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The MOTIVATOR

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A portion of this magazine has been printed on recycled paper.

COVER STORY

DEPARTMENTS

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

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

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Up Front

By Douglas G. Franklin
MSAA President and CEO

Douglas G. Franklin

I am proud to announce that MSAA will be giving three important presentations at the Consortium of Multiple Sclerosis Centers' (CMSC) Annual Meeting this May in Denver, Colorado. The first topic is "startling," a possible new MS symptom based on reader feedback from MSAA's past issues of *The Motivator*. The second topic explains the positive impact that MRIs have on patients' treatment decisions and overall healthcare. The third topic is on the premise that guided imagery (a relaxation technique) may be used to ease injection anxiety associated with disease-modifying therapies for MS.

Also at the CMSC meeting, several MS Coalition (MSC) members will present a joint workshop on advocacy, focusing on awareness of important public policy issues for MS – especially with state and federal legislators. At the CMSC meeting, we welcome The Heuga Center for Multiple Sclerosis as a new member of the MSC. Additionally, several MSC members, including MSAA, will be participating in the National Multiple Sclerosis Society's (NMSS) Public Policy Conference in May. This will be the third time I am attending this vital conference, which is held in Washington, DC.

Continuing our collaborative efforts, MSAA is working with the NMSS on developing better ways to serve the primary-progressive MS (PPMS) population. A joint conference held in Dallas, Texas this past February has yielded valuable information. One of our key goals will be to improve the quality and availability of PPMS information. In March, MSAA teamed up with other MS organizations to advocate for increased MS research funding as a part of our recognition of MS Awareness Month.

In April, MSAA hosted a President's Circle event in New York City to recognize some of MSAA's most generous donors. Held at the Metropolitan Museum, this was a proud night for MSAA, featuring talks by some of MSAA's Board members and a patient advocate to more than 60 attendees.

MSAA is moving forward in the expansion of our public education campaign for promoting therapy treatment adherence. Over $500,000 of donated television air time has helped MSAA's public service announcements (PSAs) reach thousands of people across the country. With support from Teva Neuroscience and Bayer HealthCare Pharmaceuticals, MSAA will also be producing and distributing radio PSA's in conjunction with outreach to additional TV markets.

In closing, March was the final month of nine years of service to MSAA by Board Member Jim McGuinness. Always prepared and ready to help, Jim is a wonderful example of what good governance is all about. His sense of humor and humility will always be remembered as MSAA grows in the years ahead. Jim is everything that we could want in a volunteer, leader, supporter, and friend. Thank you, Jim! ◆

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

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

Meet MSAA Board Member Jim McGuinness

(pictured left to right) Vice President of Finance & Administration Gary Wallace, Jim McGuinness, and President & CEO Doug Franklin participate in a recent golf tournament to benefit MSAA.

Jim McGuinness began the first of his three terms on MSAA's Board of Directors in March 1999 and concluded his last term this past March. Jim describes his time on the Board as exciting. "There were so many dynamic changes that occurred during my time on the Board," states Jim. "I was happy to be a part of these changes, which enabled MSAA, under the leadership of Doug Franklin, to get the job done."

Proud of all of the programs and services MSAA offers, Jim is particularly fond of the toll-free Helpline and Home Modification Program. Jim explains, "I like the Helpline because of the service it provides to the MS community. I feel that it helps to make the journey of being newly diagnosed a lot easier. The Home Modification Program was great because it improved the quality of life for an individual with MS. Whether placing a shade over a window or installing a ramp in someone's home, these were all things that eased those day-to-day challenges of anyone who is affected by MS."

According to Jim, the staff plays a key role in the programs and services MSAA provides. "The quality of the staff at MSAA is what makes the mission a working reality."

As Jim departs from MSAA, he offers well wishes for the future. "I hope MSAA continues to expand its services to the MS community, until there is no need for them because of a cure," says Jim. "I will miss being a part of the overall effort to help. I have a lot of nice memories and believe my time here was well spent."

Jim resides in Woodbury, New Jersey. While on MSAA's Board of Directors, his positions included Board chairperson, chair of the nominating committee, and finance committee member.

— *Amanda Bednar*

PARTNERS IN WELLNESS

The Importance of a Positive Doctor-Patient Relationship

By Susan Wells Courtney,
Richard Blanck, MD,
and Jack Burks, MD

A DOCTOR'S STYLE

Every doctor has a certain style, philosophy, and way of communicating with his or her patients. Finding the right doctor-patient match is not always easy, but when successful, patients and doctors may enjoy a long-term relationship with open communication and mutual understanding.

Dr. Richard Blanck is a neurologist who specializes in MS, and has been seeing patients for more than 30 years. One of Dr. Blanck's most urgent objectives has been to spread the word about the importance of doctor-patient communication. By openly speaking with a patient – and perhaps more importantly, listening closely to what the patient has to say – a solid rapport will likely develop. This helps to bring about a correct diagnosis more quickly, as well as encourage better treatment adherence and compliance.

By openly speaking with a patient – and perhaps more importantly, listening closely to what the patient has to say – a solid rapport will likely develop.

Dr. Blanck believes that much of a doctor's personality and ability to communicate is developed while growing up, and not all doctors are able to show compassion and speak comfortably with a patient. Reports of seemingly impersonal and uninterested doctors are not uncommon. While these individuals may be highly qualified and extremely knowledgeable, they may lack the interpersonal skills necessary to develop a supportive relationship through communication and compassion. Some physicians may be better suited for a career in research versus daily patient care just for this reason.

In addition to a doctor's personality, other limitations such as time constraints placed on him or her by the workload, can greatly contribute to reduced interaction with the patient. Some patients have grown accustomed to a rushed style of patient care. After a few brief questions and a quick diagnosis, the doctor vanishes, leaving someone else to wrap up the details. With this type of care, patients often leave feeling alone, dissatisfied, and frustrated.

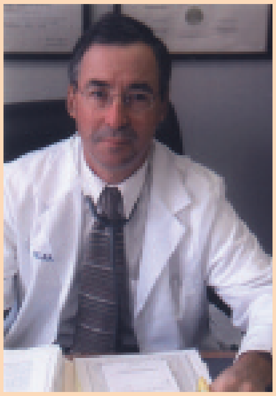
> **Making eye contact, shaking hands, smiling, and leaning in to show a sincere interest, all work toward making a patient feel welcome, relaxed, and comfortable.**

THE INITIAL INTERVIEW

Fortunately, not all doctors have a rushed bedside manner. Some doctors will spend as much time as needed with a patient so they may fully understand the patient's complaints and the degree to which they are affecting his or her quality of life. Particularly during the initial interview process, Dr. Blanck finds that a full hour or more may be required.

The initial interview is vitally important, not only to work toward an accurate diagnosis, but also to lay the foundation for a positive rapport and ongoing treatment plan. According to Dr. Blanck, a good rapport begins with a heartfelt greeting. Making eye contact, shaking hands, smiling, and leaning in to show a sincere interest, all work toward making a patient feel welcome, relaxed, and comfortable. One of the first goals is to reduce anxiety, which a new patient often experiences.

