, its causes, and its pathology. Researchers are learning more about pediatric MS as well. The presently approved DMTs are working well, and many emerging therapies – including oral medications – are showing much potential. However, toxicity is always a concern, and members of the MS community and medical fields must continue to exercise caution until the potential side effects of a treatment are known.

New symptom management strategies continue to be developed – from exercise rehabilitation (found to improve fatigue) to cooling (to reduce symptoms in heat-sensitive individuals). Other treatments such as Fampridine-SR for walking speed and leg strength, and Duloxetine for depression, pain, bladder problems, fatigue, and quality of life, may prove to be of great benefit to the MS community. Other drugs are being developed such as Zenvia™, to treat pseudobulbar affect (PBA), which is a condition where individuals experience emotional instability.

For a more complete list of treatments – both approved and experimental – please refer to the cover story from the Summer 2008 issue of *The Motivator*, "MS Research Update 2008." This may be viewed or downloaded from MSAA's website at www.msassociation.org. Readers may also order a copy by calling MSAA's Helpline at (800) 532-7667. The upcoming Winter 2009 issue of *The Motivator* will focus on approved and experimental treatments for symptom management.

### **Other News**

### Betaseron Offers Thinner Needle

A new, thinner needle and new autoinjector will soon be available for individuals taking Betaseron for the long-term treatment of MS. The thinner needle is being offered as a way to potentially help reduce the pain and anxiety often associated with injections. For more information on Betaseron and its thinner needle, readers may visit www.betaseron.com/thinner or call BETAPLUS™ at (800) 788-1467.

### Changes to Tysabri's Labeling

Two changes have recently been made to the labeling and prescribing information for Tysabri® (natalizumab). The first change may help individuals to be approved sooner by their health insurance company for Tysabri, after failing to respond adequately to (or not able to tolerate) another single disease-modifying therapy for MS. The second change is in response to the two newly discovered cases of progressive multifocal leukoencephalopathy (PML), in patients taking Tysabri as a monotherapy (in conjunction with no other disease-modifying therapy) for the long-term treatment of MS. PML is an often-fatal viral infection of the brain. (Please note, a third case of PML was confirmed on October 29, 2008.) •

Additional information on these and other topics is available on MSAA's website at www.msassociation.org, under "Recent News." Readers without internet access may call MSAA's Helpline at (800) 532-7667 for more information.

### **RESOURCE DETECTIVES™ NEEDED**

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

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

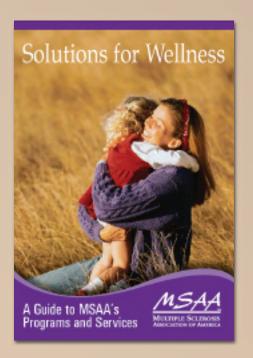


You may also email Bonnie Yares at byares@msassociation.org

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

# MSAA's New Booklet is Now Available!

MSAA's latest booklet, **Solutions for Wellness**, gives detailed information about all of our programs and services. This publication serves as a comprehensive and upbeat guide on everything from our toll-free bilingual telephone Helpline to our Equipment Distribution Program, awareness events, volunteering opportunities, and more.



Copies may be viewed and downloaded from MSAA's website at www.msassociation.org or ordered by calling MSAA at (800) 532-7667.

# Program Notes

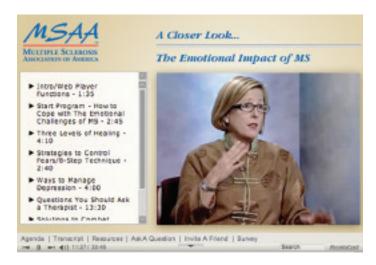
### MS Experts May Be Accessed Through Your Computer: Let Them Help You

On-demand... 24 hours a day... Seven days a week... Whenever you need them... Whenever it's most convenient for you...

