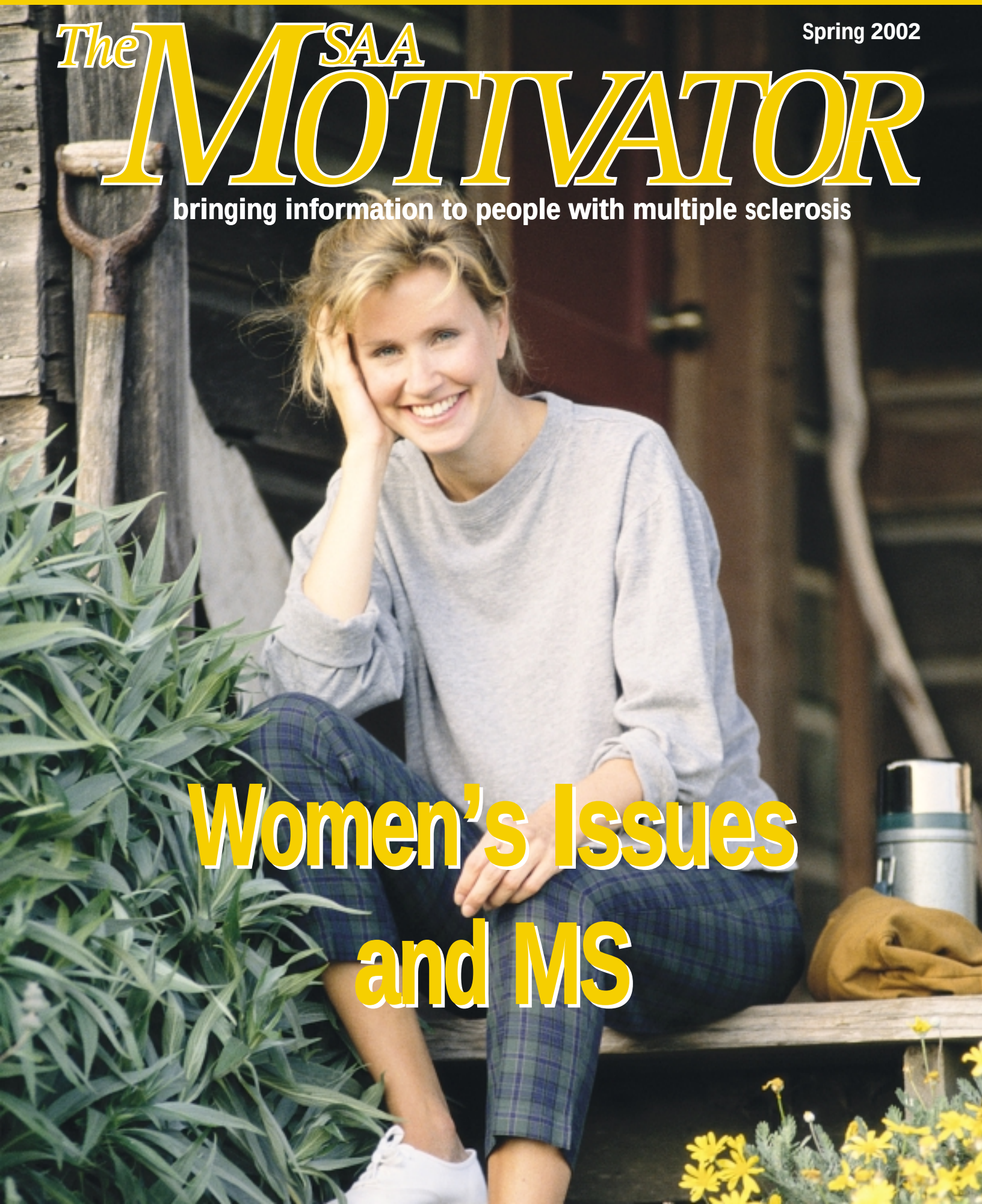
Rebif FDA Approved • Epstein-Barr Virus and MS

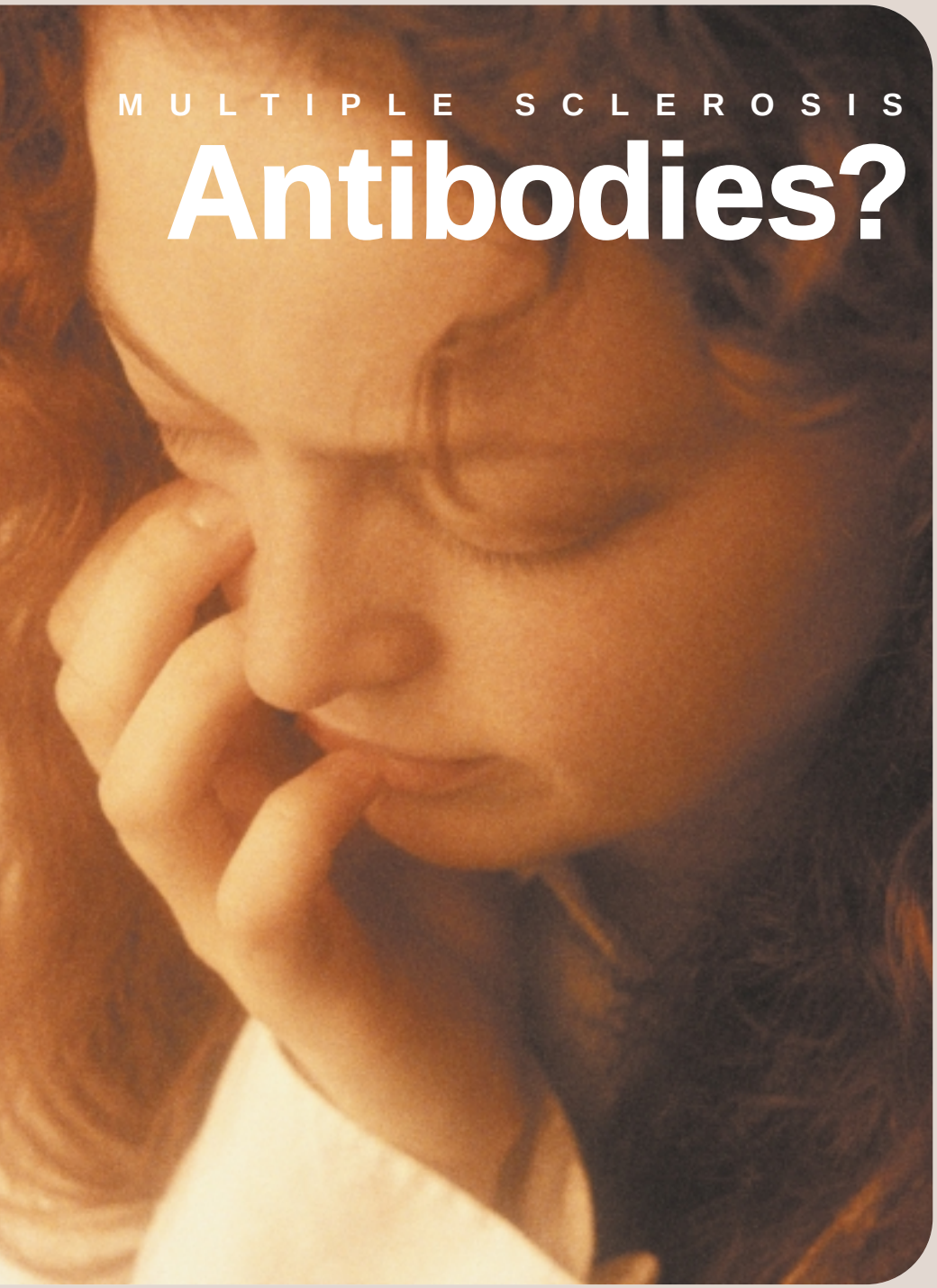
Spring 2002

The SAA MOTIVATOR

bringing information to people with multiple sclerosis



Women's Issues and MS



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- ***Neutralizing antibodies can develop within 12 to 18 months of being on interferon therapies[2]***
- ***Studies have shown that up to one-third of patients on some interferon therapies can develop neutralizing antibodies[2]***

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www.athenadiagnostics.com

1. M. Freedman, "Long-term efficacy of interferon-beta 1a (Rebif) in relapsing-remitting MS: 4-year results of the PRISM study." Paper presented at the American Academy of Neurology 52nd Annual Meeting, San Diego, CA, April 2000.
2. The IFNB Multiple Sclerosis Study and the University of British Columbia MS/MRI Analysis Group. Neutralizing antibodies during treatment of multiple sclerosis with interferon beta-1b: Experience during the first three years. *Neurology* 1996; 47:889-894.

The MSAA MOTIVATOR

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1-800-LEARN MS

Web Site: www.msaa.com

FEATURES

DEPARTMENTS

Breaking Down Barriers • Building Up Hope

UP FRONT

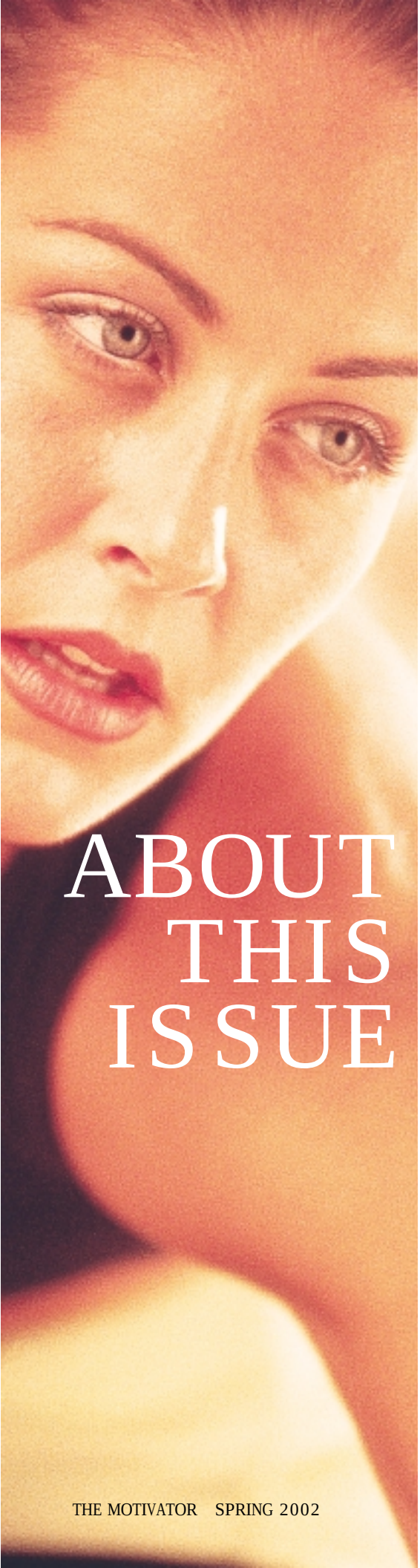
By Douglas G. Franklin

Douglas G. Franklin has been President and Chief Executive Officer of MSAA since April 1999. Mr. Franklin has vast experience in the nonprofit field and is a recognized expert in social marketing. He recently published a book, "Social Marketing for the New Millennium," and he lectures internationally about how charitable organizations can strategically demonstrate the benefits of social involvement to corporate and industrial leaders who can make a difference.

This edition of *The Motivator* features Womens Issues and Multiple Sclerosis. I will never forget the original orientation I had upon taking over the presidency of MSAA, when I learned that women diagnosed with MS outnumber men more than 3 to1. The other shoe dropped for me when I learned that the excessively high divorce rate for people with MS was twice the national average. I've been a single parent looking after someone with special needs and I know what it takes to meet such an important responsibility. How much more difficult it must be to face such challenges without someone who can share or take the job of caregiver. I believe MSAA has an obligation as a charity to reach out to people in need, as is emphasized in the organization's mission statement, "To ease the day-to-day challenges of individuals with MS and their caregivers" especially to those struggling alone.

As I have travelled around the country and attended public education briefings and support group meetings in all regions, the seriousness of the case for support of a nurturing caregiver for everyone fighting MS has been driven home to me time and again. Just recently in Houston, Texas I had the privilege of meeting Alan Osmond from the singing family the "Osmond Brothers." The oldest brother to Donny and Marie, Alan has had to give up his singing, dancing, and musical instruments, but he hasn't given up his fight against MS as he so emphatically states, "I may have MS, but MS doesn't have me." His wife was at the conference with him, and she spoke of how important strong family support was. They have 8 sons and 3 granddaughters, and everyone supports Alan in every way they can. Kelly Sutton was also at the conference. You may remember her from the cover story in the Summer 2000 issue of *The Motivator*. She races cars for Team Copaxone and despite having MS, she fulfilled a lifelong dream when she raced in competition at the Daytona Speedway last year. Her indomitable will to never give up was an inspiration to everyone at the conference.

This edition of *The Motivator* makes a point of holistic responses to women's health issues. It's not just about emotional well-being and nurturing caregivers. It's not just about what drug therapy you're on or should be on. It reminds everyone to advocate for their own health care. MSAA is proud of its efforts to assist with these issues. Our client services team is ready and willing to talk about your issues and offer support and advice. There is so much information available for people with MS. Check out our website, www.msaa.com for other links to useful sites where you can learn from others. Chat with people who are experiencing both the challenge and success of living with MS. Networking with others is critical to your own well-being. It is a big family, and we are all in it together in one manner or another. Together, good things can happen. We are here for you and anxious to help. ■



ABOUT THIS ISSUE

Strive to take charge of your health care. Research shows that when you are not in control of your health management, your immune system may be seriously compromised.