During the initial interview, Dr. Blanck spends most of his time inquiring about the patient's symptoms and their impact on daily life. He points out that learning a patient's history is the most important part of the neurological exam. The first part of taking a patient's history is to ask about his or her



Dr. Richard Blanck is a neurologist who specializes in MS at Neurology Associates of Long Island, PC, in Great Neck, New York. For the past 31 years, he has held the positions of instructor of neurology and clinical associate professor at the Cornell University Medical College in New York, and clinical associate professor at the New York University Medical College.

Dr. Blanck has been seeing patients for more than 30 years, and from this experience, has authored several articles. He is also active with the National Multiple Sclerosis Society – chairing committees, speaking at events, and serving as a patient advocate.

chief complaint. In neurology, this often falls under one of three categories: cognitive (thinking and emotion); motor function (such as weakness, coordination, and involuntary movements); and sensation (pain, numbness, and other changes in feeling).

When a patient talks about pain or other discomfort, Dr. Blanck asks a series of questions to understand the nature of the symptom. He uses a mnemonic of six letters (**PQRSTU**) to guide him through the series of questions. To follow is an explanation of this system:

P: Where is the pain ***positioned***? This gives the location of the pain.

Q: What is the ***quality*** of the pain? This describes how the pain feels, i.e., if it is sharp or dull, aching or throbbing, etc.

R: Where does the pain ***radiate***? This explains if the pain stays in one place, or if it continues to other locations – such as a headache that may start in the front of the head and radiate to other areas of the head.

S: What events might precipitate, aggravate, or relieve these ***symptoms***? The physician may learn about outside factors that may worsen the pain, as well as treatments that may relieve the pain.

T: What is the ***time*** sequence of events? Also known as the “temporal profile” or “chronology,” this specifies if the pain comes on gradually or suddenly, how long it may last, when it first began, how often it appears, and if the frequency is increasing or decreasing.

U: Have I come to an ***understanding*** of the symptom, and the degree to which it is affecting the patient’s life? Doctors need to understand how the symptom affects the patient’s activities of daily living, including work, recreation, and relationships. This is the most important piece to the puzzle.

Of course, these questions need to be asked in a compassionate manner. The doctor needs to show that he or she cares and is truly interested in the thoughts and feelings which the patient is experiencing.

These are the types of questions that should be asked during the initial interview, and according to Dr. Blanck, he can often make a provisional diagnosis based on the history given verbally by the patient.

Also while listening, the neurologist is able to assess other functions. For instance, if a patient can tell the doctor a full history of symptoms in great detail, he or she may have a good mental status; if the patient talks about his or her senses – such as seeing, hearing, tasting, and smelling, then the doctor may infer that the cranial nerves are not affected.

Following the interview process, Dr. Blanck then conducts a neurological exam, orders lab testing (to rule out other disorders), a magnetic resonance imaging (MRI) scan, and possibly an analysis of the spinal fluid. These are done to support his initial findings suggestive of MS.

DELIVERING THE DIAGNOSIS OF MS

Delivering a diagnosis of MS is a very sensitive issue. Dr. Blanck is passionate about the importance of delivering a diagnosis in the best manner possible. He believes that the messages should be clear and precise, using understandable terms. The physician should also show compassion and convey hope for the future. To follow are the eight ideals which Dr. Blanck strives for when delivering a diagnosis.

1) Deliver the diagnosis in person… giving someone a diagnosis over the phone, leaving a message on an answering machine, or having a nurse deliver the news, is not acceptable.

2) Include others when appropriate… since this can be a stressful time, having a family member present, such as a spouse or significant other, is very helpful for the patient in terms of understanding and remembering what is said.

3) Communicate properly… the doctor needs to listen to the patient, understand his or her concerns, and address those concerns.

4) Allay anxiety… while every patient is different, a doctor needs to “read” a patient’s personality, working to reduce anxiety and building a rapport.

5) Deliver the information clearly… doctors need to use understandable language and avoid medical terminology as much as possible, providing definitions whenever needed.

6) Never play God… patients need to know that only God may predict the future; physicians can only make educational guesses and offer appropriate treatment options.

7) Educate the patient… doctors are responsible to answer specific questions about treatments (detailed later in this article). When a patient knows the answers, he or she may make informed decisions about his or her own treatment.

8) Have a sense of humor… lighter moments enable doctors and patients to enjoy one another, and to serve as a momentary escape from the more serious issues surrounding MS. Everyone needs laughter.

Despite the need to provide as much information as possible to newly diagnosed patients, care must also be taken not to overwhelm a patient with too many details. Dr. Blanck tries to provide information in manageable amounts, allowing individuals time to digest what they have heard and to prepare questions for the next visit.

SUCCESSFUL DOCTOR-PATIENT COMMUNICATION

In the book, *How to Talk to Your Doctor: Getting the Answers and Care You Need* (Quill Driver Books, 2006), author Patricia Agnew states:

> *"If you are to be successful in communicating with your doctor, first you must have a doctor with whom to talk. The choice of your primary-care physician, the doctor you call first in case of illness or accident, is critical. You will talk to him more often than any other physician or surgeon involved in your health care.*
>
> *"You should develop a relationship of mutual trust with this doctor. You must feel that you can trust him with your health care, and he will need to trust you to follow his directions. It is imperative that he be open to questions and not bristle when you question his treatment or suggestions."*

Dr. Blanck explains, "Doctors often don't realize the impact they have on their patients. Once a doctor crosses a line, the patient never forgets. A patient may leave a doctor's care and not give a reason, so the physician never knows that he or she has done anything wrong or has been remiss in any way.

"Often doctors learn about patient relationships after becoming a patient themselves. Doctors don't always view themselves as advocates. They need to ask themselves, 'How would I approach this if the patient was a relative of mine with MS? Where would I go for help?'

"Doctors need to convey that they genuinely care about the concerns and wellbeing of their patients. Listening intently to what a patient has to say, learning about the impact of their symptoms, and asking the right questions, will go a long way toward forming the initial diagnosis and guiding patients through ongoing care and long-term treatment. Additionally, research shows that a patient needs to be able to talk without interruption to fully communicate his or her concerns."

In *The Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning How to Talk So Your Doctor Will Listen*, by Barbara M. Korsch and Caroline Harding (Oxford University Press, 1998), the authors note:

> *"Why do we complain about our doctors? Why do they complain about us? What makes the doctor-patient relationship so complex? …The medical setting itself creates many basic barriers to open, effective, and mutually satisfying communication. In addition, many small misunderstandings contribute to dissatisfaction on both sides, waste time, and ultimately adversely affect outcomes. Each individual in the interaction has perceptions of the other's behavior and very often the twain don't meet."*

Dr. Blanck continues, “Doctors are human, and they need to reflect the emotions that are appropriate to how a patient is feeling. Doctors need to convey compassion, show support, and help their patients know that they are not alone. Doctors need to step back to see how they appear to a patient. Not making eye contact, folding their arms in front of them, or asking insensitive questions, can make a doctor appear impersonal and uncaring to the patient.”

Research has shown that patients who work as partners with their physicians feel more in control, tolerate treatments well, and take more responsibility for their health.