All of the above phrases accurately define MSAA's educational video series. A Closer Look. These can be accessed at www.msassociation.org as part of our latest program initiative, Multiple Sclerosis information (MSi). Now featuring the eighth video, A Closer Look at the Emotional Impact of MS, this ever-growing video library offers a wealth of information from top medical experts and people living with MS. The information is presented in a relaxed interview style, similar to popular TV talk programs. Also, the interactive video player allows viewers to select areas of interest throughout the entire program, read along as it is playing, print full transcripts from a PDF file, and, most importantly, ask a question electronically to the MSAA Helpline staff.

"Imagine having immediate access to some of the best MS healthcare professionals in the country – right at your fingertips, right in the comfort of your own home," states Bob Rapp, MSAA vice president of programs and evaluation.

"And, they are discussing important issues about real-life situations that impact MS clients on a daily basis. It's a powerful use of technology and one of the most effective ways MSAA



can help our clients to get useful, accurate information that's so critically needed to manage the ever-changing course of MS."

Beginning with the latest video, *A Closer Look at the Emotional Impact of MS*, we took the opportunity to highlight (below) quotes from a sample of MSi videos to peak your interest in these exceptional programs. We invite you to view these and future videos in part or in their entirety on our website. You may also obtain copies on DVD through MSAA's Lending Library.

Allison Shadday, LCSW and MS client, quoted from *A Closer Look at the Emotional Impact of MS*:

"Having a disease like MS can challenge our self-esteem on so many levels – we go through many different changes... The one message I really try to get across to clients is that the beautiful thing about self-esteem is that we get to decide for ourselves how we view and value ourselves... So if we're feeling good about ourselves, regardless of what we're physically doing but in regards to who

### **Program Notes**

we actually are being, other people will pick up on that cue and they'll value us for the same reasons."

Jack Burks, MD and MSAA's chief medical officer, quoted from *A Closer Look at Multiple Sclerosis Symptoms – Part 1, Effective Symptom Management:* 

"Patients want to know how the treatments are working, are they getting the maximum benefit from the treatments? And these are very difficult questions to answer sometimes, because we have to have realistic expectations between the doctor and the patient... So it's a partnership between the patient understanding what are the realistic expectations and the doctor explaining those in a reasonable timeframe... Establishing a good relationship with your doctor is incredibly important."

Allen Bowling, MD, PhD and member of MSAA's Healthcare Advisory Council, quoted from A Closer Look at MS and Complementary and Alternative Medicine:

"In terms of the area of mind-body medicine, there's some evidence for meditation having beneficial effects for people with MS. There's a very high quality study done of yoga, looking at yoga and the various MS

symptoms. And what was shown in that study was that yoga or a standard exercise program can be quite helpful in terms of decreasing MS-related fatigue."

Antoinette, MS client and participant of the MSAA MRI Institute, quoted from *A Closer Look at the Value of MRIs*:

"There's nothing scary about having an MRI. It's just an inconvenience if you think about it. It's one of the easiest tests in the world. The reason I did the interview today is because I want to let my fellow MSers know that there is hope out there and there is the opportunity to get MRIs."

Additional MSi videos are posted on MSAA's website, offering valuable information and resources. These include:

- A Closer Look at the Importance of MS Treatment Adherence
- A Closer Look at the Future of MS Research
- A Closer Look at Intimacy and Multiple Sclerosis
- A Closer Look at Clinically Isolated Syndrome and MS

For more information, please visit MSAA's website at www.msassociation.org, or call MSAA's Helpline at (800) 532-7667. ◆

### **New MSi Video**

During the production of *The Motivator*, MSAA launched a new MSi video titled *A Closer Look at Managing Stress and MS*. Topics highlighted in this video include strategies to manage stress, tips for internal stress reduction, and how to evaluate your stress management techniques. Please visit www.msassociation.org to view this latest video.

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# Thoughts about Giving

### **Our Most Involved Supporters**

It is heartwarming to see our many supporters who not only contribute financially to help people living with MS, but who are also involved with MSAA as volunteers. Their enthusiasm



Bruce Makous

seems to know no bounds as they look for every opportunity to help MSAA.