Your health care must belong to you. You know your body better than anyone. In conversations with our clients nationwide, we have learned that our clients are not only at risk of developing problems resulting from the chronic illness of MS, but may also be leaving themselves open to other serious illnesses by putting someone else in charge of their overall health care. Often the focus is on the disability alone, while routine tests and screenings for other conditions may be neglected. Ultimately, some may forget that the person with MS is still susceptible to everything that a person faces in his or her particular age group and gender.

Because MS affects women three times more than men, this issue of *The Motivator* focuses on women's issues and MS. This edition also includes "Pregnancy and MS", which explores the positive findings about MS behavior before and after pregnancy, while providing useful information on medications, complications, delivery, and breastfeeding. In the "Men Count Too" article, helpful advice for men regarding doctor visits and life-saving diagnostic procedures is given to alert our male readers.

In late December, MSAA staff was given the opportunity to attend a conference for women with disabilities. One of the key speakers was Dr. Marie Savard, a renowned physician who recently published a book, "How to Save Your Own Life." In this issue, MSAA will share with our clients all that we have learned from this expert. Dr. Savard shares an array of tools to help us become managers of our own medical lives, from formulating a medical record system to keeping a mini statement of our medical information with us, at all times, right in our wallets!

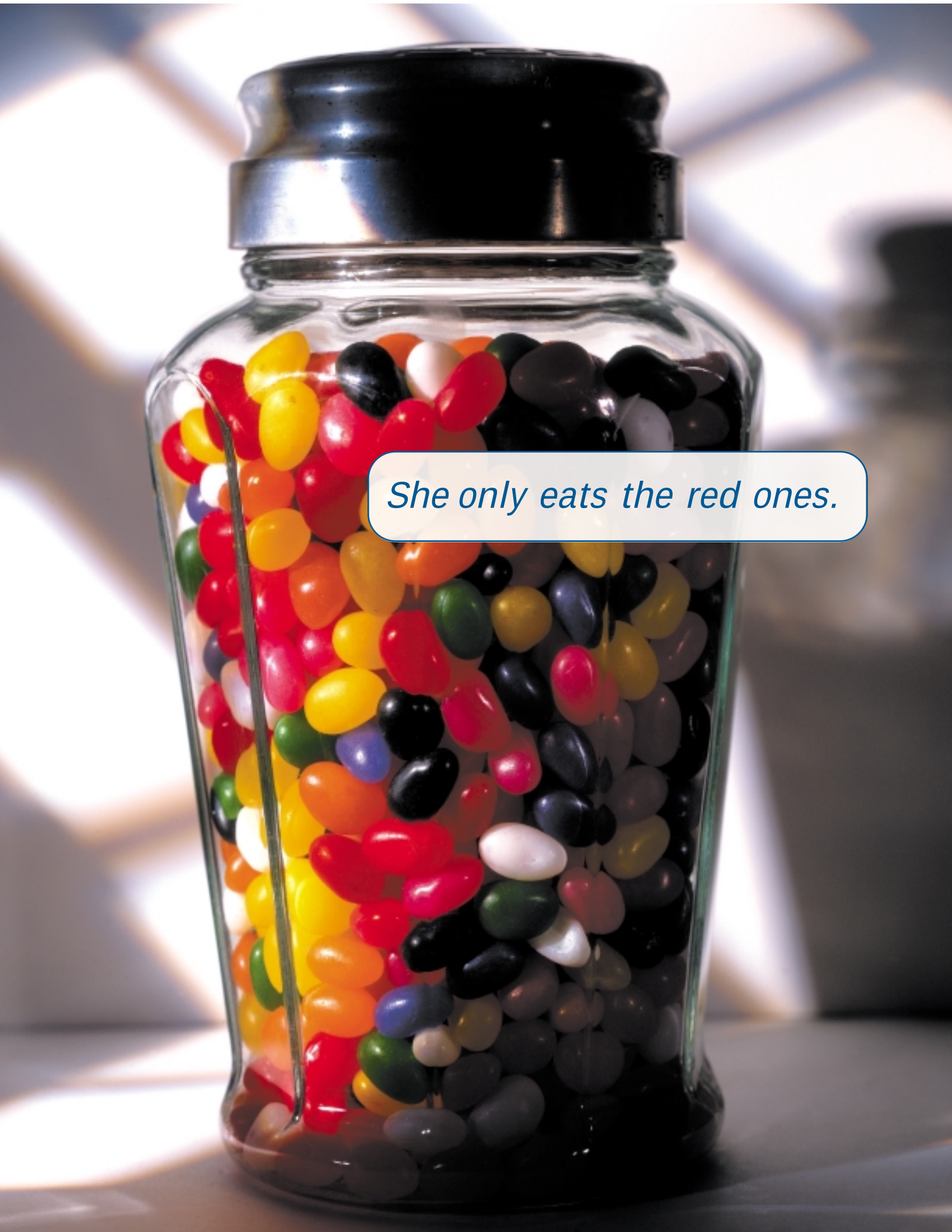
This issue of *The Motivator* may change the course of your life – by informing you of the health problems for which you might be at risk. Readers are informed of the specific diagnostic procedures and tests necessary for early diagnosis and to ensure their good health in the future.

This issue of *The Motivator* also features the recent information regarding the FDA approval of Rebif for relapsing-remitting MS. In addition, "Research News" explores the relationship between Epstein-Barr Virus and MS.

In *The Motivator's* "Program Notes," information on various cooling products is given. These products are available from MSAA's Cool Suit Distribution Program.

In "Up Front," MSAA President, Doug Franklin, expresses challenges for women with MS. Dr. Laurie Laven, a neurologist who has multiple sclerosis answers questions about medications, diet, muscle tone, and hepatitis vaccines in "Ask the Doctor." Gene Gratz reflects on the positive advances of multiple sclerosis research in his column.

— The Editors


She only eats the red ones.

COPAXONE® effectively reduces new brain lesions and relapses.

COPAXONE® reduces the number of new active brain lesions. In a study using MRI, the COPAXONE® group had a 35% median reduction in new brain lesions (11 vs. 17 for placebo, *P*=0.003).

COPAXONE® is effective in reducing relapses. Two clinical trials showed that COPAXONE® reduced relapse rates by 29% (1.19 vs. 1.68 for placebo, *P*=0.055) and 75% (0.6 vs. 2.4 for placebo, *P*=0.005) in a two-year period. Fewer relapses means less time managing the symptoms of MS.

She's just as selective about her MS therapy.

Non-interferon, nonsteroidal COPAXONE® is well tolerated.

The safety and tolerability of COPAXONE® has been well established in clinical trials and tracked over the past seven years. COPAXONE® doesn't cause an increase in fatigue, depression or flu-like symptoms when compared to placebo. There is no liver function or blood-count monitoring required with COPAXONE®. Plus, COPAXONE® now comes pre-mixed in pre-filled syringes for ready-to-use convenience.

Some important information about COPAXONE®

COPAXONE® is indicated for the reduction of relapses in relapsing-remitting multiple sclerosis.

The most common side effects of COPAXONE® are redness, pain, swelling, itching, or a lump at the site of injection, flushing, chest pain, weakness, infection, pain, nausea, joint pain, anxiety, and muscle stiffness. These reactions are usually mild and seldom require professional treatment. Be sure to tell your doctor about any side effects.

Some patients report a short-term reaction right after injecting COPAXONE®. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain with heart palpitations, anxiety, and trouble breathing. These symptoms generally appear within minutes of an injection, last about 15 minutes, and go away by themselves without further problems.

Choose wisely. NON-INTERFERON COPAXONE® (glatiramer acetate injection)

Speak with your doctor or call Shared Solutions™ at 1-800-887-8100 • www.copaxone.com

Please see additional important information at end of ad. Available by prescription only. Individual results may vary.

Pre-mixed.

Pre-filled.

Preferred.*

Get the new **Pre-Filled Syringe** for faster, easier therapy.[1] Another reason people are choosing **COPAXONE®**

- **It's Convenient**: No mixing makes the preparation process faster.
- **It's Consistent**: And easy. You get the right amount of [redacted]on.
- [redacted]eed to administer therapy [redacted]e-Filled Syringe.
- [redacted]ge can be used for manual injection. It is also compatible **only** with the autoject2 *for glass syringe*, which is specifically designed for the Pre-Filled Syringe.

To receive the autoject2 *for glass syringe* absolutely *free of charge*, please call **Shared Solutions™** at **1-800-887-8100**.

Important Information: COPAXONE® is indicated for the reduction of relapses in relapsing-remitting multiple sclerosis.

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*Compared to conventional COPAXONE® method.

Ask your doctor about COPAXONE® and the NEW Pre-Filled Syringe or call 1-800-887-8100.

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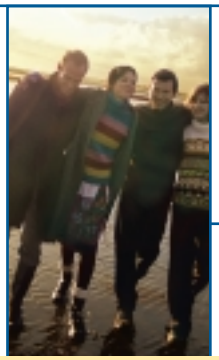
1. Data on file, Teva Neuroscience, Inc.



NON-INTERFERON

COPAXONE®

(glatiramer acetate injection)

Choose wisely.

There are many factors to consider when making an MS therapy decision.

Below are some important issues to discuss with your health care provider.

Aside from the injection frequency, what are the major differences between the therapies?

Will I feel tired or sick because of therapy? Will I experience muscle pains and flu-like symptoms because of therapy? How will this affect my lifestyle?

Are additional tests to monitor my blood, liver or other functions of my body recommended?

Have the effects been studied long-term? How many studies have been done to show efficacy? Do they all have similar results?

Are there differences between the therapies in terms of fatigue?

If I (or someone in my family) have a history of depression or suicidal thoughts, is this the right therapy choice for me?

If you are interested in speaking to someone about his or her experiences on an MS drug therapy,

Call Shared Perspectives™ at 1-800-887-8100 today.

240116/0228C2

PATIENT INFORMATION

COPAXONE® (glatiramer acetate injection)

Read this information carefully before you use COPAXONE®. Read the information you get when you refill your COPAXONE® prescriptions because there may be new information. This information does not take the place of your doctor's advice. Ask your doctor or pharmacist if you do not understand some of this information or if you want to know more about this medicine.

What is COPAXONE®?

COPAXONE® (co-PAX-own) is a medicine you inject to treat Relapsing-Remitting Multiple Sclerosis. Although COPAXONE® is not a cure, patients treated with COPAXONE® have fewer relapses.

Who should not use COPAXONE®?

- COPAXONE® is not recommended for use in pregnancy. So, tell your doctor if you are pregnant or if you plan to become pregnant while taking this medicine.
- Tell your doctor if you are nursing. It is not known if COPAXONE® is passed through the breast milk to the baby.
- Do not use COPAXONE® if you are allergic to glatiramer acetate or mannitol.

What are the possible side effects of COPAXONE®?

- **Call your doctor right away if you develop any of the following symptoms: hives, skin rash with irritation, dizziness, sweating, chest pain, trouble breathing, or severe pain at the injection site.** Do not give yourself any more injections until your doctor tells you to begin again.
- The most common side effects of COPAXONE® are redness, pain, swelling, itching, or a lump at the injection site. These reactions are usually mild and seldom require medical care.
- Some patients report a short-term reaction right after injecting COPAXONE®. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain with heart palpitations, anxiety, and trouble breathing. These symptoms generally appear within minutes after an injection, last a few minutes, then go away by themselves without further problems.
- **If symptoms become severe, call the emergency phone number in your area.** Do not give yourself any more injections until your doctor tells you to begin again.

These are not all the possible side effects of COPAXONE®. For a complete list, ask your doctor or pharmacist. Tell your doctor about any side effects you have while taking COPAXONE®.

How should I use COPAXONE®?

- The recommended dose of COPAXONE® for the treatment of Relapsing-Remitting Multiple Sclerosis is 20 mg once a day injected subcutaneously (in the fatty layer under the skin).
- Look at the medicine in the pre-filled syringe. If the medicine is cloudy or has particles in it, do not use it. Instead, call Shared Solutions at 1-800-887-8100 for assistance.
- Have a friend or relative with you if you need help, especially when you first start giving yourself injections.
- Each pre-filled syringe should be used for only one injection. Do not reuse the pre-filled syringe. After use, throw it away properly.
- Do not change the dose or dosing schedule or stop taking the medicine without talking with your doctor.

How do I inject COPAXONE®?

There are 3 basic steps for injecting COPAXONE® pre-filled syringes:

1. Gather the materials.
2. Choose the injection site.
3. Give yourself the injection.

Step 1: Gather the materials

1. First, place each of the items you will need on a clean, flat surface in a well-lit area:
   - 1 blister pack with COPAXONE® Pre-Filled Syringe
     Remove only 1 blister pack from the COPAXONE® Pre-Filled Syringe carton. Keep all unused syringes in the Pre-Filled Syringe carton and store them in the refrigerator.
   - Alcohol prep (wipe)
   - Dry cotton ball (not supplied)
2. Let the blister pack with the syringe inside warm up to room temperature for 20 minutes.
3. To prevent infection, wash and dry your hands. Do not touch your hair or skin after washing.
4. There may be small air bubbles in the syringe. To avoid loss of medicine when using COPAXONE® pre-filled syringes, do not expel (or do not attempt to expel) the air bubble from the syringe before injecting the medicine.

Step 2: Choose the injection site

- There are 7 possible injection areas on your body: arms, thighs, hips and lower stomach area (abdomen) (See Figure 1).