A good rapport will positively affect a patient’s adherence to ongoing treatment. Without this rapport, patients are more likely to stray from their doctor’s recommendations. With MS, this can greatly impact one’s quality of life as well as long-term disease progression.

Nonverbal communication is also important. Dr. Blanck explains, “A comprehensive understanding of the patient’s problems requires me to study his behavior, observe his general appearance, listen to his manner of speaking and tone of voice, and note whether or not he makes eye contact with me. Other observations include his facial expression, gestures, and body movements. All of these nonverbal signs can indicate various issues, including a display of emotions or tearfulness, which can help me to understand the impact of the symptoms on the patient.”

Author Nancy Keene, in her book, *Working with Your Doctor: Getting the Healthcare You Deserve* (Patient-Centered Guides, 1998) comments:

> “*You need to be involved to get the best medical care. A crucial first step is to invest the time to find a doctor who is smart, caring, and up to date. You’re also more likely to trust a doctor who really knows you – one who knows your medical history, understands your needs, and talks to you about your likes and dislikes. Research has shown that patients who work as partners with their physicians feel more in control, tolerate treatments well, and take more responsibility for their health. Moreover, if you have a close relationship with your doctor, you are more likely to be diagnosed accurately and recover quickly.”*

PREPARING FOR DOCTOR APPOINTMENTS

Having at least one family member, friend, or care partner present at a doctor’s appointment can be extremely helpful and may enhance communication. Often a new patient may feel overwhelmed, anxious, or confused, and the support of a loved one – who observes the patient everyday – can usually shed light on various symptoms and behaviors. A family member can also help by noting what the doctor says and assisting the patient at home with remembering the details.

Preparing questions and recording different symptoms are important for patients to do prior to the office appointment. This ensures

that the doctor will address any questions that the patient may have, as well as be aware of any changes in symptoms. It also helps the doctor to recommend the best possible treatment options for the patient at that time.

From a doctor's point of view, the book titled, *YOU: The Smart Patient: An Insider's Handbook for Getting the Best Treatment*, by Michael F. Roizen and Mehmet C. Oz (Free Press 2006) states:

> *"Most people think they communicate with their doctors just fine. Better than fine, in fact. Fantastic. Given that most of the communication consists of nodding or a request for antibiotics, there's little to find fault with. That's the problem, of course. Most patients don't do a great job of communicating with their doctors because patients often give us too little pertinent information to go on (remember, just like the detective, we're looking for the facts). At the same time, they may also give us too many distracting or off-topic details. It reminds us a little bit of what a mechanic must think when we try to explain a noise in our car. We're not sure when it started, we're not sure what makes it worse, we think it's a whining sound but aren't sure... We bet this becomes a tedious monologue for those earnest professionals trying to help us. An almost identical conversation goes on in doctors' offices every day…"*

For guidelines to help patients prepare for a visit with their doctor (and a wealth of other topics relating to healthcare), readers may visit **www.healthcarecoach.org** and search for "Maintaining a Good Relationship with Your Doctor," for more information (this is an article under the "Your Health" tab, in the "Get the Care You Need" section). For maintaining a good relationship with their doctor, patients are given several tips, such as "choosing the right doctor," "preparing questions and concerns in advance," "knowledge is power," and "speak up for your right to understand." Many of these topics have links to specific articles for more details.

"Preparing for a Visit to Your Doctor" is a separate article listed on the Health Care Coach website. It lists questions to consider, including:

- *What is my main problem?*
- *What do I need to do?*
- *Why is it important for me to do this?*

Other questions relate to one's health in the recent past. Sample questions include:

- *Have you noticed anything different in your sleeping, eating, or other daily habits?*
- *Have you noticed any new or unusual pains, aches, lumps, or bruises?*
- *Have you seen any changes in your moods?*
- *Do you have more trouble getting up in the morning?*

If seeing a doctor for a particular problem, Health Care Coach lists these questions:

- *How and when did you first become aware of the problem?*
- *How would you describe what you are feeling or how the problem felt at that time you noticed it?*
- *Does it tend to happen at certain times of the day or when you are doing certain activities?*
- *What other patterns have you noticed, if any?*
- *What did you do when you noticed the problem to try to make it better?*

The article also suggests that patients make a list of any medications they are taking. They should check their own health records to see they are due for any immunizations or tests. An excellent form for tracking medical history may be found at **www.realage.com**. Readers may download a copy of "Your Health Journal" by searching the website or at **http://utility2.realage.com/media/pdfs/SP_HealthJournal.pdf** for a copy of the detailed, patient-friendly chart.

In addition to preparing for the doctor visit with a list of questions and concerns, Dr. Blanck encourages his patients to take advantage of reliable resources to learn about the disease and its treatments on their own. The authors of *Making Informed Medical Decisions: Where to Look and How to Use What You Find* (by Darol Joseff, Nancy Oster, and Lucy Thomas (Patient Centered Guides, 2000) agree:

> *"Regardless of your treatment outlook, when you are newly diagnosed with a medical condition, you are likely to feel yourself thrust into a world of medical jargon, tests, personnel, and processes that are unfamiliar and frightening. On top of being emotionally and physically stressed, you have to learn a new language and way of thinking about disease. Doing research can provide a way of gaining clarity and getting back some sense of control over your life. You may want to find out more about your condition, the range of treatments, or where to find the best doctor or treatment center for this condition."*

When you are newly diagnosed with a medical condition, you are likely to feel yourself thrust into a world of medical jargon, tests, personnel, and processes that are unfamiliar and frightening.

"Patients need to assert themselves," notes Dr. Blanck. "It's crucial for any patient who does not feel comfortable with their present physician, to know that they may look for a second opinion, and possibly consider changing doctors. I encourage my patients to go for a second opinion if they have any doubts or unresolved concerns." (Readers may find more information by visiting **www.healthcarecoach.com** and searching for "second opinions." It provides a general overview with several links to other articles on the topic.)

"People with a chronic condition such as MS should not visit a doctor and go away feeling as though their questions have not been answered. Long-term treatment requires an ongoing rapport of mutual understanding with not only the treating physician, but with the entire healthcare team. Patients need to know that they are not alone, and they must receive support, guidance, and hope for the future."

PHYSICIAN MODELS OF CARE FOR PATIENTS AND THEIR FAMILIES

MSAA Chief Medical Officer Dr. Jack Burks has written about some of the vital issues involved with the doctor-patient relationship in MS. Dr. Burks wrote a chapter entitled, "A Dynamic Model for Understanding the Physician's Relationship with Patients and Their Families," which appears in the book, *Multiple Sclerosis and the Family* (edited by RC Kalb and LC Scheinberg, Demos Medical Publishing, 1992). The following information was taken from this chapter.

Traditional Models of Care

According to Dr. Burks, the traditional role of the physician has been to consult with and examine the patient, determine a diagnosis, and prescribe or discuss a treatment to provide a cure. This type of relationship is categorized as one of two established models of care.

The first model of care is referred to as the "Acute Model," representing a paternalistic type of relationship where the doctor sees the patient, makes a diagnosis, and prescribes a treatment. The thoughts and values of the patient and his or her family are given little consideration in this model of care.