Our national volunteers, members of MSAA's Board of Directors and our Healthcare Advisory Council, are extremely dedicated, contributing a great deal of time in leading MSAA, and include many of our most generous financial contributors. There are also many very enthusiastic supporters among our general constituents nationwide.

We recently held a President's Circle recognition event at the inspiring National Constitution Center in Philadelphia. This event honored our most significant donors in the area, and provided the opportunity to highlight a special group of supporters from Bucks County, Pennsylvania, who have been helping MSAA by holding fundraising events and by making generous personal contributions. The family group, which crosses three generations, includes Linda Somers, her daughter, Lynne Goldberg, and Lynne's daughter Alyssa Lewanowicz, age fourteen.

After Linda's mother passed away from complications of multiple sclerosis, the three family members created Nana's Cookies, an annual fundraising event for MSAA through which they sell delicious cookies made with "Nana's" special recipe. This is the third year for this event. Linda also recruited the Oxford Valley Golf Club to dedicate the proceeds of their annual fundraising golf tournament to benefit MSAA.

Another good example is Tamara Gerkin, an artist in Florida whose daughter is living with multiple sclerosis. Tamara not only provides financial support, but also creates paintings with universal themes related to providing comfort for people with multiple sclerosis. She is donating the proceeds of her print sales to MSAA.

There are many examples of enthusiastic supporters like Linda and Tamara and our national leaders in many locales around the country. These individuals hold events, participate in volunteer leadership opportunities, and contribute in a variety of ways to MSAA.

Programs that invite your involvement include our Resource Detectives, Public Education Ambassadors, President's Circle Advisory Council, Regional Volunteers, and others. For a complete listing of volunteer programs, please go to **support.msassociation.org/volunteer**. And if you have your own idea about how you would like to support MSAA, we would love to hear from you.

This type of multi-level activity can help you achieve greater satisfaction and participation as a constituent of MSAA. It also, of course, helps MSAA deliver its programs and services that improve the quality of life for everyone living with MS. For your outstanding support, we are extremely grateful.



### NHL Player Raises Funds for MSAA

On August 17, more than 300 hockey fans from the Philadelphia area raised \$18,000 for MSAA at the Cote Carnival, hosted by Riley Cote of the Philadelphia Flyers. The carnival was held at Swanky Bubbles (a Philadelphia-area restaurant). Jaime Cote, Riley's sister, has multiple sclerosis. From left to right: Bruce Makous, vice president of development for MSAA; Jaime Cote; Riley Cote; Jennifer Ebling; Joe Fisher III; and Maureen Fisher.

### How to Diversify and Bolster Your Sagging Retirement Portfolio

As we near the end of 2008, a year in which the financial markets, as of this writing, have not performed very well, many people are looking at their retirement portfolios wondering how they can increase the income payout today, and diversify against market fluctuations in the future. Consider a gift annuity with MSAA as one alternative that may help in this situation.

### A Gift Annuity

A gift annuity provides a contractual amount paid by MSAA to you for life, in return for your contribution. Thus, the creation of a gift annuity is an excellent way to establish a contracted quarterly income payment for yourself that is not affected by the financial markets. As such, a gift annuity helps to diversify your retirement portfolio.

The payout rates for annuities today are better than most other options for increasing income in your portfolio. A gift annuity provides income to the donor or couple for lifetime, at a rate based on age at the time of creation of the annuity. (See the gift annuity rate chart on the back cover.) Additionally, 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 six percent, or \$600 per year, for life. They will also qualify for a federal income tax deduction of approximately \$3,624, which will save them \$1,015 in taxes in the 28 percent marginal tax bracket. In addition, \$389 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.