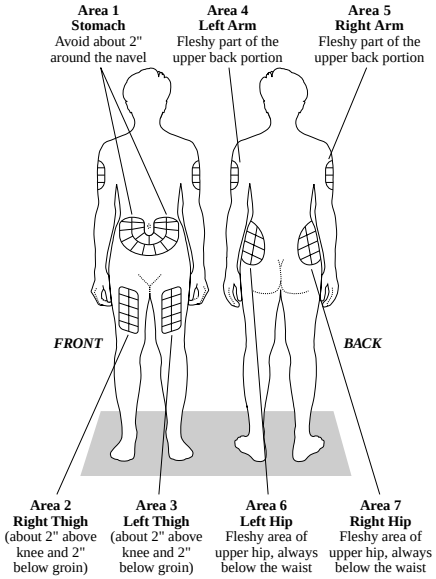
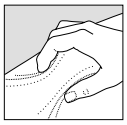


Figure 1

- Each day, pick a different injection area from one of the 7 areas. **Do not inject in the same area more than once a week.**
- Within each injection area there are multiple injection sites. Have a plan for rotating your injection sites. Keep a record of your injection sites, so you know where you have injected.
- There are some sites in your body that may be hard to reach for self-injection (like the back of your arm), and you may need help.

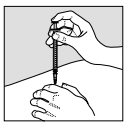
Step 3: Give yourself the injection

1. Remove the syringe from its protective blister pack by peeling back the paper label. Before use, look at the liquid in the syringe. If it is cloudy or contains any particles, do not use it and call Shared Solutions at 1-800-887-8100 for assistance. If the liquid is clear, place the syringe on the clean, flat surface.
2. Choose an injection site on your body. Clean the injection site with a new alcohol prep and let the site air dry to reduce stinging.
3. Pick up the syringe as you would a pencil. Remove the needle shield from the needle.



4. With your other hand, pinch about a 2-inch fold of skin between your thumb and index finger (See Figure 2).

Figure 2



5. Insert the needle at a 90-degree angle (straight in), resting the heel of your hand against your body. When the needle is all the way in release the fold of skin (See Figure 3).

Figure 3

6. To inject the medicine, hold the syringe steady and push down the plunger.
7. When you have injected all of the medicine, pull the needle straight out.
8. Press a dry cotton ball on the injection site for a few seconds. **Do not rub the injection site.**
9. Throw away the syringe in a safe hard-walled plastic container.

What is the proper use and disposal of Pre-Filled Syringes?
Each Pre-Filled Syringe should be used for only 1 injection. Throw away all used Pre-Filled Syringes in a hard-walled plastic container, such as an empty liquid laundry detergent bottle. Keep the container closed tightly and out of the reach of children. When the container is full, check with your doctor, pharmacist, or nurse about proper disposal, as laws vary from state to state.

How should I store COPAXONE® Pre-Filled Syringes?
Keep the COPAXONE® Pre-Filled Syringe carton in the refrigerator, out of the reach of children.

The COPAXONE® package should be refrigerated as soon as you get it, at 36-46°F (2-8°C). If you cannot store COPAXONE® in a refrigerator, you can store it at room temperature, 59-86°F(15-30°C), for up to 7 days. Do not store COPAXONE® at room temperature for longer than 7 days. **Do not freeze COPAXONE®.** If a COPAXONE® pre-filled syringe freezes, throw it away in a proper container.

COPAXONE® is light sensitive. Protect it from light when not injecting. Do not use the pre-filled syringe if the solution contains particles or is cloudy.

General advice about prescription medicines
Medicines are sometimes prescribed for conditions that are not mentioned in patient information leaflets. Do not use COPAXONE® for a condition for which it was not prescribed. Do not give COPAXONE® to other people, even if they have the same condition you have. It may harm them.

This leaflet summarizes the most important information about COPAXONE®. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about COPAXONE® that is written for health professionals. Also, you can call Shared Solutions for any questions about COPAXONE® and its use. The phone number for Shared Solutions is 1-800-887-8100.

TEVA® NEUROSCIENCE

Manufactured For: **TEVA Neuroscience, Inc.,** Kansas City, MO 64131
Manufactured By: **Baxter Pharmaceutical Solutions LLC,** Bloomington, IN 47403
Distributed by: **Aventis Pharmaceuticals Inc.**, Kansas City, MO 64137

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PLEASE NOTE: In the last issue of *The Motivator* (Pain: Unnecessary With or Without MS, Winter 2002) the American Pain Foundation was listed as a resource. The office has moved to a new location. Their phone number has remained the same as well as their website. Their contact information with the new address is:

American Pain Foundation
201 N. Charles Street, Suite 710
Baltimore, Maryland 21201-4111
Phone: 888-615-PAIN (7246)
Email: info@painfoundation.org
www.painfoundation.org

Women's Issues and MS

Women are three times as likely to develop multiple sclerosis than men according to MSAA medical advisor, Dr. Jack Burks. Since the MS population is predominately made up of women, it seems only appropriate to address health care issues related to such a large number of MSAA clients, although there are many areas in which certain health care practices apply to both women and men.

Marie Savard, M.D., an internist and advocate of patients' rights

Marie Savard, M.D., an internist, advocate of patients' rights, and author of *How to Save Your Own Life* and *The Savard Health Record* urges people to become active participants in their own health care. She explains, "Women are not getting their health care needs addressed." In an effort to resolve some of these needs, she offers many suggestions for managing one's heath care.

Dr. Savard explains that one aspect of managing your health care is keeping a health journal. She says, "If you have a chronic condition or a history of recurring episodes of any disorder, or if you're on medications, you should keep a meticulous health journal." She adds, "You can track symptoms and have a running record of everything from weight gain or loss to vague complaints to side effects of medications. With that kind of a log at your disposal, you can help your doctor quickly spot patterns and zero in on possible problems. Remember, about 80 percent of what your doctor uses to make a diagnosis comes from what you tell him or her about yourself and your family history."

According to The National Women's Health Information Center, "Women with disabilities often do not receive adequate and necessary health care services important for all women. Among the women with disabilities who did not have regular pelvic exams, the most frequently selected reason [was] difficulty getting onto the exam table."

Accessibility within a physician's office often creates challenges for many women with disabilities. While no one typically enjoys making a visit to the doctor, many disabled

women ignore their regular health care exams because of the obstacles they may encounter within the physician's examination room. One of which can be an examination table that may be difficult, or worse, impossible to transfer to from a wheelchair.

According to Dr. Savard, most doctors don't have accessible exam tables, however, there is a more important element - people available in the office to assist the person with the disability. She says, "We must realize it may be difficult to find a physician with special equipment for people with disabilities. The physical assistance from office personnel is more critical." Dr. Savard relates an experience encountered by one of her patients who has MS and severe spasticity in her legs as a result of the disease. Dr. Savard recognizes the need for a *minimum* of two people to assist this particular patient in order to make her feel comfortable. And that is key. A person with a disability should not have to feel uncomfortable during the exam visit just because of that disability.

Even before a physical exam takes place, communication plays a key factor. In order to save one's time and energy, Dr. Savard urges anyone with a disability to communicate with the physician's office personnel. There are three things a person can do to make a visit to the doctor more effective and efficient. According to Dr. Savard, "When you call to schedule your appointment, it's important to express the need for a complete physical exam. This conveys that you are requesting the maximum amount of time permitted and therefore, the physician will schedule you in the longest time allotment available.

Another issue to consider is if you are relying on a general physician to conduct exams such as a mammogram or breast examination, be sure the physician is comfortable performing that particular exam. Although we sometimes assume all general practitioners are experienced in conducting every type of exam, Dr. Savard emphasizes that the patient needs to find out if the physician is experienced in the particular exam they require so as to receive optimum care. Ask if the physician specifically has experience in examing people with disabilities.

Calling the physician's office to make certain he or she has the resources one requires is imperative whether that resource is a special examination table, or if that is not available, extra personnel to assist. It's important to call the doctor's office the morning of the appointment to emphasize any special needs that one may require. Dr. Savard urges, "Be as specific as possible with your questions."

"Another must," says Dr. Savard "is to bring along a 'health buddy' – a friend or family member to essentially be your second set of eyes and ears. You should go to your appointment with both an agenda and a buddy to write important notes so you can be intent on listening. The one downfall to having a person join you during your appointment is the chance of the doctor communicating with your buddy rather than you. Your friend or family member may have to say, 'I'm just here to take notes' so as to direct the conversation to the patient. As much as 30 to 50 percent of information is forgotten by people with a chronic illness when they walk out of the doctor's office, which is why it is so important to have another person with you at your appointment." Dr. Savard adds, "Research has proven the more prepared you are, along with having someone else at the doctor's appointment with you, the more likely the physician will say more and spend more time with you."

Although a person may be coping with the effects of multiple sclerosis, that doesn't necessarily mean one's health care is being managed. It's important not to attribute all symptoms or problems one may be experiencing to MS. There are specific examinations women need to consider and ultimately have performed in terms of their overall health care plan. The following lists some of those exams and details at what point in her life a woman needs to address them along with how frequently.

Every woman age eighteen and older should have a professional breast exam annually. During this brief exam, the doctor will check for lumps and abnormalities. The purpose for the exam is to check for signs of breast cancer. Dr. Savard recommends women schedule their breast exam appointment one week after they have begun menstruating, which is when breasts are less likely to have lumps. Women should also perform their own breast exam once a month. After menopause, women should continue to perform the exam themselves every month.

A mammogram is an X-ray that can detect breast cancer early, sometimes before a lump can even be felt. Women should have a mammogram every year or two from ages forty to fifty. Once a woman reaches age fifty, a mammogram should be conducted every year. Men who detect breast lumps should also have mammograms. Although breast cancer is more prevalent in women, men are not immune to it. They too should see a physician if they detect any lumps or abnormalities. Most mammogram machines can be lowered to allow the test to be performed on someone using a wheelchair.

Knowing your family history and having exams performed accordingly is critical. For example, if a family member had breast cancer or colon cancer, it is advised to screen for that particular condition earlier than the recommended age of screening.

Another condition women are more prone to than men is osteoporosis. Dr. Savard recommends, "All women over sixty-five and all postmenopausal women not taking hormone therapy should have a dual X-ray absorptiometry scan (DEXA or DXA scan)." This X-ray measures bone density. A loss of bone density is a symptom of osteoporosis. Women with MS are at an increased risk for falls which may create a more severe problem when combined with osteoporosis.

Once a woman becomes sexually active, a Pap test is recommended every one to three years. It may be necessary to have this test more frequently depending on certain conditions, such as a pre-cancerous lesion. Dr. Savard notes, "It is possible to get false results from a Pap smear, but the test is accurate over 90 percent of the time."

Women also need to have a pelvic exam every year from the time they are sexually active. This exam checks for any abnormalities of the cervix and vaginal area as well as any enlargement of the uterus and/or ovaries.

Rectal exams are recommended to detect colon cancer in both men and women. The exam should be performed annually or every other year after age forty and annually after age fifty.

Women who have a uterus but are taking only estrogen without progesterone (ie unopposed estrogen) should have an endometrial biopsy every year (Women who don't have a uterus, should only take estrogen.). This test should also be conducted for postmenopausal women who are experiencing abnormal bleeding. Dr. Savard expains, "This test can detect endometrial cancer as well as

a benign postmenopausal condition in which the endometrium (lining of the uterus) is too thick."

Another important aspect of one's health care is obtaining results from blood work and cholesterol readings. One's total cholesterol is made up of low density lipoprotein (LDL) which is considered "bad cholesterol" and high density lipoprotein (HDL), known as "good cholesterol."

Dr. Savard explains, "Women naturally have higher levels [of HDL] than men, although they have less of an advantage after menopause." Being sedentary can lower your HDL to a degree. A total cholesterol of under 200 is recommended. A normal LDL is 130 or less, although a LDL of under 100 is recommended if you have already had heart disease.

In order to determine your risk for heart disease, the following information is required: total cholesterol (including HDL and LDL), triglycerides (primary form of fat in blood), and thyroid evaluation (measures the level of thyroxine 3 (T3) and thyroxine 4 (T4) which are hormones produced by the thyroid gland and regulate metabolism).

During a complete physical examination, blood may be taken in order to do a complete blood count (CBC). A CBC indicates the number, size, and shape of the different types of cells in blood. Results from a CBC can determine many aspects of one's health, including anemia, nutritional deficiencies, and different types of infections among several other conditions.

Blood tests can reveal whether or not a woman has entered menopause, at which time she may consider hormone replacement therapy (HRT). HRT carries both benefits and risks. The medical community agrees that HRT helps with the symptoms of menopause and to prevent osteoporosis or bone loss but we do not have enough research to say whether or not HRT protects from heart disease, another reason women were commonly prescribed HRT in the past. Dr. Savard explains, "What hormones do that nothing else achieves is quality of life. If you're going through mood swings or hot flashes, nothing else works as well as hormones, such as estrogen." The best advice is to discuss both the pros and cons of HRT with your physician in order to determine the best possible choice for you.

Dr. Savard encourages every person to obtain results of every test and procedure. She says, "Let your doctor know that you won't make a nuisance of yourself with your requests, and that you'll make things easy for him by handing the office manager a self-addressed stamped envelope with a note giving the current date, the records you want sent to you, your name in block letters, your signature, and your date of birth." She goes on to say, "You may assume that everything is fine if you don't hear anything, but the truth may very well be that your results were misinterpreted, filed in someone else's folder, or just plain lost." Dr. Savard adds, "Have the courage to ask questions when your instincts tell you something may not be right."