With the second model of care, known as the "Functional Model," the patient plays more of a role in his or her treatment plan. In this model, the doctor provides information on treatment options, so the patient may decide how to proceed.

Both the Acute and the Functional models of care exclude any involvement with the needs and dynamics of the patient's family. Information is kept confidential. While these models may work well in some instances, this is not the case for an ongoing condition such as MS, which at this time has no cure and the symptoms impact not only the patient, but the entire family.

The Evolving Educational Model of Care

With MS, the initial symptoms and diagnosis can be overwhelming for everyone involved. Once any urgent medical issues have been addressed, the physician can begin an educational process to inform the patient and family members of treatment options available. Over time, as symptoms are treated and life becomes more balanced, the patient and family may then play active roles in choosing treatments and making plans for the future.

This type of care plan is referred to as the "Evolving Educational Model." It allows the patient and family to have an interactive, open, and ongoing relationship with an entire healthcare team.

Dr. Burks explains, "While the Evolving Educational Model incorporates aspects of the earlier approaches – including the initial diagnosis and treatment recommendations – it also provides the patient and family with a more equal, active role in the long-term planning and decision-making process. The healthcare team, patient, and family members work together to decide who will give and receive medical information, and who will be involved in the treatment planning. At the same time, careful attention is still given to issues of confidentiality, privacy, and autonomy."

As the name implies, this model is designed to evolve according to the changing needs, roles, and issues of the patient and family. For instance, if the patient is under 18, his or her patients will be the primary decision makers until the child becomes an adult. Additional issues arise as parents worry about their child, who is becoming more independent and may be making his or her own decisions. Another example of changing roles occurs when an adult with MS experiences cognitive or other changes, which may require other family members to take on a more active role in the decision-making process.

"One of the most important features of the Evolving Educational Model," notes Dr. Burks, "is the concept of the entire healthcare team working in conjunction with the patient and family, to provide the most appropriate and effective care options at that time. Recommendations will change according to the patient and family's current needs and medical issues."

Healing is a Process

When stress, depression, or other emotional factors arise – often affecting the relationships and family functioning, and possibly aggravating the symptoms of MS – members of the healthcare team may recognize the hidden emotional problems behind the physical complaints, and recommend interventions such as counseling to resolve these issues. Without this model of care, unnecessary medications or hospitalizations may be prescribed to address what might otherwise seem to be a symptom of MS.

Dr. Burks continues, "The initial contacts between the patient and doctor can set the stage for the entire therapeutic relationship. Using a supportive and educational approach, the physician should engage the family in the treatment process and create an atmosphere that encourages open communication and cooperation over the course of the relationship.

"Medical treatment per se is only one component of the ongoing doctor-patient relationship. Healing is the process component, which takes place with the patient and family, as they understand and appreciate the changes they are experiencing. The doctor and healthcare team create a safe, respectful, and nonjudgmental place for the patient and family to cope with these changes. The doctor and healthcare team help to make the fears, uncertainties, and negative feelings more manageable by serving as a supportive presence and a role model."

GIVING TREATMENT OPTIONS

Once the diagnosis of MS has been established, Dr. Blanck's next step is to provide information to the patient about the treatment plan. He envisions the treatment as having four arms:

First arm: Optimization of General Health… Patients may help themselves by: not smoking; eating healthy foods and maintaining an ideal weight; participating in moderate and appropriate exercise; and seeking help for emotional issues, such as anxiety or depression.

Second arm: Managing Symptoms… Dr. Blanck asks his patients and their families to give him a list of symptoms they are experiencing, and to put them in order of most impairing to least impairing. From this list, he is able to create a treatment plan that addresses the various problems, giving greater attention to those symptoms having the greatest impact on quality of life.

Third arm: Treating an Acute Attack… Also known as an exacerbation or disease flare-up, Dr. Blanck explains that the most commonly prescribed treatment for an acute attack is intravenous steroids, which work by reducing inflammation. While this treatment can help to speed one's recovery from a flare-up, he also points out that no long-term benefits have been observed; studies show that after approximately six months, patients have similar outcomes, regardless of whether or not they received steroid treatment. Dr. Blanck recommends treatment if the symptoms are severe enough that they interfere with one's activities of daily living. If symptoms are mild, he feels that patients may be better advised to "ride out the episode," reserving treatment for a more severe disease flare-up.

Fourth arm: Modifying the Course of the Disease… This area encompasses the six medications approved by the Food and Drug Administration (FDA) for the long-term treatment of MS. As many know, four medications may be self-injected at one's home; these include Avonex®, Betaseron®, Rebif®, and Copaxone®. The latter two medications (Mitoxantrone® and Tysabri®) are each given via intravenous infusions at hospitals or infusion centers.

Dr. Blanck informs his patients of the American Academy of Neurology (AAN) position on the value of early and aggressive treatment of individuals diagnosed with MS (or a "clinically isolated syndrome"). Studies show that patients with relapsing forms of the disease may experience reduced disease activity (as shown on MRI, as well as fewer and less severe exacerbations). Dr. Blanck's personal philosophy is "to treat the patient with the best available agent, until something better comes along."

In regards to any type of specific test or treatment recommended by a doctor, Dr. Blanck believes that he or she has an ethical and professional obligation to answer the following five questions.

- *Why is the test or treatment recommended?*
- *How is the test performed or the treatment administered?*
- *What are the risks, both short term and long term?*
- *What are the benefits?*
- *What are the alternatives?*

Without answers to these questions, patients and their families do not have the information necessary to make their own decisions and ultimately receive the best care. In a world of uncertainty, doctors need to enable patients to make informed decisions. He advises patients to be proactive and ask the right questions.

MAKING EVERY DAY COUNT

Dr. Blanck wants patients to know the power of the human mind, noting the placebo effect, and the concept of harnessing the power to help heal one's own body. Making every day count is vital, and MS can be a springboard to make life more meaningful.

He also emphasizes hope. He sees much hope for the future, in terms of treatments that may one day offer restorative properties to reverse lost function, as well as research into potential cures for MS. His dream is that one day, MS may be prevented from ever developing.