Please note that after the tax savings from the income tax deduction, their initial contribution is actually only \$8,985, so the \$600 annual payment to them actually represents an after-tax rate of return of 6.7 percent. Also, since \$389 of the annuity payment is tax-free, the \$600 annuity is equivalent to \$751 of taxable income for a beneficiary in the 28 percent income tax bracket. Based on the \$8,985 initial contribution, this is an equivalent rate of return of 8.4 percent. It's hard to find an investment today that is guaranteed for life and will provide you with rates this high. This will also provide funding to a charity you support.

"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

### **GIFT ANNUITY ILLUSTRATION**

Annuitants:Couple	both age 75
Principal Donated:	\$10,000
Annuity Rate:	<b>6</b> %
Annuity, paid quarterly:	\$600
Charitable Deduction:	\$3,625
Tax Savings at 28% bracket:	\$1,015
Net Donation after Savings:	\$8,985
Tax-free Portion of \$600:	\$389
Effective Return Rate:	8.4%

After 16.4 years, the entire annuity becomes ordinary income.

MSAA and will receive income from this gift throughout their lifetime. The balance will provide general support for MSAA.

### Charitable IRA Rollover Provision Extended

There's good news for individuals aged  $70\frac{1}{2}$  or older with individual retirement



# President's Circle Reception in Philadelphia Honors MSAA Donors and Volunteers

MSAA held a special reception for its top supporters at the National Constitution Center in Philadelphia. Douglas Franklin, president and CEO of MSAA, and the MSAA Board of Directors had the opportunity to personally thank MSAA's donors and volunteers in the region. More than 350 individuals from across the country currently receive recognition as President's Circle donors. Shown in the photo is Diana Anderson receiving an award from National President's Circle Chair, Ross Maclean, (left) and MSAA's Chair Eric Simons (right).

accounts (IRAs). Thanks to the extended charitable IRA legislation, you can once again make outright gifts using IRA funds without tax complications.

If you are required to receive minimum distributions from your IRA and you do not need the money for personal use, consider using those funds as a charitable gift. 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, and in most cases, the transfer counts toward your minimum required distributions. You must transfer

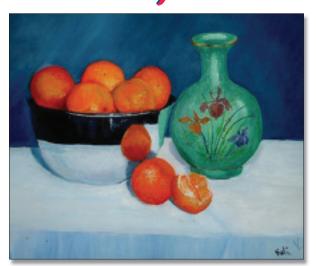
funds from your IRA directly to one or more public charities, like MSAA. You may transfer up to \$100,000 this way in 2008 and in 2009. The gift generates neither taxable income nor a tax deduction, so even those who do not itemize their tax returns receive the benefit. •

— Bruce Makous

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

### Submit Your Best Work!

# 2008 MSAA Art Contest



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

Art contest paint tube image by Rachel Slepekis

Artwork will only be accepted from individuals with MS. Paintings and drawings in oils, watercolors, pen, and ink are acceptable. Artwork will be judged by an MSAA committee, and the winner announced by January 31, 2009.

Deadline for submissions is December 31, 2008. For complete contest rules and submission guidelines, visit **support.msassociation.org/artcontest** 

### For further information, contact:

Kathy Giles, Direct Fundraising Manager MSAA

706 Haddonfield Road Cherry Hill, NJ 08002

Email: kgiles@msassociation.org

Phone: (800) 532-7667, extension 113

# Symptom Awareness

### **Mobility Independence and Safety**

Written by Patricia G. Provance, PT, MSCS

#### **Part I: Ambulation**

(Please note that Part II and Part III will appear in future issues of The Motivator.)

When we hear the word "mobility," most thoughts turn to walking. However, being mobile amounts to much, much more. If we think back to how we developed, we first learned to roll over, sit up, crawl, pull up and stand steadily before we started to walk. As many people challenged with the rainbow of symptoms associated with MS have discovered, maintaining safe and independent mobility can sometimes be difficult.

Unfortunately, the result is often a marked decrease in overall activity – which leads to preventable disuse weakness and de-conditioning. If the downward spiral from inactivity continues, other problems can develop. These include: muscle tightness and/or weakness; increased spasticity; bowel problems (usually constipation); decreased heart and lung function; pressure sores; depression; and social isolation.