In addition to regular health screenings, there are other factors that need to be considered. One of which is fatigue related to MS. Fatigue can often be a dominating symptom for people with multiple sclerosis. Many women with MS may be experiencing fatigue as a result of juggling many responsibilities such as a career, parenting, and coping with a chronic illness along with other daily challenges. Over-exertion can lead to fatigue which in serious cases, may lead to an exacerbation.

Over-exertion or over-functioning factors according to Dr. Savard include lack of sleep,

mental stress, and physical stress. She says, "Although most people probably think physical stress is more draining, lack of sleep and mental stress can actually affect a person more. Sleep is a critical factor in managing one's health care. Getting enough sleep is one of the healthiest habits a person can have and should be considered one of the most important factors. An adequate amount of sleep makes all the difference in a healthy lifestyle.

"Mental stress can sometimes drain a person more than physical activity. In order to combat this, identify the things that give you the stress. Often we can't rid ourselves of the everyday stresses, but the first step is to recognize that you're more vulnerable to stress because of having MS. You need to be aware and understand that you have these additional stressors. Once they have been recognized, they will be more manageable. Similar to mental stress, the key to physical stress is knowing what your limits are."

One important tool for both men and women is keeping a health calendar. Dr. Savard recommends including when inoculations are required according to standard guidelines, with dates and times of exams. Additional exams can then be included after discussing risk factors with your physician. The health calendar should also include appointments and when prescriptions need refilling.

Dr. Savard also recommends carrying a personal health information list in your wallet including the following information: name, date of birth, address, phone, email address; serious adverse reactions to drugs, bee stings, food, X-ray "contrast dyes;" medical conditions; a current list of medications, including dose and directions; significant family condition; date of last immunization of tetanus/diphtheria, pneumonia, and flu; physician's name, address, and phone number; emergency contact; living will information; and durable power of attorney.

Dr. Savard recommends *The Merck Manual of Diagnosis and Therapy*, *Harrison's Principles of Internal Medicine*, and *Dorland's Illustrated Medical Dictionary* for researching health and medical information. In addition, the following web sites may be helpful: **www.DrSavard.com**, Dr. Marie Savard's web site; **www.4woman.gov**, The National Women's Health Information Center; **www.guidelines.gov** for information pertaining to screening guidelines, and **www.ahcpr.gov**, the Agency for Healthcare Research and Quality. In addition, MSAA's client services department (1-800-532-7667) is available to address your health care concerns. ■

— Andrea Borkowski

MS and Pregnancy

MS does not impede one of a woman's most important rites of passage, having a baby.

Women with MS can conceive and carry a child to term with no increased risk of complicating MS or causing exacerbations. Studies also show that childbearing has no long-term effect on the progression of MS or the number of relapses a woman might have during her lifetime.

More clinical tests must be done to establish conclusive, or at least "rule of thumb," data. From studies that have taken place, it seems clear that women with MS usually go into symptom remission during pregnancy, particularly during the last trimester, but have a better than average chance of experiencing relapses and exacerbations during the six months immediately following delivery.

Pregnancy and how gestation affects MS is an important issue for women with MS because many will be diagnosed with the disease while in the midst of their childbearing years.

While having a baby does not affect the long-term course of the disease, some women choose to forgo pregnancy because they worry about taking care of a child in the event their MS will progress. Decisions about whether to bear children are personal and are left up to the individual woman to ponder and make.

In general, "MS does not appear to reduce a woman's fertility," wrote Dr. Herman J. Weinreb in a 1996 article. "In one study," Weinreb continues, "the number of pregnancies in women with MS was not different from control groups. Uncomplicated MS has no effect on pregnancy, labor, or delivery, and MS does not affect the duration of the stages of labor."

Weinreb also reports that pregnancy has no lasting effect on MS. One test, however, showed that compared to other females with MS, women who have had children show a decrease in disease activity. In *Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation* by Dr. Jack Burks and Dr. Kenneth P. Johnson, Dr. Patricia Coyle cites a European study that involved 254 women and 269 pregnancies and showed a 70 percent decline in clinical relapse rate in the last trimester. Coyle goes on to say that "the protective state of late pregnancy undoubtedly relates to the fact that pregnancy is an immunosuppressive state." This, she adds, "derives from a combination of factors, including the presence of pregnancy-related immunoregulatory proteins and the pregnancy-related hormone, prostanglandin."

Weinreb says MS acts like other autoimmune disorders by improving during pregnancy and worsening in the postpartum period. "Exacerbation rates during the first six months postpartum," he writes, "consistently show significant increase. Overall, the risk of relapse in the pregnancy year increases by twofold. Studies show that risk is greatest

during the first three postpartum months when about 20 to 40 percent of women with MS develop a postpartum exacerbation. Coyle also says there is an increased risk of relapse in the three months following delivery but adds some postpartum attacks may be preventable with available immunotherapies. In any case, a woman with MS who becomes pregnant should set up a mutual consultation schedule between her neurologist and obstetrician. This gives them the chance to work together to make sure the women is getting the information she needs to account for all of her medical circumstances.

Pregnancy is not associated with any negative effects on MS over the short or long term. Coyle reports several studies that state pregnancy may improve a woman's long-term prognosis. (A recent Australian study, conducted at the University of New South Wales, says EPF, a hormone produced early in pregnancy might actually offer a breakthrough treatment for dealing with MS in general.)

Treatment of MS may have to be altered during pregnancy. Weinreb and Coyle both say that pregnant women with MS should stop all immunosuppressive drugs and all non-essential medicines. Some therapies, e.g. diazepam, phenytoin, and carbamazpine, Weinreb says, have been associated in the first trimester with congenital anomalies, premature delivery, low birth weights, and malformations. Coyle says most physicians will discontinue interferon-beta treatment for women with MS who become pregnant. She adds no data indicates glatiramer acetate has a negative effect on the fetus and adds further that interferon-beta 1a (Avonex and Rebif), interferon-beta 1b (Betaseron), and glatiramer acetate (Copaxone) have all been used during pregnancy without obvious negative effect. The FDA has rated Copaxone potentially safer for

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pregnancy than the interferons, although none of them are recommended for use during pregnancy. Again, it is best for a woman to have her neurologist and obstetrician discuss her individual needs and precautions regarding MS treatments during her pregnancy.

Weinreb reports that MS symptoms that could increase during pregnancy include fatigue, urinary tract infections, mechanical effects of bowel and bladder function, and problems with ambulation. Some of these are common to all women, with MS or not. Aetna Insurance's InteliHealth website, the medical portions of which are reviewed by Harvard Medical School, suggests that pregnant women with MS install grab bars in their homes if they feel more unsteady on their feet than usual.

Coyle and Weinreb agree that no special precautions for labor and delivery are necessary for women with MS. However, before a pregnant women with MS gets a spinal anesthesia, she should discuss it with her physician or MS expert to weigh the risks and benefits.

Weinreb warns spasticity may increase during labor and delivery. He adds baclofen may be effective in managing spasticity during labor and delivery.

Coyle says the European study that reported a decrease in MS activity during pregnancy also noted a trend towards less disease activity in women who breastfeed their newborns. Weinreb cautions, however, that breastfeeding should "be abandoned if corticosteroids and immunosuppressants are prescribed because they are secreted in breast milk." He adds that corticosteroids may help resolve postpartum exacerbations and that their effectiveness in that situation may have to be weighed against the desire to breastfeed. ■

— Neal Zoren

Men Count Too

Men, like women, are composed of more than myelin and axons.

Unlike women, men have prostates that need to be tested regularly – annually after age 50 – for evidence of cancer, prostate cancer being, statistically, one of the leading killers of men.

Many men tend to neglect regular medical examinations, and delay treatment for symptoms such as chest pain, ignore rules of good diet or general physical wellness, and, compared to women, often do less purposeful, targeted exercise even if they are athletically active.

Therefore, men with MS, men who no doubt regularly visit their neurologists and faithfully take their drug treatments, have to be as cognizant and careful about their overall health as they are about medical issues related to their MS.

Men with MS must join most of their male brethren in developing habits of good health maintenance, starting with annually scheduled physical exams and continuing with measures that may prevent health problems from occurring, or at least detect them early enough to give doctors a chance at treating them effectively.

Prostate cancer is a leading killer of men. It's especially dangerous because it often sneaks up silently, with no presenting symptoms. Men aged 50 and older are advised to get a Prostate Specific Antigen (PSA) screening every year. This is a simple blood test that measures a protein in the blood that if elevated, may signal prostate cancer. African American men and men whose fathers, grandfathers, or siblings have had prostate cancer should be checked annually after age 40.

My doctor, in prescribing a colon screening, said the more silently a disease comes, the more deadly it's likely to be if treated too late. That was enough to get me to schedule a colonoscopy, which can detect colon cancer anywhere in the colon even when it is in the pre-malignant stage. This test can be done every five to ten years. A sigmoidoscopy checks only the lower part of the colon and should be done approximately every three years so doctors can get early signals of colon or rectal cancer or other problems. These tests are done with a flexible tube that has a mini-camera and light attached to it, as well as pincers that can snip polyps or collect suspicious tissue for biopsy. Annual rectal examinations and tests for blood in the stool are recommended for men age 40 and older to check for early colon cancer as well.

Lifestyle can contribute to heart disease, the number one killer of men and women. Diets dominated by fatty or fried foods, high blood pressure and cholesterol, smoking, activity that doesn't amount to exercise, and daily stress can greatly increase your chances of heart disease. One's blood pressure should be taken regularly. Blood tests should be conducted annually. These tests can reveal a lot, especially those that measure cholesterol, lipids (fatty acids such as triglyceride), and blood sugar, tests which can be used to detect or predict clogged

arteries or arteriosclerosis and diabetes. To truly test the soundness of one's heart, doctors recommend men have an EKG (electrocardiogram) done every four years after age 40 and every three years after age 50. If you are over 40 and have one or more risk factors for heart disease including a family history, ask your doctor about doing a baseline EKG and stress test.

During a routine examination, doctors often sound lungs to test respiratory health. Limbs and muscle tone are examined. So are eyes, ears, the esophagus, and nasal passages. Weight and diet are discussed (a necessary talk considering many men are overweight, if not morbidly, obese). Weight control can be of special importance to men with MS who struggle to maintain a comfortable number of pounds while often having to remain sedentary. Exercise and stretching is especially important, even for individuals who have limited mobility.

And remember, one possible – and frequent – byproduct of regular physical examinations and routine tests is the peace of mind that comes when you're issued a clean bill of health or told that anything that is going awry is manageable.

The point is a man with MS cannot be aware of everything about his health if he concentrates only on his MS. More and more, conventional wisdom among doctors is a team approach that attends to all parts of the body, bloodstream, and nervous system.

Men with MS may have many of the same issues with accessibility at clinics and doctor's offices as women do. Better to address and correct these impediments than to use them as an excuse to avoid seeking regular, often preventative, medical care and find one's MS is being managed well, but one's heart, liver, lungs, colon, and prostate are causing more dire problems. ■

— Neal Zoren

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Common side effects of Betaseron therapy include flu-like symptoms, shortness of breath, menstrual disorders, and injection-site reactions; redness, pain, swelling, and blue-black discoloration have been reported.

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BRIEF SUMMARY

INDICATIONS AND USAGE

Betaseron is indicated for use in ambulatory patients with relapsing-remitting multiple sclerosis to reduce the frequency of clinical exacerbations. Relapsing-remitting MS is characterized by recurrent attacks of neurologic dysfunction followed by complete or incomplete recovery. The safety and efficacy of Betaseron in chronic-progressive MS has not been evaluated.

CONTRAINDICATIONS

Betaseron is contraindicated in patients with a history of hypersensitivity to natural or recombinant interferon beta, Albumin Human USP, or any other component of the formulation.

WARNINGS

One suicide and 4 attempted suicides were observed among 372 study patients during a 3-year period. All five patients received Betaseron (three in the 0.05 mg group and two in the 0.25 mg group). There were no attempted suicides in patients on study who did not receive Betaseron. Depression and suicide have been reported to occur in patients receiving interferon alfa, a related compound. Patients to be treated with Betaseron should be informed that depression and suicidal ideation may be a side effect of the treatment and should report these symptoms immediately to the prescribing physician. Patients exhibiting depression should be monitored closely and cessation of therapy should be considered.

Injection site necrosis (ISN) has been reported in 5% of patients in controlled clinical trials (see **ADVERSE REACTIONS** section). Typically, injection site necrosis occurs within the first 4 months of therapy, although post-marketing reports have been received of ISN occurring over 1 year after initiation of therapy. Necrosis may occur at single or multiple injection sites. The necrotic lesions are typically 3 cm or less in diameter, but larger areas have been reported. While necrosis has commonly extended only to subcutaneous fat, there are also reports of necrosis extending to and including fascia overlaying muscle. In some lesions where biopsy results are available, vasculitis has been reported. For some lesions debridement and, infrequently, skin grafting has been required.

As with any open lesion, it is important to avoid infection and, if it occurs, to treat the infection. Time to healing has varied depending on the severity of the necrosis at the time treatment was begun. In most cases healing was associated with scarring.

Some patients have experienced healing of necrotic skin lesions while Betaseron® (Interferon beta-1b) therapy continued; others have not. Whether to discontinue therapy following a single site of necrosis is dependent on the extent of necrosis. For patients who continue therapy with Betaseron after injection site necrosis has occurred, Betaseron should not be administered into the affected area until it is fully healed. If multiple lesions occur, therapy should be discontinued until healing occurs.