Dr. Blanck remarks, "I believe that MS, as well as life in general, is like walking through a minefield. An unexpected flare-up or new problem can burst onto the scene at any time. People need to be 'artfully dodgeful,' and doctors must serve as guides to help people through their challenging times. As a physician, I am privileged to be invited into people's lives, to share their sorrows and secrets, while assisting them to become happy and fulfilled." ◆

> *"The definition of success – To laugh much; to win respect of intelligent persons and the affections of children; to earn the approbation of honest critics and endure the betrayal of false friends; to appreciate beauty; to find the best in others; to give one's self; to leave the world a little better, whether by a healthy child, a garden patch, or a redeemed social condition; to have played and laughed with enthusiasm, and sung with exultation; to know even one life has breathed easier because you have lived – this is to have succeeded."*
>
> **— Ralph Waldo Emerson**

ADDITIONAL READING

How Doctors Think, by Jerome Groopman, MD; Mariner Books (2008)

How to Save Your Own Life, by Marie Savard, MD; Warner Books Trade Paperback Original (2000)

How to Survive Your Doctor's Care, by Pamela F. Gallin, MD, FACS; LifeLine Press (2003)

How to Talk to Your Doctor: Getting the Answers and Care You Need, by Patricia Agnew; Quill Driver Books (2006)

How to Talk with Your Doctor: The Guide for Patients and Their Physicians Who Want to Reconcile and Use the Best of Conventional and Alternative Medicine, by Ronald L. Hoffman, MD; Basic Health Publications (2006)

Making Informed Medical Decisions: Where to Look and How to Use What You Find, by Nancy Oster, Lucy Thomas, and Darol Joseff, MD; Patient Centered Guides (2000)

Making the Patient Your Partner: Communication Skills for Doctors and Other Caregivers, by Thomas Gordon, PhD and W. Sterling Edwards, MD; Auburn House Paperback (1997)

Multiple Sclerosis: A Guide for Families, by Rosalind C. Kalb, PhD; Demos Vermande (1998)

Patient Self-help Guide: How to Talk to Your Doctor, by Jane Williams; Principle Publications (2006)

Special Treatment: Ten Ways to Get the Same Special Health Care Your Doctor Gets, by Kevin J. Soden, MD, MPH and Christine Dumas, DDS; The Berkley Publishing Group (2003)

The Essential Patient Handbook: Getting the Health Care You Need - From Doctors Who Know, by Alan B. Ettinger, MD and Deborah M. Weisbrot, MD; Demos Medical Publishing (2004)

The Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning How to Talk So Your Doctor Will Listen, by Barbara M. Korsch, MD and Caroline Harding; Oxford University Press (1998)

The Most Unhealthy Relationship of All: A Guide to Better Doctor-Patient Communication, by Dr. Mark A. Hertzberg; iUniverse (2003)

The Savard Health Record, by Marie Savard, MD; Time-Life Trade Publishing (2000)

The Savvy Patient: How to Get the Best Health Care, by Mark C. Pettus, MD; Capital Books (2004)

What to Ask the Doc: The Questions to Ask to Get the Answers You Need, by Margaret Fitzpatrick, RN, Linda Burke, RN, and Daryl Lee, RN; RN Interactive, Inc (2003)

Working with Your Doctor: Getting the Healthcare You Deserve, by Nancy Keene; Patient Centered Guides (1998)

YOU: The Smart Patient: An Insider's Handbook for Getting the Best Treatment, by Michael F. Roizen, MD and Mehmet C. Oz, MD; Free Press (2006)

Your Doctor Said What? Exposing the Communication Gap, by Dr. Terrie Wurzbacher; LifeSuccess Publishing (2006)

Ask the Doctor

By Dr. Jack Burks
Chief Medical Officer for MSAA


Dr. Jack Burks

Q: I have been on Provigil for nine years, since it works better for me than other drugs on the tremendous fatigue I experience. It now is not covered by Medicare Part D. FDA wording changed after I had two years of coverage for Provigil, as an "off-label" prescription. I am working to see if this can be changed, but now with the added symptoms of extreme stress.

Also, I have seen articles on low-dose Naltrexone and a study at UCSF conducted with Naltrexone for MS last year. I can't find anything on the study results, which were to be published in February.

A: Provigil® (modafinil) is FDA approved for narcolepsy (sudden sleep attacks), shift work sleep disorders, and obstructive sleep apnea. Check out your sleep situation with your doctor. I have found Provigil to be a good treatment for MS fatigue in many MS patients. I would also recommend you contact the company, Cephalon, to see if you can get the drug less expensively. Individuals may learn more about Provigil at **www.provigil.com**. Readers may also call **(800) 896-5855** for more information. Please keep trying to get the Medicare situation changed. The FDA needs more positive clinical research data before approving Provigil for MS.

Low-dose Naltrexone (LDN) is still being studied in MS at the University of California in San Francisco (UCSF) as well as other sites in the United States, Italy, and other counties. However, no results are available yet. I expect to see results very soon and MSAA will be sure to include such information when it becomes available.

Q: Does cigarette smoking lead to MS? I keep reading about studies which say that it may, but I want to know for sure. I want to know if this bad habit I used to have could have been the source of my MS! No one will commit to a definite answer, but for me, I fit those study profiles to a "T!"

A: Since we do not know what causes MS, it is hard to incriminate any one factor. Viral, genetic, and environmental factors are the leading candidates. Many people with MS have never smoked a cigarette. Therefore, it is not possible to say whether smoking contributed to your development of MS. However, the studies that link smoking to MS are an added incentive to avoid cigarettes.

The effect of smoking on MS, once diagnosed, may be of more importance. Some data has indicated that smokers may have more problems with their MS. In addition, cigarettes have impurities which enter your body, and may cause lung and other problems not related to your MS. Also, cigarettes contain nicotine, which is a stimulant that may cause circulatory problems. In summary, smoking may cause a worsening of MS symptoms for some patients and I recommend that my patients quit smoking.

Q: I'm 41 and was diagnosed in 2001 with relapsing-remitting MS (RRMS). My son is 11 and he is having a lot of pain in his legs, knees, and back. Sometimes he complains of headaches and problems with vision. Is there a simple blood test that can be done to see if he has a specific gene for MS? An MRI of his brain was negative. Could this just be growing pains or something more serious? Thinking back, I've had symptoms of MS for most of my life. Is it possible that I've had MS since I was a child, and I could have passed it on to my son?

A: No specific blood tests can determine if your son has or will get MS in the future. MS beginning in childhood is possible, but unusual. His normal MRI (magnetic resonance imaging) scan of the brain is reassuring. While a genetic association is seen in MS, most people with MS have no relatives with MS. I recommend that your son continue to be monitored, but his risk of developing MS is less than five percent.

Q: I was diagnosed in 2001 with RRMS at age 66, and two years ago, I was rediagnosed with primary-progressive MS (PPMS). After educating myself about MS and some likely "culprits" for causes, I suspected that the onset of my MS may have been a result of bouts with chlamydia I experienced prior to 2001. I would like to know where I might find the latest research on this topic.

A: A number of infectious agents have been postulated as being associated with MS. Chlamydia is one possible association.

Scientific, published, research papers on chlamydia and other agents can be found by going to **www.pubmed.gov** and typing in the key words "chlamydia and multiple sclerosis." Some scientific data support the association, but other data are less definite. Chlamydia has not been proven as "the cause" of MS. More research is needed in this area to conclusively identify the causative agent(s) involved with MS.

Q: I have MS and my aunt also has MS, leading me to believe we have a genetic propensity for this disease. My 10-year-old son had mono three years ago, and with all the information I keep hearing about Epstein-Barr virus (which causes mono) and a possible correlation with MS, I am worried my son could develop MS. Could you give me your thoughts on this?