Everyone should have the goal of achieving, and then maintaining, the highest possible level of independent function. This includes safe mobility – both at home and in the community. Since the primary goal of most individuals with MS is "to keep walking" or "to walk better," this first of three articles will focus on issues related to gait (ambulation).

My recommendation is for everyone with MS to receive a baseline evaluation from a

physical therapist (PT) experienced in MS care. Ideally, this should be done soon after diagnosis – but at the very least, at the first sign of problems with balance, walking, or endurance.

An evaluation can spotlight many subtle symptoms that can be addressed before they worsen into significant issues. These symptoms might include:

- Fatigue/decreased endurance
- Foot drop/drag (especially at the end of the day)
- Weakness in leg(s) and/or trunk
- De-conditioning
- Mild spasticity (increased tone, which gets worse with fatigue)
- Muscle tightness from inactivity
- Compensatory movement patterns (such as "hiking" or lifting of the hip; leaning to clear the weak leg when walking; or using arms to help stand up)
- Problems with balance (which may include a history of falls, "near-falls," and/or difficulty on stairs)
- Impaired vision or sensation
- "Wobbly" walking

All of the above problems will affect independent walking and can be targeted in a corrective program.

The invisible and disabling symptom of fatigue requires behavioral or lifestyle modifications, including wise, energymanagement practices. One good strategy is to follow the adage of "Pro-active REST instead of re-active COLLAPSE!" Employing the "4 P's" of PACING, PRIORITIZATION, PLANNING, and POSITIONING can be helpful. Additional wise energy-management practices are to avoid over-heating, work toward appropriate strengthening and conditioning, employ good sleep practices, eat a healthy diet, and when needed, use an ambulation aid. Individuals who are heat-sensitive may use cooling techniques, such as taking a cool bath, sucking on ice chips, or using cooling devices such as collars or vests, to help fight fatigue.

Muscle tightness and spasticity will respond to slow-stretching and regular position changes. Weakness and balance dysfunction can be improved with corrective and compensatory strategies.

Evaluation of walking and gait training are extremely important and should be done both at the beginning and at the end of the therapy session to gauge the effect of fatigue. It is quite helpful if the therapy department has a variety of trial ambulation aids to see which (perhaps several) works best.

Understandably, many individuals with MS are initially quite reluctant to accept a walking aid and often delay going to therapy. Common reasons include: "...because I know they'll want me to use a cane;" "...if I start using a walking aid, I'll be dependent on it;" "...people will stare at me;" or "...it means that my MS is getting worse!"

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.

# THE PHILANTHROPY CIRCLE

CHAMPIONS (\$100,000 and up)
Bayer HealthCare Pharmaceuticals
Bayer USA Foundation
EMD Serono, Inc. and Pfizer Inc
Genentech Foundation
Novartis Pharmaceuticals Corporation
Teva Neuroscience

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

Acorda Therapeutics

Medtronic Foundation

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

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

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

### Symptom Awareness: Mobility Independence and Safety

From the standpoint of a PT – an "attitude adjustment" is often needed. I encourage my MS patients to view ambulation aids as "tools" that have the potential to "normalize" their walking pattern. By doing so, this can result in less fatigue, improved posture and balance, less pain, more endurance, and the correct training of the walking muscles.