Patient understanding and use of aseptic self-injection techniques and procedures should be periodically reevaluated, particularly if injection site necrosis has occurred.

PRECAUTIONS

General: Patients should be instructed in injection techniques to assure the safe self-administration of Betaseron. (See **PRECAUTIONS: Information to patients**, and **Betaseron Patient Information** sheet.)

Information to patients:

Instruction on self-injection technique and procedures. Patients should be instructed in the use of aseptic technique when administering Betaseron. Appropriate instruction for reconstitution of Betaseron and self-injection should be given including careful review of the **Betaseron Patient Information** sheet. If possible, the first injection should be performed under the supervision of an appropriately qualified health care professional.

Patients should be cautioned against the re-use of needles or syringes and instructed in safe disposal procedures. A puncture resistant container for disposal of used needles and syringes should be supplied to the patient along with instructions for safe disposal of full containers.

Patients should be advised of the importance of rotating areas of injection with each dose, to minimize the likelihood of severe injection site reactions or necrosis (see **Rotating Injection Sites** section of **Patient Information** sheet).

Patients should be cautioned not to change the dosage or the schedule of administration without medical consultation.

Awareness of adverse reactions. Serious adverse reactions associated with the use of Betaseron have been reported including depression and injection site necrosis (see **WARNINGS** section).

Patients should immediately report symptoms of depression or suicidal ideation to their physician. The symptoms of depression should be closely monitored by a physician.

Injection site necrosis was reported in 5% of patients in a controlled MS trial. If the patient experiences any break in the skin, which may be associated with blue-black discoloration, swelling, or drainage of fluid from the injection site, the patient should be advised to promptly contact their physician prior to continuing their Betaseron therapy.

Other injection site reactions occurred in eighty-five percent of patients in the controlled MS trial, at one or more times during therapy. There was redness, pain, swelling and discoloration. In general, these were transient and did not require discontinuation of therapy, but the nature and severity of all reported reactions should be carefully assessed (see **ADVERSE REACTIONS** section).

Flu-like symptoms are common following initiation of therapy with Betaseron. In the controlled MS clinical trial, acetaminophen was permitted for relief of fever or myalgia (see **ADVERSE REACTIONS** section).

Patients should be cautioned about the abortifacient potential of Betaseron (see **PRECAUTIONS, Pregnancy - Teratogenic effects**).

Laboratory tests: The following laboratory tests are recommended prior to initiating Betaseron therapy and at periodic intervals thereafter: hemoglobin, complete and differential white blood cell counts, platelet counts and blood chemistries including liver function tests. In the controlled MS trial, patients were monitored every 3 months. The study protocol stipulated that Betaseron therapy be discontinued in the event the absolute neutrophil count fell below 750/mm^3. When the absolute neutrophil count had returned to a value greater than 750/mm^3, therapy could be restarted at a 50% reduced dose. No patients were withdrawn or dose reduced for neutropenia or lymphopenia.

Similarly, if hepatic transaminase (SGOT/SGPT) levels exceeded 10 times the upper limit of normal, or if the serum bilirubin exceeded 5 times the upper limit of normal, therapy was discontinued. In each instance during the controlled MS trial, hepatic enzyme abnormalities returned to normal following discontinuation of therapy. When measurements had decreased to below these levels, therapy could be restarted at a 50% dose reduction, if clinically appropriate. Two patients were dose reduced for increased liver enzymes; one continued on treatment and one was ultimately withdrawn.

Drug interactions: Interactions between Betaseron and other drugs have not been fully evaluated. Although studies designed to examine drug interactions have not been done, it was noted that corticosteroid or ACTH treatment of relapses for periods of up to 28 days has been administered to patients (N=180) receiving Betaseron.

Betaseron administration to three cancer patients over a dose range of 0.025 mg to 2.2 mg led to a dose-dependent inhibition of antipyrine elimination. The effect of alternate-day administration of 0.25 mg of Betaseron on drug metabolism in MS patients is unknown.

Carcinogenesis: The carcinogenic potential of Betaseron was evaluated by studying its effect on the morphological transformation of the mammalian cell line BALBc-3T3. No significant increases in transformation frequency were noted. No carcinogenicity data are available in animals or humans.

Betaseron® (Interferon beta-1b) was not mutagenic when assayed for genotoxicity in the Ames bacterial test in the presence or absence of metabolic activation.

Impairment of fertility: Studies in rhesus monkeys at doses up to 0.33 mg/kg/day (32 times the recommended human dose based on body surface area comparison*) in normally cycling rhesus female monkeys had no apparent adverse effects on the menstrual cycle or on associated hormonal profiles (progesterone and estradiol) when administered over 3 consecutive menstrual cycles. The extrapolability of animal doses to human doses is not known. Effects of Betaseron on normal cycling human females are not known. *body surface dose based on 70 kg female

Pregnancy - Teratogenic effects: Pregnancy Category C: Betaseron was not teratogenic at doses up to 0.42 mg/kg/day in rhesus monkeys, but demonstrated a dose-related abortifacient activity when administered at doses ranging from 0.028 mg/kg/day (2.8 times the recommended human dose based on body surface area comparison) to 0.42 mg/kg/day (40 times the recommended human dose based on body surface area comparison). The extrapolability of animal doses to human doses is not known. Lower doses were not studied in monkeys. Spontaneous abortions while on treatment were reported in patients (n=4) who participated in the Betaseron MS clinical trial. Betaseron given to rhesus monkeys on gestation days 20 to 70 did not cause teratogenic effects, however, it is not known if teratogenic effects exist in humans. There are no adequate and well-controlled studies in pregnant women. If the patient becomes pregnant or plans to become pregnant while taking Betaseron, the patient should be apprised of the potential hazard to the fetus and it should be recommended that the patient discontinue therapy.

Nursing mothers: It is not known whether Betaseron is excreted in human milk. Because many drugs are excreted in human milk and because of the potential for serious adverse reactions in nursing infants from Betaseron, a decision should be made as to whether either to discontinue nursing or discontinue the drug, taking into account the importance of drug to the mother.

Pediatric use: Safety and efficacy in children under 18 years of age have not been established.

ADVERSE REACTIONS

Experience with Betaseron in patients with MS is limited to a total of 147 patients at the recommended dose of 0.25 mg every other day or more. Consequently, adverse events that are associated with the use of Betaseron in MS patients at a low incidence may not have been observed in premarketing studies. Clinical experience with Betaseron in other populations (patients with cancer, HIV positive patients, etc.) provides additional data regarding adverse reactions; however, experience in non-MS populations may not be fully applicable to the MS population.

Injection site reactions (85%) and injection site necrosis (5%) occurred after administration of Betaseron. Inflammation, pain, hypersensitivity, necrosis, and non-specific reactions were significantly associated ($p<0.05$) with the 0.25 mg Betaseron-treated group. Only inflammation, pain, and necrosis were reported as severe events (see **WARNINGS** and **PRECAUTIONS** sections). The incidence rate for injection site reactions was calculated over the course of 3 years. This incidence rate decreased over time, with 79% of patients experiencing the event during the first 3 months of treatment compared to 47% during the last 6 months. The median time to the first occurrence of an injection site reaction was 7 days. Patients with injection site reactions reported these events 183.7 days per year. Three patients withdrew from the 0.25 mg Betaseron-treated group for injection site pain.

Flu-like symptom complex was reported in 76% of the patients treated with 0.25 mg Betaseron. A patient was defined as having a flu-like symptom complex if flu-like symptoms or at least two of the following symptoms were concurrently reported: fever, chills, myalgia, malaise, or sweating. Only myalgia, fever, and chills were reported as severe in more than 5% of the patients. The incidence rate for flu-like symptom complex was also calculated over the course of 3 years. The incidence rate of these events decreased over time, with 60% of patients experiencing the event during the first 3 months of treatment compared to 10% during the last 6 months. The median time to the first occurrence of flu-like symptom complex was 3.5 days and the median duration per patient was 7.5 days per year.

Laboratory abnormalities included absolute neutrophil count less than 1500/mm^3 (18%) (no patients had absolute neutrophil counts less than 500/mm^3), WBC less than 3000/mm^3 (16%), SGPT greater than 5 times baseline value (19%), and total bilirubin greater than 2.5 times baseline value (6%). Three patients were withdrawn from treatment with 0.25 mg Betaseron for abnormal liver enzymes including one following dose reduction (see **PRECAUTIONS, Laboratory Tests**).

Twenty-one (28%) of the 76 premenopausal females treated at 0.25 mg Betaseron and 10 (13%) of the 76 premenopausal females treated with placebo reported menstrual disorders. All of these reports were of mild to moderate severity and included: intermenstrual bleeding and spotting, early or delayed menses, decreased days of menstrual flow, and clotting and spotting during menstruation.

Mental disorders have been observed in patients in this study. Symptoms included depression, anxiety, emotional lability, depersonalization, suicide attempts, confusion, etc. In the treatment group, two patients withdrew for confusion. One suicide and four attempted suicides were also reported. It is not known whether these symptoms may be related to the underlying neurological basis of MS, to Betaseron treatment, or to a combination of both. Some similar symptoms have been noted in patients receiving interferon alfa and both interferons are thought to act through the same receptor. Patients who experience these symptoms should be closely monitored and cessation of therapy considered.

Additional common adverse clinical and laboratory events associated with the use of Betaseron® (Interferon beta-1b) are listed in the following paragraphs. These events occurred at an incidence of 5% or more in the 124 MS patients treated with 0.25 mg of Betaseron every other day for periods of up to 3 years in the controlled trial, and at an incidence that was at least twice that observed in the 123 placebo patients. Common adverse clinical and laboratory events associated with the use of Betaseron were: injection site reaction (85%), injection site necrosis (5%), palpitation (8%), hypertension (7%), tachycardia (6%), peripheral vascular disorders (5%), gastrointestinal disorders (6%), absolute neutrophil count <1500/mm^3 (18%), WBC <3000/mm^3 (16%), SGPT >5 times baseline value (19%), total bilirubin >2.5 times baseline value (6%), somnolence (6%), dyspnea (8%), laryngitis (6%), menstrual disorder (17%), cystitis (8%), breast pain (7%), pelvic pain (6%), and menorrhagia (6%).

A total of 277 MS patients have been treated with Betaseron® (Interferon beta-1b) in doses ranging from 0.025 mg to 0.5 mg. During the first 3 years of treatment, withdrawals due to clinical adverse events or laboratory abnormalities not mentioned above included: fatigue (2%, 6 patients), cardiac arrhythmia (<1%, 1 patient), allergic urticarial skin reaction to injections (<1%, 1 patient), headache (<1%, 1 patient), unspecified adverse events (<1%, 1 patient), and "felt sick" (<1%, 1 patient).

The table that follows enumerates adverse events and laboratory abnormalities that occurred at an incidence of 2% or more among the 124 MS patients treated with 0.25 mg Betaseron every other day for periods of up to 3 years in the controlled trial and at an incidence that was at least 2% more than that observed in the 123 placebo patients. Reported adverse events have been reclassified using the standard COSTART glossary to reduce the total number of terms employed in the table. In the following table, terms so general as to be uninformative, and those events where a drug cause was remote have been excluded.

Adverse Reactions and Laboratory Abnormalities

Adverse Reaction	Placebo N=123	0.25 mg N=124
Body as a Whole		
Injection site reaction*	37%	85%
Headache	77%	84%
Fever*	41%	59%
Flu-like symptom complex*	56%	76%
Pain	48%	52%
Asthenia*	35%	49%
Chills*	19%	46%
Abdominal pain	24%	32%
Malaise*	3%	15%
Generalized edema	6%	8%
Pelvic pain	3%	6%
Injection site necrosis*	0%	5%
Cyst	2%	4%
Necrosis	0%	2%
Suicide attempt	0%	2%
Cardiovascular System		
Migraine	7%	12%
Palpitation*	2%	8%
Hypertension	2%	7%
Tachycardia	3%	6%
Peripheral vascular disorder	2%	5%
Hemorrhage	1%	3%
Digestive System		
Diarrhea	29%	35%
Constipation	18%	24%
Vomiting	19%	21%
Gastrointestinal disorder	3%	6%
Endocrine System		
Goiter	0%	2%
Hemic and Lymphatic System		
Lymphocytes less than 1500/mm^3	67%	82%
ANC < 1500/mm^3*	6%	18%
WBC < 3000/mm^3*	5%	16%
Lymphadenopathy	11%	14%
Metabolic and Nutritional Disorders		
SGPT > 5 times baseline*	6%	19%
Glucose < 55 mg/dL	13%	15%
Total bilirubin > 2.5 times baseline	2%	6%
Urine protein > 1+	3%	5%
Metabolic and Nutritional Disorders (continued)		
SGOT > 5 times baseline*	0%	4%
Weight gain	0%	4%
Weight loss	2%	4%
Musculoskeletal System		
Myalgia*	28%	44%
Myasthenia	10%	13%
Nervous System		
Dizziness	28%	35%
Hypertonia	24%	26%
Anxiety	13%	15%
Nervousness	5%	8%
Somnolence	3%	6%
Confusion	2%	4%
Speech disorder	1%	3%
Convulsion	0%	2%
Hyperkinesia	0%	2%
Amnesia	0%	2%
Respiratory System		
Sinusitis	26%	36%
Dyspnea*	2%	8%
Laryngitis	2%	6%
Skin and Appendages		
Sweating*	11%	23%
Alopecia	2%	4%
Special Senses		
Conjunctivitis	10%	12%
Abnormal vision	4%	7%
Urogenital System		
Dysmenorrhea	11%	18%
Menstrual disorder*	8%	17%
Metrorrhagia	8%	15%
Cystitis	4%	8%
Breast pain	3%	7%
Menorrhagia	3%	6%
Urinary urgency	2%	4%
Fibrocystic breast	1%	3%
Breast neoplasm	0%	2%

*Significantly associated with Betaseron treatment.