A: Like chlamydia in the previous question, Epstein-Barr virus (EBV) is another "candidate" as an infectious agent associated with an increased risk of MS. In fact, a recent article linked EBV and genetic risk factors. However, it is still premature to apply these data to your son's specific risk of MS. If you want to pursue the issue, an MS center consultation is advisable. They can review the genetic link and EBV with you. However, if your son has no neurological symptoms, he is unlikely to have MS. A normal MRI might be added comfort. In summary, his risk for developing MS is low (less than five percent), but greater than the general population.

Q: **I was diagnosed with MS in 1984. For the last six years, along with many other symptom-controlling medications, I have been taking 4-aminopyridine (4-AP). I take 20 mg. every six hours around the clock. If I happen to miss a dose, I get very sick. Since 4-AP is not FDA approved, the $168.00 every five weeks comes out of my pocket. I would like to know if any more research has been done on 4-AP and if FDA approval is in the future.**

A: I have good news for you. Recent studies with 4-AP (called Fampridine SR®) have been encouraging. AND, it is a slow-release drug, which will likely make it better tolerated. Another clinical trial is underway, and if the results are positive, this new drug may get FDA approval. So far, it appears to help both strength and endurance in people with MS. I am keeping my fingers crossed that it proves effective and will become available to MS patients. You can get more information on Fampridine SR at Acorda Therapeutic's website through the following address: **www.acorda.com/pipeline_fampridine_ms1.asp.**

A summary of study results may be found in the Summer 2007 issue of *The Motivator* in the "MS Research Update" cover story. The information is on page 17, and readers without this issue of the magazine may call MSAA at **(800) 532-7667** to request a copy; the article may also be viewed on MSAA's website at the following address: **www.msassociation.org/publications/summer07/cover.story.asp.** (Please note that individuals considering this drug or any other treatment for MS should consult their physician before making any changes to their treatment regimen).

Q: **I'm 51 and was diagnosed with chronic-progressive MS 10 years ago. I tried Betaseron® for a year without noticeable changes. I then took Avonex® for five years and I only noticed a possible minimal slowing of progression. Is it possible those drugs do not really work as well for chronic-progressive MS? I never had an exacerbation. I have tried Solu-Medrol® (IV methylprednisolone) five times, Novantrone® three times, and intravenous immunoglobulin (IVIg) therapy three to five times, all with no effects. Why or how is chronic-progressive MS so different?**

A: Chronic progressive MS is divided into two main subtypes. Secondary-progressive MS (SPMS) starts out with relapses but transitions to "progressive" after several years. You may have another subtype called primary-progressive MS (PPMS), which is not associated with preceding attacks. PPMS has no known effective treatment. The current treatments are aimed at reducing inflammation as seen in relapsing MS. On the other hand, PPMS is not associated with much inflammation. Therefore, I am not surprised that you have not seen much treatment effect. However, new treatments are being developed, and I'm happy to point out that research is ongoing. Drugs that promote remyelination and protect brain stem cells from dying are also being evaluated. ◆

To Submit Questions to Ask the Doctor…

If you have a question that you would like to ask, please submit your question to:

MSAA
Questions for Ask the Doctor
c/o Dr. Jack Burks
706 Haddonfield Road
Cherry Hill, New Jersey 08002

Readers may also send in questions via email to **agriese@msassociation.org.** Please be sure to write “Ask the Doctor” in the subject line.

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

Do You Speak Spanish?

Call the Helpline for:

- Share your MS Experience
- Multiple Sclerosis (MS) Information
- Disability/Insurance Issues
- Reassurance and Support
- Connect to Other MS Resources

Are your needs being met?
Let us hear from you.

MSAA's Bilingual Helpline Offers Assistance for the Spanish-Speaking MS Community

Helping Spanish-speaking MS clients find access to health care, information, and community resources are just a few examples of the support offered through the MSAA Bilingual Helpline.

Helpline Consultant Richard Palacio reports that calls from Spanish-speaking MS clients and a growing network of social workers are steadily increasing as awareness of service expands throughout the United States and Puerto Rico. MSAA is offering this service in an effort to assist individuals in the Spanish-speaking community receive information, referrals, and reassurance in the fight against this disease.

Individuals requiring assistance may contact MSAA's Helpline at (800) 532-7667, extension 108.

This Helpline service is another way MSAA strives to enrich the quality of life for everyone affected by multiple sclerosis.

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

¿Habla usted español?

Llame a la Línea de Ayuda:

- Compartir sus experiencias con la EM
- Para conseguir información sobre la esclerosis múltiple (EM)
- Problemas con su seguro de salud o beneficios por incapacidad
- Para recibir apoyo
- Para encontrar otros recursos ofrecidos por EM

¿Tiene usted todas sus necesidades?
Llámenos.

La línea de ayuda bilingüe de la MSAA ofrece asistencia al hispano-hablante afectado por la EM

Ayudamos a los clientes hispano-hablantes con EM a encontrar atención médica, información y recursos en su comunidad. Esto es sólo un ejemplo del apoyo que prestamos a través de la Línea de ayuda de la MSAA.

Richard Palacio, nuestro asesor bilingüe informa que las llamadas por clientes hispano-hablantes con EM es cada vez mayor y el uso de la red por trabajadores sociales está aumentado continuamente, mientras que el conocimiento de los servicios que existen en los Estados Unidos y en Puerto Rico se amplía. La MSAA ofrece este servicio para asistir a los individuos de la comunidad hispano-hablante a recibir información, ser referidos y apoyados en la lucha contra esta enfermedad.

Los individuos que necesitan ayuda pueden contactar la línea de ayuda de la MSAA al (800) 532-7667, extensión 108.

Este servicio de la línea de ayuda es una de las muchas maneras que la MSAA se esfuerza para enriquecer la calidad de vida de todas las personas afectadas por la esclerosis múltiple.

Este servicio se ha hecho posible a través de la ayuda de la Medtronic Foundation.

Research News

Recent MS News

A one-year study in Germany found that 1157 patients with relapsing-remitting multiple sclerosis (RRMS) who began and continued on **Avonex**® for one year, benefited from nursing support. They also experienced a modest improvement in quality of life during this treatment period, as measured through the EuroQol questionnaire (EQ-5D).

In the BENEFIT trial, 468 patients experiencing a first event suggestive of MS (also known as a "clinically isolated syndrome") were randomized to receive immediate treatment with **Betaseron**®, or delayed treatment with **Betaseron** following two years on a placebo (or earlier if a second event occurred). A three-year follow-up showed that patients who received immediate treatment had a 40-percent less risk of sustained disability progression compared to those with delayed treatment. Those receiving immediate treatment also had a 41-percent reduced risk of advancing to clinically definite MS (CDMS) within the three-year time period.

The BEYOND trial compared the effectiveness of three treatment arms (regular-dose **Betaseron**, double-dose **Betaseron**, and **Copaxone**®) in 2244 patients with RRMS. The primary endpoint was relapse risk, and all three treatments showed a robust, equal effectiveness (average follow-up time was just over two years). The annualized relapse rate fell by almost 80 percent, compared to the year prior to entry. Dropout rates showed that all drugs were well tolerated, with the lowest dropout rate in the regular-dose **Betaseron** group.