I have witnessed dramatic improvement in patients' gait and endurance by initially using these aids for "training," and later, just "as needed" for issues such as distance, energy conservation, and worsening symptoms during MS flare-ups. Another factor often overlooked is shoe type, which should be supportive (having an enclosed heel) as well as lightweight. A rubber sole can add to stability, and supportive sneakers with a good cushioned insole and arch support may be an

MSAA, in conjunction with Acorda Therapeutics, Inc., recently conducted a survey on mobility and exercise. More than 2500 of MSAA's clients responded. Based on the results, MSAA found that a significant majority of the respondents indicated that limitations in walking affected the activities in which they were able to participate. While many could benefit from exercise, 25 percent of the respondents had not spoken with their healthcare team about exercise, and 38 percent either never or only occasionally exercise. We hope that MSAA's articles, such as this one on the topic of ambulation, will help to support and encourage individuals to speak to their healthcare team about the possible benefits of appropriate exercise and/or physical therapy.

excellent option. However, rubber soles or sneakers may not be appropriate for everyone, particularly if foot drag or slide might be a problem – because a rubber sole can cause the foot to occasionally "stick."

Many different ambulation "tools" are on the market, so a professional should be involved in assessing and prescribing those best suited to each person's needs. The experienced PT can advise the physician regarding the needed prescription or letter of medical necessity (LOMN). It is not unusual for several aids to be prescribed in order to meet the varying needs for support, distance, and other factors. Some of the most popular ambulation aids are:

- Folding canes (those with a "palm-grip" are the most comfortable)
- *Lightweight* forearm crutches (those with cushioned hand grips and full cuffs are the most desirable)
- Four-wheeled rolling walkers (for the active community user, a lightweight model is preferred, along with the following favorite features: a flip-up seat, no frontcross bar, user-friendly brakes, and a flexible backrest)
- Foot-drop brace (the new lightweight carbon models are popular, but expensive, and only work for certain types of foot drop)
- Functional Electrical Stimulation (FES) this new wireless technology is only appropriate for some; it is also extremely expensive and is not yet covered by insurance; a PT evaluation is highly recommended before purchasing this type of aid

Achieving and maintaining smooth, safe, and independent ambulation will certainly result in improved health and quality of life. However, when that is not possible, numerous wheeled mobility options are available for those with limited or no ambulation abilities. Exercise at any level of ambulation also plays an important role. These will be the topics of the next two articles in this series, which will include "Improving Functional Mobility with Exercise" and "Wheeled Mobility."

This article is one of a series of three that have been written and generously provided to MSAA by Patricia G. Provance, PT, MSCS. Pat is an esteemed member of MSAA's Healthcare Advisory Council.

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





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# Stories to Inspire

# It's the *Little*Things that Count

### Written by Connie Auran

I am a 76-year old woman who has been living with MS for approximately 40 years. I was finally diagnosed at the age of 70, and learning what has been wrong with me all this time has been an eye opener. I have come to realize that it is possible to live easier with this disease, if you just pay attention to the *little* things. I break them into three groups: exercise, water, and food.

I have a good friend who is a does that nurse. When I first told her about my diagnosis, she said, "I will tell you what to do in two words: 'Keep moving!'" I have found several ways to follow this advice. Waking up early is very important. I first get up at about 6:30 am and take my medicine. I then go back to bed for an hour with a cup of coffee and the morning paper. By 7:30 am, I am feeling much better and I am ready to start my day.

One note of caution: the earlier I wake up in the morning, the earlier I need to go to bed at night. Getting enough sleep is just as important as doing appropriate exercise.

Several days each week I go to water aerobics, and I believe this is the best possible exercise for MS. It is wonderful for stretching your muscles and joints. Not only do



Connie Auran cites exercise as one of the many little things she does that pays large dividends for her well-being.

you enjoy a good cardio-respiratory workout, but it also increases muscular strength, muscular endurance, flexibility, and aerobic conditioning.

We are told that heat is one of our enemies. I have read that water cools the body approximately four times – or more (depending on the water temperature) – faster than air. In aquatic fitness classes, the water temperature is below normal body temperature. Because the body is surrounded by the cooler water, heat dissipation through radiation is facilitated. In addition, because participants are surrounded by water, most do not experience the negative effects of heat when exercising in the pool.

### Stories to Inspire: It's the Little Things That Count

"I have come to realize

that it is possible to live

easier with this disease

if you just pay attention

to the little things."