It should be noted that the figures cited in the table cannot be used to predict the incidence of side effects in the course of usual medical practice where patient characteristics and other factors differ from those that prevailed in the clinical trials. The cited figures do provide the prescribing physician with some basis for estimating the relative contribution of drug and nondrug factors to the side effect incidence rate in the population studied.

Other events observed during premarketing evaluation of various doses of Betaseron in 1440 patients are listed in the paragraph that follows. Because most of the events were observed in open and uncontrolled studies, the role of Betaseron in their causation cannot be reliably determined.

Body as a Whole: abscess, adenoma, anaphylactoid reaction, ascites, cellulitis, hernia, hydrocephalus, hypothermia, infection, peritonitis, photosensitivity, sarcoma, sepsis, and shock; **Cardiovascular System:** angina pectoris, arrhythmia, atrial fibrillation, cardiomegaly, cardiac arrest, cerebral hemorrhage, cerebral ischemia, endocarditis, heart failure, hypotension, myocardial infarct, pericardial effusion, postural hypotension, pulmonary embolus, spider angioma, subarachnoid hemorrhage, syncope, thrombophlebitis, thrombosis, varicose vein, vasospasm, venous pressure increased, ventricular extrasystoles, and ventricular fibrillation; **Digestive System:** aphthous stomatitis, cardiospasm, cheilitis, cholecystitis, cholelithiasis, duodenal ulcer, dry mouth, enteritis, esophagitis, fecal impaction, fecal incontinence, flatulence, gastritis, gastrointestinal hemorrhage, gingivitis, glossitis, hematemesis, hepatic neoplasia, hepatitis, hepatomegaly, ileus, increased salivation, intestinal obstruction, melena, nausea, oral leukoplakia, oral moniliasis, pancreatitis, periodontal abscess, proctitis, rectal hemorrhage, salivary gland enlargement, stomach ulcer, and tenesmus; **Endocrine System**: Cushing's Syndrome, diabetes insipidus, diabetes mellitus, hypothyroidism, and inappropriate ADH; **Hemic and Lymphatic System:** chronic lymphocytic leukemia, hemoglobin less than 9.4 g/100 mL, petechia, platelets less than 75,000/mm^3, and splenomegaly; **Metabolic and Nutritional Disorders:** alcohol intolerance, alkaline phosphatase greater than 5 times baseline value, BUN greater than 40 mg/dL, calcium greater than 11.5 mg/dL, cyanosis, edema, glucose greater than 160 mg/dL, glycosuria, hypoglycemic reaction, hypoxia, ketosis, and thirst; **Musculoskeletal System:** arthritis, arthrosis, bursitis, leg cramps, muscle atrophy, myopathy, myositis, ptosis, and tenosynovitis; **Nervous System:** abnormal gait, acute brain syndrome, agitation, apathy, aphasia, ataxia, brain edema, chronic brain syndrome, coma, delirium, delusions, dementia, depersonalization, diplopia, dystonia, encephalopathy, euphoria, facial paralysis, foot drop, hallucinations, hemiplegia, hypalgesia, hyperesthesia, incoordination, intracranial hypertension, libido decreased, manic reaction, meningitis, neuralgia, neuropathy, neurosis, nystagmus, oculogyric crisis, ophthalmoplegia, papilledema, paralysis, paranoid reaction, psychosis, reflexes decreased, stupor, subdural hematoma, torticollis, tremor, and urinary retention; **Respiratory System**: apnea, asthma, atelectasis, carcinoma of lung, hemoptysis, hiccup, hyperventilation, hypoventilation, interstitial pneumonia, lung edema, pleural effusion, pneumonia, and pneumothorax; **Skin and Appendages:** contact dermatitis, erythema nodosum, exfoliative dermatitis, furunculosis, hirsutism, leukoderma, lichenoid dermatitis, maculopapular rash, psoriasis, seborrhea, skin benign neoplasm, skin carcinoma, skin hypertrophy, skin necrosis, skin ulcer, urticaria, and vesiculobullous rash; **Special Senses:** blepharitis, blindness, deafness, dry eyes, ear pain, iritis, keratoconjunctivitis, mydriasis, otitis externa, otitis media, parosmia, photophobia, retinitis, taste loss, taste perversion, and visual field defect; **Urogenital System:** anuria, balanitis, breast engorgement, cervicitis, epididymitis, gynecomastia, hematuria, impotence, kidney calculus, kidney failure, kidney tubular disorder, leukorrhea, nephritis, nocturia, oliguria, polyuria, salpingitis, urethritis, urinary incontinence, uterine fibroids enlarged, uterine neoplasm, and vaginal hemorrhage.

HOW SUPPLIED

Betaseron is supplied as a lyophilized powder containing 0.3 mg of Interferon beta-1b, 15 mg Albumin Human USP, and 15 mg dextrose, USP. Drug is packaged in a clear glass, single-use vial (3 mL capacity); a separate vial containing 2 mL of diluent (Sodium Chloride, 0.54% solution) is included for each vial of drug. Store under refrigeration, between 2° to 8°C (36° to 46°F).

NDC 50419-521-03 0.3 mg/vial
NDC 50419-521-15 15 vials, 0.3 mg/vial

Caution: Federal law prohibits dispensing without prescription.

Manufactured by: CHIRON Corporation, Emeryville, CA 94608, U.S. License No. 1106
Distributed by: BERLEX Laboratories, Richmond, CA 94804
U.S. Patent No. 4,588,585; 4,959,314; 4,737,462; 4,450,103

Printed in U.S.A.
October 1996

Manufactured by CHIRON Corporation, Emeryville, CA 94608
Distributed by BERLEX Laboratories, Inc., Montville, NJ 07045
02-521-0028 01-521-0127 Printed in USA April 2002

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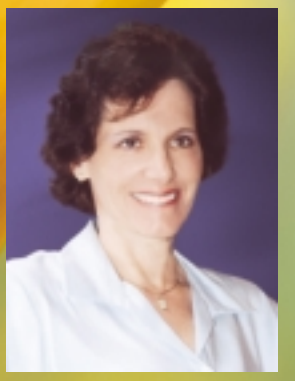
† In a market research study conducted by TDR.
Please see brief summary of prescribing information, including important safety information, on adjacent page.

BERLEX

ASK THE DOCTOR

By Dr. Laurie Laven



Q: How long does it take for side effects to subside when beginning treatment with the ABC drugs? Also, can they interact with other medications?

A: Individuals vary enormously in their reactions to the drugs. I strongly recommend everyone on these drugs register with the appropriate telephone support programs provided by each drug manufacturer. I have found the superb nurses for the existing programs to be the best source of up-to-date information on handling injections and drug side effects. They may have information before the drug representatives or doctors do. The affiliated websites are also helpful. Another excellent source of information is local nurses with vast MS experience.

With those caveats, I'll give some basic guidelines. Injection site reactions with Betaseron and Copaxone tend to diminish over three to six months. They are decreased for many people by using auto-injectors, by icing, allowing alcohol to dry before injection, and using cotton balls following the injection. Copaxone has demonstrated, and Betaseron has anecdotal evidence now being studied, that injecting with a dry needle (not getting the air out of the needle) is less irritating. Thin people may have difficulty with FDA approved injection sites. I can't use the thighs or arms as recommended, so I use other sites on my thighs and hips where I have more fat. These are not FDA approved sites. If you are having difficulty with current sites, you should discuss using alternate sites with your doctor or clinic nurse.

The flu-like symptoms with Avonex and Betaseron are markedly less when beginning injections with dose escalation, taking small doses of prednisone with the first few injections, and taking a long-acting analgesic (like arthritis-strength Tylenol, Aleve or similar) with the injections.

There are few drug interactions with the ABC drugs. Some side effects from these drugs, such as fatigue, depression (Avonex and Betaseron) and increased spasticity, may require the alteration of your existing medications.

Q: Can the drugs used to treat multiple sclerosis be more effective if the individual on the treatment adheres to a good diet?

A: The drugs' efficacy is not affected by diet, but I will use this question as an excuse for my sermon on good diet and a full exercise program for all people with MS. I am fellowship trained in rehabilitation and have prescribed healthy diets and weight-training, exercise programs, and fun for every one of my MS patients, even those who are neurologically normal and in "good" shape. MS is a disease that can weaken us, so it makes sense that we need to be in the best shape possible to weather attacks. There is no diet that is therapeutic for MS, and no "best" diet for weight loss. Exercise plus calorie restriction results in much more permanent weight loss than dieting alone.

Of course even an Olympic athlete can be severely disabled in a severe attack, but I know being in excellent physical shape can protect you from some functional disability during many MS attacks. Being much stronger than most women my age kept me functioning well despite a loss of almost half my strength during a recent attack.

Many MS doctors and therapists underestimate the ability of people with MS to increase their strength and endurance or believe in rest during exacerbations. Most individuals with MS can benefit from weight-training and aerobics, and all need range of motion and stretching routines. Some ambulatory patients are sent to physical therapy once a week to "maintain their strength." This is nearly useless. We need to exercise regularly at home or at a gym. Be sure to consult experts in MS rehab, such as MS clinics with active affiliated rehab departments (which many prestigious MS clinics do not have); get a recommendation for an experienced rehab professional from your local MS organization, or attend a Jimmie Heuga seminar. People with minor deficits can train like anyone else, taking extra precautions against heat if necessary by drinking lots of iced drinks, wearing wet T-shirts, using a fan, or wearing a cooling vest (cooling information is available from MSAA).

Q: Can a person regain muscle tone once it is gone?

A: Motor function is evaluated as tone - resistance against stretch; bulk - the size of the muscle; and strength - the power of the muscle. Most people with MS who have an abnormality of tone have an increase, or spasticity. This may be helpful in some cases of weak legs when the spasticity adds enough stiffness to allow a person to walk even though leg strength is not adequate for support. With less spasticity and the same weakness, the person may not be able to walk, but the real problem is the weakness, not the tone. Harmful effects of spasticity include painful stiffness or spasms, increased energy requirements for movement, restriction of movement leading to contractures, and difficulty with hygiene and positioning. Spasticity can be decreased with stretching, exercise, and medications. (Dr. Jack Burks discussed medications in the last issue of *The Motivator.*) Severe contractures may have to be surgically released and prevented from recurring with active rehabilitation and proper medication. I have never seen low muscle tone as a primary source of disability.

Tone is mildly reduced in limbs affected by cerebellar lesions. Severe loss of tone, or flaccidity, may accompany spinal shock or stroke-like attacks with sudden weakness, and occasionally occurs with long-standing severe weakness, but then the real problem is the weakness, not the loss of tone. Loss of muscle bulk also accompanies long-term weakness and disuse of a muscle and may improve with exercise, depending on the degree and time course of the weakness. I again emphasize the importance of exercise, including stretching, range of motion, conditioning, and resistance training to the best of your abilities. Even those who are paralyzed or severely weak need stretching and range of motion routines. As discussed above, consult an expert in MS rehabilitation for a personal program.

Q: What are your thoughts regarding hepatitis vaccines for individuals in the medical profession?

A: Medical professionals are at high risk and should be vaccinated for hepatitis B and flu. Several recent excellent studies have shown that vaccines against hepatitis B, flu, and tetanus are safe and effective in people with MS, causing no increase in symptoms or attacks. Since flu is a febrile illness that can increase the symptoms of MS, people who are infirm or otherwise at high risk for the flu should definitely get the flu vaccination, and even healthy minimally affected people with MS should strongly consider it. I am symptom-free between attacks, but would get the flu vaccine even if I weren't a doctor because I am heat sensitive and want to take all possible steps to avoid a severe febrile illness with my MS. This should be discussed with your physician. ■

Dr. Laurie Laven has been a neurologist for 19 years and has treated many people with multiple sclerosis. She began specializing in MS rehab after a neurorehabilitation fellowship in 1992. She has published several articles, and has conducted research in symptomatic treatment of MS and health care utilization of women with MS. During her career, she has been a member of the American Academy of Neurology, the American Society of Neurorehabilitation, and the Consortium of MS Centers. She was diagnosed with MS in November of 2001 and says, "I know my new knowledge will make me a better doctor, and I hope other neurologists will also learn from it."

We invite you to send medical questions about multiple sclerosis to:
Dr. Jack Burks, c/o MSAA,706 Haddonfield Road, Cherry Hill, NJ 08002
Questions may be edited to include as many as possible.

MS picked the wrong person.

Emmy Award-winning talk show host Montel Williams knows first-hand what it's like to feel excruciating pain and lose his vision and balance. But until he heard the three little words, "You have MS," he had no idea why.

"When I was diagnosed, the answers weren't easy to come by. Now they are."

Since his diagnosis with multiple sclerosis in 1999, Montel has made the commitment to fight back aggressively against this often debilitating disease.

"MS picked the wrong person. I make my living talking, and I have one of the biggest mouths on this planet. I'm going to continue flapping it until everyone knows the facts, gets the treatment they need, and a cure is found."