Early treatment with **Copaxone** was compared to placebo in the PRECISE trial, to determine **Copaxone's** effectiveness in delaying the development of CDMS, for individuals with a first event suggestive of MS. An interim analysis of the study's 481 participants showed a 45-percent risk reduction in the treated group compared to the placebo group. Due to the effectiveness of the treatment, the researchers recommended that the placebo portion of the study be discontinued early, and all patients be switched to active treatment.

The REGARD trial was conducted to compare the effectiveness of **Copaxone** versus **Rebif**® in 764 patients with RRMS. The primary endpoint was time to first relapse during a treatment period of nearly two years. The entire study group's population had much less disease activity (based on the pivotal studies conducted earlier) with 45-percent fewer relapses than expected and an annualized relapse rate of just 0.3, which is less than one relapse every three years. No significant difference was seen between the two groups for the primary outcome (time to first relapse).

In a small study in Italy, nine women patients with worsening RRMS (who were not responding to interferon treatment and had no neutralizing antibodies), were given low-dose **Novantrone**® (mitoxantone) via IV every three months, in addition to their interferon treatment. The **Novantrone** dose was adjusted for each patient, according to lymphocyte counts. After six months, total relapses dropped from 17 to 1; disability scores improved; and enhancing lesions decreased from 27 to 4. No serious side effects occurred during the treatment period. This reinforces the use of low-dose **Novantrone** as an add-on rescue therapy in RRMS patients not responding to interferon treatment. The combination therapy may also reduce the risk of adverse events due to the accumulation of high doses of **Novantrone**. In Turkey, another small study with 23 secondary-progressive MS (SPMS) patients and four individuals with worsening RRMS showed that **Novantrone** not only improved physical disability, but also improved cognition. With both of these studies, larger, placebo-controlled trials are needed to determine the actual benefits and risks.

As of March 2008, more than 26,000 patients were on **Tysabri**® worldwide. Since the re-launch of **Tysabri** in July 2006, no new cases of progressive multifocal leukoencephalopathy (PML) have been reported. PML is an often-fatal viral infection of the brain. Data from the PLEX study suggest that plasma exchange may be an effective procedure for accelerating the removal of **Tysabri** from the blood if PML infection is suspected. A new warning has been added to **Tysabri's** label about possible liver injury, and two cases of melanoma (skin cancer) have also been reported in women taking **Tysabri**, but a connection has not yet been confirmed.

Disappointing results from the OLYMPUS trial show that **Rituxan**® (rituximab) did not

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New lift seats like the one pictured at left are among items to be included in MSAA's expanded Equipment Distribution Program.

MSAA Expands Equipment Distribution Program

Through a generous charitable contribution from the Genentech Foundation, MSAA is expanding its Equipment Distribution Program with the addition of several products to assist with safety and daily living. These include plans to create a video, along with printed materials, for the safe use of products offered through the program. An evaluation component will also be developed to assess product usage, satisfaction, and the impact on quality of life.

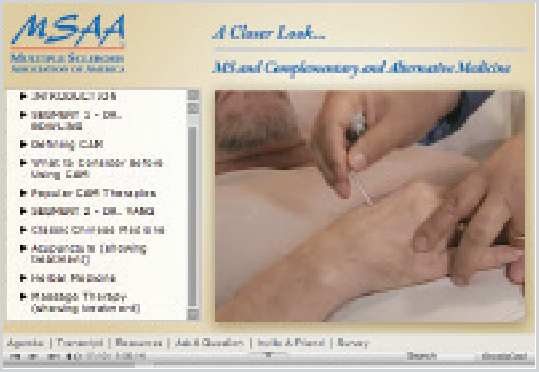
As you may know, the MSAA Equipment Distribution Program provides clients with a wide array of durable medical products and daily-living aids at no charge, in order to increase clients' safety, mobility, and independence. Some of the more popular items include grab bars, hospital bed tables, reachers, and bed rails. Through the Genentech grant, MSAA will purchase and include the following new items: lift seats (pictured above), Super Pole™ transfer systems, large-button keyboards, magnifiers, and slip-on doorknob levers.

"These items are commonly used by individuals to regain independence, improve safety, and increase participation in daily activities," according to MSAA Healthcare Advisory Council Member Carrie Bruce, MA, CCC-SLP, ATP. "Lift seats and transfer poles help people to sit down and stand up from beds, toilets, and chairs. This promotes movement around the home. Keyboards with large buttons and magnifiers enable people to stay connected with the world by facilitating reading, writing, and computer tasks. Lever doorknobs minimize or eliminate the difficulties that people have with opening and closing doors. All of these products make living easier and enhance a person's quality of life. It's wonderful that these products are now available through MSAA."

MSAA clients interested in obtaining these items and other products through the Equipment Distribution Program can download the application from **www.msassociation.org** or request a mailed copy by calling **(800) 532-7667, extension 130**.

Cooling Program

As summer temperatures begin to rise, so does the need for many with MS to cool down. As a reminder, the MSAA Cooling Program offers free cooling products such as vests, wrist bands, and accessories to help lessen heat sensitivity and allow people to spend time outdoors during the summer months.



Acupuncture is one of the many treatment modalities featured in MSAA's latest educational web video, "A Closer Look at MS and Complementary and Alternative Medicine."

MSAA has received a significant charitable contribution from Teva Neuroscience which will ensure that all eligible MSAA clients have the opportunity to receive cooling relief and enhance their quality of life. If you are interested in receiving cooling items and have not received products from MSAA within the past five years, please download the Cooling Equipment application from **www.msassociation.org** or request a mailed copy by calling **(800) 532-7667, extension 130**.

Multiple Sclerosis Information (MSi) Program

Through the MSi Program, MSAA's latest educational web video, *A Closer Look at MS and Complementary and Alternative Medicine*, explores the worlds of Western and Eastern medicine and includes discussions and demonstrations of acupuncture, massage therapy, and other popular alternative therapies. Sponsored by Bayer HealthCare Pharmaceuticals, the two-part video features Dr. Allen Bowling, director of the Complementary and Alternative Medicine Program at the Rocky Mountain MS Center; and Dr. Jingduan Yang, medical director of the Tao Institute of Mind and Body Medicine.

Our next video is *A Closer Look at The Value of MRIs*. Sponsored by EMD Serono and Pfizer, this three-part video will feature an MS client who gives a first-hand account of her experiences in receiving a diagnostic and follow-up MRI. It also features neurologist Dr. Diego Cadavid of the University of Medicine and Dentistry of New Jersey, who explores the science behind MRIs and the benefits of follow-up MRIs. Additionally, Bob Rapp, MSAA's vice president of programs and evaluation, explains the easy process of receiving assistance from MSAA through the MRI Diagnostic and MRI Institute programs. At the time of this writing, MSAA is nearing completion of this new web video.

Readers who are interested in viewing the program may access it through **www.msassociation.org** or request a copy from the MSAA Lending Library (please see page 48 of this issue for contact information).

— Peter Damiri

Mobility and Exercise Survey Results

More than 2500 of MSAA's clients responded to a recent survey on mobility and exercise, conducted by MSAA in conjunction with Acorda Therapeutics, Inc. The extraordinary number of people responding to this email survey – more than 25 percent of those who received it – underscores the importance of these issues to individuals affected by MS. To follow are some of the key findings of this study.