When I can't get to the pool, I exercise with a video tape. There are many good ones available. I have an old tape by Angela Lansbury, which I use on days when the weather or other circumstances keep me at home. I also have a couple of good tapes demon-

strating chair exercises. I just strive to keep moving!

Remember that consistency and repetition are very important. For me, the good effects of an hour's exercise on my body only lasts about 48 hours, and then my body

goes back to zero and I need to start over again. I find that it is best to start slowly and increase my time by small increments every day, or every other day. Exercise is a *little* thing that pays large dividends.

Now my day is off to a good start. I try to make a plan to keep moving during the day. If I do not have a preconceived plan, I tend to spend too much time sitting in front of the computer or at my desk. To avoid sitting too long, I get up whenever the phone rings and walk around the house while I am talking on a cordless phone. This is especially good exercise when talking to a long-winded friend!

Although I work at my computer or desk for part of every day, I also try to get up and do a household chore every 20 minutes. For instance, I might make the bed, put in a load of laundry, or empty the dishwasher. By day's end, I have most of my household chores done as well as having my bills paid! I remember past times when the exercise gurus were telling us that housework could not be

considered exercise because it was not using the right muscles. I am happy to report that the gurus have changed their minds and housework is now considered good exercise!

When I go to the mall, I park at a distance and force myself to walk a block or

two. I use the stairs in a building instead of the elevator. I look for outside adventures that encourage me to walk for short distances. Even if I walk just a *little* bit, it helps.

Next, let's look at water. I

already mentioned water aerobics, which I personally believe is one of the exercises that truly help me to stay active. The next couple of things you have heard many times before, but now I want you to seriously think about them one more time, in relation to you and MS.

Staying hydrated is very important.

Remember that dehydration is one of the causes of fatigue! We often hear that we should drink six to eight glasses of water each day, but you might have trouble doing so unless you have a plan. I try to drink a glass of water with every meal and give one to everyone else who sits at my table. Next, after being outside, I consume a glass of water every time I come into my house. I may be coming in from the yard, shopping, or from visiting neighbors, and it takes some practice, but over time, it can easily become a habit.

Water-based beverages and water-based foods also help. My experience has found that this is very important in hot weather,

### Stories to Inspire: It's the Little Things That Count

"I think I will be able

paying more attention

to live a long and

to small details."

independent life by

and I can almost guarantee that you will feel just a *little* bit better.

"Wash your hands!" Your mother may have said to you constantly. You see a sign with those same instructions in most restau-

rant bathrooms. I have trained myself to be fairly consistent about hand washing, to keep from getting infections which can slow me down. I even wash my hands just before I empty the dishwasher. How long to wash? Try singing "Happy

Birthday" – that's about the length of time it takes to rid your hands of harmful germs. Hand washing is another *little* thing that can be very important.

Do you have trouble sleeping or perhaps cough during the night? Very dry air can sometimes be a factor. I purchased a humidifier and find that I sleep just a *little* bit better. Prices range from \$19 to \$190. I shopped until I found one that is almost silent so it does not keep me awake.

The role of diet and dietary supplements in MS continues to be controversial. I have heard arguments that the evidence is inconclusive and that diet does not play a significant role in MS treatment. As a registered dietitian in my "first life," I do believe that nutrition plays a very important role in maintaining my good health, as it does in all chronic diseases. Good nutrition may also prevent other diseases that can complicate my overall health, which already includes MS. Eating well and exercise helps me make the most of my potential muscle strength

and can even help me to build more strength.

I try very hard to control my weight. I know that extra pounds can increase fatigue, limit my mobility, put a strain on my respira-

tory and circulatory systems, and increase the risk of other chronic diseases. "Temporary" or "fad" diets are not a good idea. I need to remind myself that I have spent a lifetime developing the way I eat and it would be easier for someone to change my reli-

gion than it would be to change the way I eat!