Experience Montel's inspiring and candid story via streaming video coupled with the very latest medical information from the world's foremost MS experts—all on the most comprehensive and dynamic Web site designed to educate, support and encourage MS patients, their caregivers and loved ones.

To receive your free "MS Take Action Kit" please log on to www.MontelMS.org or call The Montel Williams MS Foundation at 877-MontelMS.

www.spotlighthealth.com

MONTEL WILLIAMS MS FOUNDATION

Rebif Approved for Relapsing-Remitting MS

Individuals with relapsing-remitting multiple sclerosis now have an additional treatment option available. The US Food and Drug Administration (FDA) approved Rebif (interferon beta-1a) on March 7 for relapsing-remitting MS. The approval was based on results from the PRISMS and EVIDENCE trials which are described below. Five drugs are now available for the treatment of MS in the United States including Avonex, Betaseron, Copaxone, Novantrone, and Rebif.

The PRISMS (Prevention of Relapses and Disability by Interferon beta-1a Subcutaneously in MS) study compared the long-term effectiveness and safety of Rebif to placebo. The trial was conducted with 560 individuals who were diagnosed with relapsing-remitting MS and exhibited mild to moderate disability. They were given a lower dose, higher dose, or placebo three times a week for two years.

The results showed a significant decrease in the number and severity of relapses, as well as a delay in time to the second relapse, and a delay in the time to confirmed progression as measured by EDSS (Expanded Disability Status Scale). The percentage of participants in the treated groups who remained relapse-free was increased. MRI disease activity as measured by gadolinium enhancement (indicating active lesions) was significantly reduced along with total T2 lesion load (total amount of MS plaques).

The EVIDENCE (Evidence for Interferon Dose-response: European-North American Comparative Efficacy) study compared Rebif to Avonex and is the largest prospective, randomized, comparative study of two drugs for relapsing-remitting MS to date. It included 677 individuals with relapsing-remitting MS at 56 centers in the United States, Canada, and Europe. In this Rebif company-funded study, the participants and treating physicians were not blinded, but the evaluating physicians and the physicians reading the MRIs were blinded.

After 24 weeks into the one-year study, results showed “statistically significant differences” in favor of Rebif. A higher percentage of people in the Rebif group were relapse-free (75 percent) during these 24 weeks, versus the 63 percent who were relapse-free in the Avonex group. The

Rebif-treated group also had one-third fewer active brain lesions (as measured by MRI) than those in the Avonex group. These findings gave the FDA the evidence they needed to deem Rebif "clinically superior," and grant the drug early approval.

Two independent trials were recently conducted with Avonex (known as the "CHAMPS" study) and with Rebif (known as the "ETOMS" study) to determine if early treatment could delay the second disease event leading to a diagnosis of clinically definite multiple sclerosis (CDMS).

Investigators found that compared to the placebo group, the rate of conversion to CDMS was decreased by 44 percent in the Avonex (CHAMPS) study. MRI scans showed reductions in the number of new lesions, the number of enhancing lesions, and the percentage of change in T2 lesion volume for the treated group.

Similar results were observed with the Rebif (ETOMS) study, although the dose used was one-sixth of the normal dose. At two years, a 24-percent reduction in the rate of conversion was realized, along with reductions in T2 active lesions and T2 disease burden.

Rebif and Avonex are the same drug, but the doses, route of administration, and frequency differ. Rebif is administered in a higher dose and more frequently (44 micrograms three times per week), just under the skin (subcutaneously). The dose for Avonex is 30 micrograms given once a week deep into the muscle (intramuscularly). To date, there have not been any head-to-head studies comparing Rebif to Betaseron or Copaxone.

Rebif was approved in Europe in 1998 for the treatment of MS and is available in over 70 countries worldwide. The Orphan Drug Act protected Avonex in the United States and prevented Rebif's approval until at least May 2003. This law prevents the manufacturers of identical drugs for rare or "orphan" diseases to compete in the US marketplace until the first manufacturer has had time to recoup the costs for the initial research. In order to be approved sooner, Serono, the manufacturer of Rebif, had to demonstrate "clinical superiority" over the existing orphan drug (Avonex).

The most commonly reported side effects are injection-site reactions and flu-like symptoms. Because of its increased dose and frequency as compared to Avonex, liver function disorders and reduced white blood cell counts were observed with greater frequency with Rebif. All of these problems were usually temporary.

Rebif became available for physicians to prescribe in the United States on March 11, 2002. The medication is provided in single-use, pre-filled syringes and costs just under $14,000 annually.

Serono, S.A., headquartered in Geneva, Switzerland, manufactures Rebif. Their affiliate in the United States, Serono, Inc. is located in Rockland, Massachusetts.

For more information regarding Rebif, call MS LifeLines at 1-877-44-REBIF (1-877-447-3243) or log on to www.Rebif.com.

— Andrea Borkowski
— Susan Wells Courtney

Research News continues on next page.

Epstein-Barr Virus and MS

Separate studies, two conducted in the United States and one in Germany, indicate that high levels of specific antibodies that fight a range of Epstein-Barr Virus (EBV) antigens may be associated with the onset of multiple sclerosis.

Though none of the studies conclusively demonstrates EBV to be a cause of MS, results from them encourage further research into the relationship between MS and definite viral diseases that affect people based on increased autoimmune activation.

In particular, results from a study conducted at the Harvard School of Public Health, as published in the December 26, 2001 issue of the *Journal of the American Medical Association (JAMA)*, show that 144 women with MS had significantly higher average levels of antibodies for EBV antigens in their blood before the onset of MS as compared with 288 women without MS who served as a control group. The strongest association was found for Epstein-Barr Nuclear Antigen-2 (EBNA-2), elevated levels of which were linked with a four-fold increase in the risk of MS.

Dr. Alberto Ascherio, lead author of the JAMA article and associate professor in the Departments of Epidemiology and Nutrition at Harvard School of Public Health, said, "For decades it has been suspected that MS is caused by some form of infection in genetically susceptible individuals, but the micro-organisms that are responsible for it have remained elusive. Our results suggest that EBV may be the culprit or, at least, one of the culprits.

"I'm not saying it's the only micro-organism that causes it, but I would be very surprised if it turns out it is not involved," Ascherio continued.

Critics say the Harvard study, while interesting, may be flawed. "Antibodies," says an article by Victoria Stagg Elliott in American Medical News, "are not conclusive proof of the presence of high levels of the virus, particularly in people who have a disease characterized by an overactive immune system."

Also, a Dutch study, the results of which were reported in *Neurology*, concluded that its findings, which are "the first to include both brain tissue with MS lesions and cerebrospinal fluid samples," could not establish a role for EBV in association with MS. Researchers from that study said, however, that the presence of EBV-derived proteins in participants could be involved in the inflammatory processes in MS lesions.

The findings in all studies suggest the jury remains out and that more research is warranted to fully determine any links between EBV and MS.

EBV, a member of the herpesvirus family, is one of the most common viruses in the world. Harvard researchers say it infects as many as 95 percent of adults in the United States by the time they reach age 40. Most people show no symptoms in reaction to this infection.

The Harvard study was conducted to determine whether elevation in specific antibodies that fight EBV antigens precede an occurrence of MS.

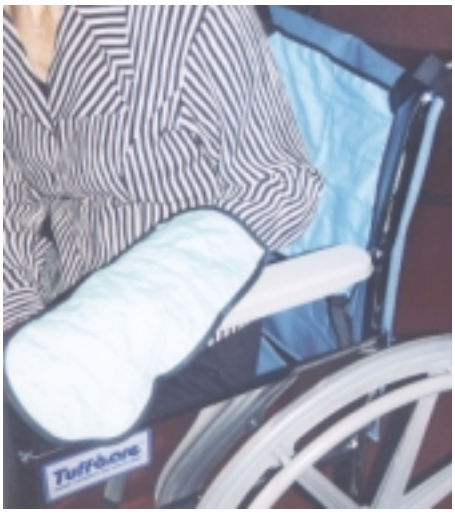
Participants were selected from more than 62,000 women who offered blood samples to researchers between 1989 and 1999. From this group were chosen 144 women with definite or probable MS. Eighteen of these women were diagnosed with MS when the study began. The other 126 were diagnosed after the study began. Each woman with MS was matched to two women the same age without MS, randomly selected as controls. Compared with these controls, the women with MS had higher serum levels of antibodies to EBV. Elevations were significant for antibodies to EBNA-1 and particularly strong for antibodies for EBNA-2, evidence of which, in the Harvard tests, brought with it a four-fold risk of a person being diagnosed with MS.

— Neal Zoren

IF YOU CAN'T STAND THE HEAT, CALL MSAA

MSAA strives to make your life easier. In the summertime, that often means making your life COOLER due to the adverse effects of heat and humidity on MS. MSAA has added several new cooling accessories to its Cool Suit Distribution Program. In addition to our standard inventory of cool suits, vests, and collars, these accessories also provide temporary cooling relief from the heat. For a full listing of available products or to receive an application, please call 1-800-532-7667.

The Coolband™ features a gel pack that's frozen and inserted into a soft rubber pocket attached to a terry cloth armband. The Coolband™ is placed at the radial artery - a key highway for the body's circulation system. By cooling this location, the cooling effect is naturally circulated through the body.



The Body Cooler® Bandana is soaked in cool tap water for 10 – 20 minutes, wrung out, and dried to the touch. After soaking, crystals inside the garment absorb up to 400 times their weight in water. Airflow activates cooling through a simple process of heat transfer.

Most body heat is lost through the top of the head. The Body Cooler® Skull Pad is worn under ball caps and other hats and used in the same manner as the Bandana.

The two products featured in this photo are the Body Cooler® Wheelchair Pad and Glove. The Pad is Velcro-ed to the back of the wheelchair and the Glove is worn over the hand. Both use the soaking and evaporation method described in the other Body Cooler® products above.

Regional News

NORTHEAST REGION

As the warm weather approaches, the Northeast Region prepares for its annual MS Awareness Conference, set for May 22 in New Jersey, in addition to various health fairs and conferences.

Recent public awareness workshops included a presentation by the president of the local Lupus Foundation, who spoke about similarity of some symptoms to lupus and MS and about how many women are affected by both diseases simultaneously. Another workshop was presented by Douglas Fenderick, Esq., who spoke about estate planning and wills, a subject of interest to MSAA clients and staff. In March, MSAA, along with Immunex Corporation, makers of Novantrone, invited clients to attend a presentation on updates in secondary-progressive MS by Dr. Thomas Leist of Philadelphia's Thomas Jefferson Comprehensive MS Center.

The Northeast Region has been helped greatly by a volunteer, Nelson Wechter, who has donated 65 hours to MSAA since November. Nelson has conducted surveys, made reassurance calls, and supplied much needed clerical assistance. Many thanks to Nelson, an example of how important dedicated volunteers are.

A thank you is given to all Northeast Region volunteers who have donated time to facilitate support groups, participate in *Pathways for Independence*, and offer clerical assistance. Thanks also to Northeast Region clients who have submitted articles for the regional newsletter, *Common Vision*. The newsletter continues to bring helpful educational information to clients, and all writers and readers are appreciated.

MSAA Northeast Regional Office; Susan Freund, Director; 706 Haddonfield Road, Cherry Hill, New Jersey 08002; 1-800-833-4672, extension 106.

MID-SOUTH REGION

The Mid-South Region was a proud partner in a new type of motivational conference, *Changed by Multiple Sclerosis: Messengers of Hope,* which was attended by more than 750 people on March 9 at the Edwin Hornberger Conference Center of the Texas Medical Center in Houston. The conference was made possible through an unrestricted educational grant from Teva Neuroscience, Inc., makers of Copaxone and sponsors of Shared Solutions.

The keynote speaker was Annette Howard, M.D., founder and director of the MS Institute of Texas, who offered a clear clinical perspective in her presentation, Treating MS in the Year 2002. Following her speech, Dr. Howard remained to answer questions for almost two hours.

Judith Bennie, Client Services Coordinator for the Mid-South Regional Office distributes literature at the Changed by Multiple Sclerosis: "Messengers of Hope conference".

Alan Osmond, oldest of the popular Osmond Brothers, gave an uplifting and humorous presentation that was deeply emotional. By the time he delivered his tag line, "I may have MS, but it doesn't have ME," no eye in the house was dry.

Other speakers included Kelly Sutton, racecar driver and top finisher in NASCAR's Goody's Dash Series Daytona 500, who presented *My Dream Fulfilled in Spite of MS,* which chronicled her fight to go from wheelchair to racecar; and Linda Crossett, MSN, APRN, BC, an advance nurse practitioner who has MS and spoke on *Getting Past "Why Me*?" *and On To "What's Next."*

The same week as the Messengers of Hope conference, the Mid-South Region launched a new support group in Northwest Houston. For more information about it, please call the Mid-South Office at 1-877-677-6884.

People calling Mid-South's toll-free line (1-877-677-6884) will now be greeted with a recorded menu designed to provide better service. If callers would like to speak directly with the office, they can skip the menu by entering extension number 137.

In the last issue of The Motivator, we reported the total number of volunteer hours for the Mid-South Regional Office over the past year as 300. The total number of volunteer hours was actually 3,000.

MSAA Mid-South Regional Office; Adam Roberts, Director; 107 Avonshire Terrace, Diamondhead, Hot Springs, Arkansas 71913-2205; 1-877-677-6884, extension 137, 501-262-9380.

NORTHWEST REGION

The memory of TransMontana 2002 will remain for a lifetime. The six-day, 550-mile snowmobile ride from the Canadian border to West Yellowstone was not only a successful fundraiser but a wonderful experience that attracted riders from all over the world, including five from Finland. A special thank you goes to the Montana Snowmobile Association for sponsoring the ride, to Teva Neuroscience, Inc. for its generous support, and to

the riders of TransMontana 2002 who made the tremendous effort to participate, meeting all challenges to assist those facing another challenge, multiple sclerosis.

John R. Bermingham, Jr., PhD, from the McLaughlin Research Institute in Great Falls, Montana, spoke about his research into "Genes and the Formation of Myelin" at the Northwest Region's educational program on April 25 in Great Falls. Dr. Bermingham has been awarded a $1.5 million grant from the National Institutes of Health to continue his study, one that may have important impact on future treatments of MS.

The Group Leader Training Conference, set for May 17 and 18 in Helena, Montana, will provide a unique opportunity for support group facilitators in the Northwest Region to meet each other, receive training, and share information about their groups. New support groups have recently formed in Great Falls, Montana and Spokane, Washington.

(L-R) Andy Young, Mark Eaton, Mike Mercer, and Dan McKinley from Teva Neuroscience are waist-deep in Montana snow.

(L-R) Kalevi Viitanen, Jari Tuuri, Ilpo Varha, Arto Ansas, and Seppo Lehtinen traveled from Finland to participate in TransMontana 2002.

(L-R) Dan Kempa, Ted Liss, Sue Pencoske, Andrea Borkowski, and Harry Liss take a break from snowmobiling for a picture.

(L-R) Ted Liss, Sue Pencoske and Doug Franklin are all smiles as they enjoy Montana's scenery.

Participants gather before the next part of the ride.

MS AWARENESS MONTH

blossoms with valuable information!

Join us as we celebrate May with a series of free educational conferences to help you better manage the daily challenges of MS.

On Saturday, May 4, 2002:

The MSAA Mid-South Regional Office presents:
Mastering MS 2002, A New Look at MS
9:30 am to 3:30 pm
Walton Auditorium
University of Arkansas for Medical Sciences
4301 W. Markham, Little Rock, AR
For Reservations, CALL 1-877-677-6884, Ext. 137

The MSAA Midwest Regional Office presents:
MS Awareness Month Conference
9:30 am to 1:30 pm
Cleveland Hilton South
6200 Quarry Lane, Independence, OH
For Reservations, CALL 1-800-589-7962, Ext. 140

On Wednesday, May 22, 2002:

The MSAA Northeast Regional Office presents:
MS Awareness Month Conference
9:00 am to 3:30 pm
Cherry Hill Hilton, Rt. 70, Cherry Hill, NJ
For Reservations, CALL 1-800-532-7667, Ext. 106

Support Group Leader Training:

May 17 – 18, 2002; Westcoast Hotel, Helena, MT
Presented by MSAA Northwest Regional Office
For Reservations, CALL 1-800-565-6722, Ext.131

MSAA Northwest Regional Office; Sue Pencoske, Director; 600 Central Plaza, Suite # 13, Great Falls, Montana 59401; 1-800-565-6722, 406-454-2758.

MIDWEST REGION

The Midwest Region introduces Scott J. McDonald as a Client Services representative serving Illinois. Scott is based in the Chicago area and is involved in forming more support groups and planning more programs in that area.

The annual MS Awareness Month program will take place from 9:30 a.m. to 1:30 p.m. Saturday, May 4 at the Cleveland Hilton South, 6200 Quarry Lane, in Independence, Ohio. Continental breakfast and lunch will be served.

A conference is set for the Chicago area on Saturday, May 18 at the Holiday Inn Willowbrook in Hinsdale, Illinois.

Other programs held or scheduled for April include a Spring Fling Social at Cucina Pazza Restaurant on April 11; a class in self-defense and crime prevention with Ken Rubin at the Outlook Pointe Assisted Living Community at 10 a.m. April 13; and an Invitational Volunteer Appreciation Day on Wednesday, April 24.

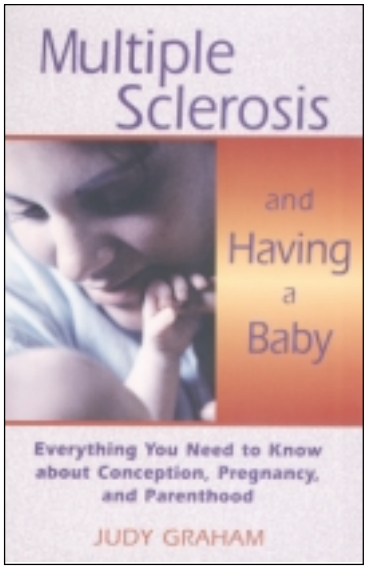
The Steubenville, Ohio support group will hold its MSAA Benefit Banquet starting at 6 p.m. on June 14 at Lenora's Club Hollywood in Steubenville. Please call Sylvia Woods at 740-282-2524 for more information.

Currently, support groups are meeting in Twinsburg, Ohio; Sagamore Hills, Ohio; Proctorville, Ohio; Morris, Illinois; Steubenville, Ohio; Warrensville Heights, Ohio, Ironwood, Michigan, and Hobart, Indiana.

MSAA Midwest Regional Office; Renée Williams, Director; 1893 East Aurora Road, Twinsburg, Ohio 44087; 1-800-589-7962.

"Spread the Word"

MSAA's Lending Library



Multiple Sclerosis and Having a Baby
By: Judy Graham

Multiple Sclerosis and Having a Baby by Judy Graham (Healing Arts Press, 1999) is subtitled "Everything You Need to Know about Conception, Pregnancy, and Parenthood." Although that might seem like an ambitious undertaking for a slim volume (168 pages plus appendices), the author does a credible job exploring the life-altering decisions pregnancy entails. The book is written in an easy-to-understand, non-clinical style and proceeds through MS-specific concerns including chapters such as "Will I Get Worse If I Have a Baby," "Can You Pass MS On to Your Child," "Effects of Medications for MS," to more general chapters about relationships, prenatal care, and labor, and childbirth. I found "Deciding Whether to Have a Baby" a good compilation of the questions any woman, MS-affected or not, usually asks herself during her child-bearing years.

Succeeding chapters deal with breast-feeding, household help, fatigue and depression, and other post-natal issues right through long-term planning including "Having More Children," "Older Children," "Working for A Living," "Single Mothers," and "Being a Parent with MS." The emphasis on reaching out for help from others, a recurring theme throughout the book, is useful for mothers at all parenting stages. Medical authorities are quoted occasionally, but it's the frequent quotes from women with MS that are particularly affecting. One in the "tips" section says simply, "I fear I won't be able to do what normal people do with young children. I get jealous of people running in the park."

Chapter 4, entitled "Can You Stop Yourself from Getting Worse?" however, caused me some concern. It is an exhaustive presentation of recommended dietary and lifestyle changes including the Swank low-fat diet and nutritional supplements, as well as complementary therapies (acupuncture, magnet therapy, etc.). Graham, also the author of "Evening Primrose Oil," presents a compelling case for the power of certain foods to control MS symptoms.

But the course of pregnancy and parenthood may be the one thing as truly individual as the course of MS itself-one size definitely does not fit all! Although anecdotal statements supporting the benefits of such alternative therapies do exist, many are largely unproven by clinical trials. Women with MS may or may not benefit from such therapies and might find it prudent to coordinate all pre- and postnatal care through their health provider, be it a midwife, physician, nurse practitioner, or other medical professional.

"…The general conclusion is good news: women with MS who have children are no worse off in the long run than those who do not," the author (who is herself a mother with MS) tells us. Weighing the pros and cons of having a child and making a decision remains a personal process that each woman must decide for herself. This book could help.

Reviewed by:
Kathleen Quinn Copeland
MSAA Client

If you would like to donate a book about multiple sclerosis, please send it to: Manuela Bechtel, MSAA, 706 Haddonfield Road, Cherry Hill, NJ 08002.

If you would like to read or review a book from MSAA's Lending Library, please send your name and address to: Manuela Bechtel, MSAA, 706 Haddonfield Road, Cherry Hill, NJ 08002. A list of books from the Lending Library and an application will be sent to you.

MULTIPLE SCLEROSIS
MS
ASSOCIATION OF AMERICA

The 1st Resource

MSAA wants to be first to help people with MS, their families, and caregivers.

1st Resource for those just diagnosed

1st Resource for those expecting diagnosis

1st Resource for those who need information about MS

1st Resource for those who need consultation or a sympathetic ear

1st Resource for those who need referrals or a guide through bureaucratic matters

1st Resource for equipment distribution, educational material, and enhancements that ease day-to-day living

If you know someone who has MS, or if you are of the 400,000 people in the United States who has MS, think of MSAA as an arm around your shoulder, ready to ease the day-to-day challenges you face.

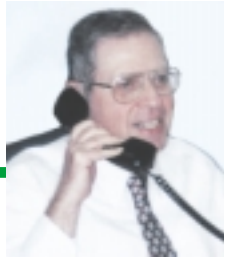
Call 1-800-LEARN MS

(1-800-532-7667)

Visit our website at www.msaa.com

Think of MSAA.

Your 1st Resource is always thinking of you!



Gene's Column

By Gene Gratz

Hang In There

More than 30 years ago, when I was misdiagnosed with MS, there was scant reason for feeling optimistic.

Doctors knew precious little about the malady and diagnosed me – incorrectly – based on presenting symptoms and a spinal tap.

Today, with the steady march of medical advance and therapeutic progress, one can reasonably look forward to a more manageable future and brighter tomorrow.

Modern medicine routinely does things that were considered unthinkable a decade ago, let alone a few generations ago.

Only nine years ago, none of the long-term treatments for MS – Avonex, Betaseron, Copaxone, Novantrone, and now, Rebif – were available to anyone who was not in a pre-approved clinical trial. At present, these drugs are significant weapons in the battle against MS.

All of this recent progress makes one message clear. Always focus on the positive! Keep in your mind that astonishing developments occur constantly in medicine.

So, hang in there. Never lose hope! The good derived by one person can be derived by a second. And, even more awesome, you can become the precedent for success of a treatment that has helped no one before you!

"Tomorrow may be your day!"

MSAA is into making everything accessible.

Especially when it concerns getting in touch with us.

If you have a question, need to speak to a consultant, have a great idea for advancing MSAA, or even a concern you want to air, please get in touch with us.

There are several ways to do that. National Headquarters can be reached by mail at **706 Haddonfield Road, Cherry Hill, NJ 08002**. Our toll-free telephone number is **1-800-LEARN MS (1-800-532-7667)**. Our general **fax number is 856-661-9797**. Our web site is accessed by keying in **www.msaa.com**. We can be e-mailed via **msaa@msaa.com**. If you want to reach someone specific at National Headquarters, use the first initial of the first name and attach it without any spaces to the intended recipient's last name. For instance, if you were trying to reach John Doe, you would address the e-mail to jdoe@msaa.com.

Accessibility is easy. So, stay in touch with MSAA. We are always happy to hear from our constituents.

NETWORKING PROGRAM APPLICATION

The Networking Program encourages the sharing of information and mutual support among individuals that are affected by multiple sclerosis. Through letters or Emails, the Networking Program helps link people who are unable to attend support group meetings but would like to share with others who face similar challenges.

Here's how it works: **First**, complete, sign, and return this application to: *MSAA Networking Program, 706 Haddonfield Road, Cherry Hill, NJ 08002*. **Second,** MSAA will place your information on a list that is distributed to others in the program. **Finally,** MSAA will send you a list of participants to correspond with. Listings are updated periodically, and you can discontinue participation at any time by notifying MSAA at 1-800-532-7667 or MSAA@MSAA.com.

Please check the appropriate box to indicate your networking preference. You may participate in more than one type of network.

I am

☐ an INDIVIDUAL with MS

☐ a CAREGIVER for someone with MS

I wish to participate in:

☐ LETTER WRITING ONLY (only your name, address, and special interests will be listed)

☐ E-MAIL ONLY (only your name, Email address, and special interests will be listed)

☐ LETTER AND E-MAIL (your name, address, Email address, and special interests will be listed)

Name _____ Year Diagnosed _____

DOB _____ Sex : ☐ male ☐ female Marital Status _____

Address _____

_____

City _____ County _____ State _____ Zip _____

Home Telephone: _____ Email _____

If you do not have MS, please specify who does:

☐ child ☐ spouse ☐ Parent ☐ Relative ☐ Friend ☐ Other

Special interests or activities (please share anything that will help describe yourself): _____

_____

_____

Your signature below grants MSAA permission to distribute the applicable information above to those enrolled in the Networking Program. Please be aware that MSAA does not monitor correspondence and has no control over content. MSAA may not be held liable for any actions that may result from this program. MSAA reserves the right to deny participation or continuation in the program. All information must be kept confidential by those enrolled. You must be 18 years of age or older to participate.

Signature: _____ **Date:** _____

Support MSAA directly

Become a Net Donor

Making a contribution to MSAA has become much easier. You can help us ease the day-to-day challenges faced by individuals by logging on to **www.msaa.com** and VISITING NET DONOR, a safe, secure, simple way to donate to MSAA via the Internet.

JUST FOLLOW THESE STEPS

1. Log on to MSAA's website at **www.msaa.com.**
2. Choose "Make a Donation" from the buttons at the top of the screen.
3. Click on the bar that allows you to make on-line donations.
4. Follow the Net Donor instructions.
5. Let us thank you for your kind support.

With NET DONOR, you can make an outright gift
OR
you can make a donation In Honor Of, In Memory Of, or In Celebration Of a person or event.

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