I concentrate on simply making some *little* changes. This includes getting into the habit of emphasizing a wide variety of fruits and vegetables, choosing foods with whole grains, and eating moderate portions. If I could sum it all up in one word, it would be moderation. Portion sizes are one of our biggest problems today. By eating things in moderation, we may be able to enjoy a wider variety of foods.

How about vitamin tablets? We know we need a large variety of vitamins, minerals, enzymes, carotenoids, antioxidants, fatty acids, and many other different agents which will keep our bodies healthy. Some may be found naturally in the foods we eat. You may also find twenty or so of these agents in most multi-vitamins. But everything needed cannot be found in one food or one tablet. The course I follow is to eat as healthy a diet as possible and talk to my doctor about supplements.

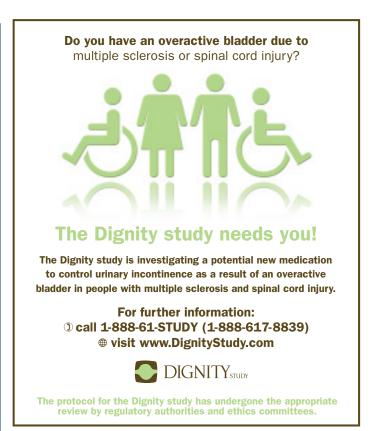
I have recently read two very good books

on the subject of supplements and non-traditional medicine. They are: Alternative Medicine and Multiple Sclerosis and Complementary and Alternative Medicine and Multiple Sclerosis, both by Allen C. Bowling, MD, PhD. Dr. Bowling is the associate medical director of the Rocky Mountain Multiple Sclerosis Center in Englewood, Colorado. (Please note that both of these books are available through MSAA's Lending Library. For ordering information, please see page 48.)

I found that I did not have to change my entire life because I have multiple sclerosis. Instead I found that by making a variety of *little* changes, I was pleasantly surprised at how all of these small improvements added up to a better quality of life for me. The new research is very promising and the future holds a lot of hope. I think I will be able to live a long and independent life by paying more attention to small details.

My advice is to put the gusto back into your life and concentrate on life around you. We may not be able to reverse this disease, but I believe with a bit of work we can manage it, and aim toward feeling our best!

EDITOR'S NOTE: MSAA does not endorse or recommend any specific products or therapies. The lifestyle, exercise, and diet routines of this writer refer to her own personal experiences, and should not be taken as medical advice. Readers are advised to consult their physician before making any changes to their medication, diet, exercise, or other regimen.





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# Spread the Word

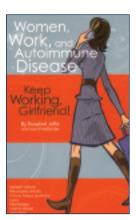
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Guide to Pregnancy and Birth
Written by Judith Rogers, OTR
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THE DISABLED
WOMAN'S GUIDE
to Programmy and Chiefe
Internationals, OTA

Based on the experiences of 90 women with disabilities

MSAA Book #282

who chose to have children, this book is a practical guide for disabled women planning for pregnancy. Health professionals may also find this book to be useful. Topics cover: parenting; emotional concerns; nutrition and exercise; pregnancy, labor, and delivery; postpartum period; and breastfeeding.



Women, Work, and
Autoimmune Disease:
Keep Working, Girlfriend!
Written by Rosalind Joffe, MEd
and Joan Friedlander
Published by Demos
Medical Publishing
MSAA Book # 298

Filled with tips, tricks, and first-person accounts from women who have made similar choices in their own lives, this book encourages women with chronic illness to stay employed to preserve their independence and sense of self. Topics include: reasons to keep working; challenges within the workplace; diagnosis, disease course, and career development; building a support team; and hope and resilience.

Write It Down,
Make It Happen
Written by
Henriette Anne Klauser, PhD
Published by Fireside

MSAA Book # 132



According to the author, simply writing down one's own goals in life is a first step toward achieving them. Dr. Klauser gives "down-to-earth" tips and easy exercises to help readers get their "creative juices flowing." The 20 chapters include such topics as knowing what you want and setting goals, focusing on the outcome, and taking the initiative.

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