- 95 percent of those responding identified themselves as having MS. 75 percent were female, with 65 percent being over the age of 45. 66 percent were diagnosed more than five years ago.

- 78 percent indicated that they had some physical limitations which affected their mobility. Almost 40 percent used some type of aid for mobility; 27 percent walked with an aid, while 12 percent used a wheelchair or scooter all the time; just 1 percent of the respondents remained in bed most of the time.

- Only 11 percent of the respondents stated that they "never" had to limit their activities that involve walking due to mobility problems.

- The vast number (86 percent) of those responding felt at least somewhat knowledgeable about mobility issues and their MS.

- The majority rely on their physician for information about mobility issues and concerns, while almost 20 percent rely on "no one" for answers to their questions.

- 60 percent of the respondents exercise at least weekly, with 18 percent doing so daily. 38 percent either never exercise or do so only occasionally.

- Over 75 percent have had a member of their healthcare team discuss the benefits of exercise and 55 percent have been referred to physical therapy as part of their MS treatment plan.

Summary

Based on the results of this survey, mobility and exercise are important issues for individuals affected by MS. A significant majority of the respondents indicated that limitations in walking affected the activities in which they were able to participate. Members of the person's healthcare team generally do discuss the benefits of exercise with the MS patient and a large portion of those responding exercise regularly. However, in both categories, there is a sizeable group (25 percent) who have not spoken with their healthcare team about exercise, while 38 percent either never or only occasionally exercise. These individuals would benefit from increased education, support, and services in this area.

MSAA would like to thank all those who participated in this survey. By listening to you, our clients, we are able to provide programs and services which "enrich the quality of life for everyone affected by MS."

— Robert Rapp

Thoughts about Giving

A Legacy of Goodwill

Bruce Makous

Many different types of individuals give generously to MSAA each year. Some of these thoughtful people also choose to continue to contribute through testamentary gifts. In doing so, they create a legacy of goodwill that will live on and continue their support for the MSAA community into the future.

A donor may create a philanthropic legacy in a number of ways. Most often, people contribute a portion of their estates after death. These generous individuals remember MSAA and the people we serve through a charitable bequest. Frequently, these are individuals who have been part of the MSAA community for many years and who also want their support to continue after they are no longer able to give.

GIFT ANNUITY ILLUSTRATION

Annuitants:	Couple both age 72
Principal Donated:	$10,000.00
Annuity Rate:	6%
Annuity, paid quarterly:	$600.00
Charitable Deduction:	$3,496.30
Tax Savings at 33%:	$1,153.78
Net Donation after Savings:	$8,846.22
Tax-free Portion of $600:	$346.20
Ordinary Income Portion:	$253.80
Effective Return Rate:	8.7%

After 18.8 years, the entire annuity becomes ordinary income.

I was recently saddened to learn that Stanley, a generous man from New York who had been contributing faithfully for 11 years, had died. His estate attorney notified MSAA that we were the recipient of a five-figure bequest to help us meet our priority needs.

In another instance, Mary, a generous supporter from Texas, contributed annually to MSAA for more than twelve years. After she died in 2007, her executor informed us that we were the recipient of a generous mid-five-figure bequest.

A third, very generous person from Washington has indicated, while she is still living, that she has created a six-figure endowment which will be funded through an estate gift. Her funds will provide annual support for MSAA's Equipment Distribution Program to help people with MS for many years to come.

Herb and Selma, a generous couple from Florida, decided to establish their legacy during their lifetime by creating a gift annuity fund. The couple will receive income for life, and in the future, after both are deceased, MSAA will receive the balance of the fund to support its programs. This is a good way to fund a legacy gift today while the donor continues to receive the financial benefits from the funds.

The MSAA Legacy Circle is one way that we provide special recognition to all of our donors who make planned gifts. Any individual who remembers MSAA in his or her will, or establishes another form of legacy gift, is recognized through the MSAA Legacy Circle.

Through all of these legacy gifts, the goodwill of generous individuals toward MSAA, as well as their relationships with us, will live on. We greatly appreciate all that our supporters do to enrich the lives of individuals with multiple sclerosis.

*— **Bruce Makous***
Vice President of Development

The President's Circle reception in April at the Metropolitan Museum of Art in New York City was a gathering of numerous MSAA supporters from Connecticut, New Jersey, and New York. Below, MSAA supporters Yolanta Khalil-Maczynaska and Jeanette Elsner enjoy the beautiful setting and the good company.

President's Circle Reception in New York City

MSAA was pleased to hold a special reception for its supporters in the New York City area at the Metropolitan Museum of Art. Attendees at the packed, standing-room only event were able to tour the museum exhibits, and MSAA had the opportunity to show its appreciation for their support.

MSAA President and CEO Douglas Franklin, along with members and officers of MSAA's Board of Directors, had the opportunity to personally thank MSAA's donors and volunteers in the area. MSAA's President's Circle program provides special appreciation for loyal and generous donors. More than 350 individuals from across the country currently receive recognition as President's Circle donors.

Weight Management and MS

Written by Maryann B. Hunsberger

I lost count of how many nutrition shakes I drank as a teen in an attempt to gain weight. If I didn't consume 3,000 calories a day, I'd shrink to 97 pounds – too low for my 5'4" frame. My father kept feeding me steak and potatoes, saying it would "fill me out." Yet, no matter what I ate or drank, I couldn't get past 105 pounds. As an adult, I stayed the same weight, wearing a size-5 wedding gown and size-5 maternity clothes.

After becoming disabled at age 35, I couldn't stand up long enough to prepare healthy meals, so I began relying on convenience foods. My activity level dropped, as I could barely move some days. Adding symptom-relieving medications to that mix was a prescription for weight gain. Lots of it. Within four years, the size-5 girl became the size-3X woman.

"This scenario is common for people with disabilities, including MS," notes Gillian Goodfriend, a registered dietician at the University of Illinois at Chicago (UIC)'s Department of Disability and Human Development. "People choose fattening convenience foods because of difficulty standing, lack of energy, and sometimes stress and depression brought on by MS. Inactivity, reduced activity, and certain medications also put weight on."

Individuals with MS can take steps to prevent weight gain or reduce weight. Goodfriend emphasizes the importance of eating three meals each day. "People shouldn't deprive themselves by skipping meals. Skipping breakfast causes people to eat too much at lunch, because they are starving. Their metabolism also slows down from not eating."

In her book, *Apples and Pears: The Body Shape Solution for Weight Loss and Wellness*, Marie Savard, MD, points to studies showing that people who eat breakfast are half as likely to be obese as people who don't eat breakfast. So, what's good to eat for breakfast? Goodfriend says the healthiest, most satisfying breakfast is one that combines protein and whole grains or fruits. "Protein helps keep people more satisfied and less hungry. Whole grains and fruit provide filling fiber."

A common mistake dieters make at lunch is eating something that isn't satisfying, such as a salad with no protein or fat. "The protein in some added chicken or beans and the fat in salad dressing provide a feeling of fullness," states Goodfriend.

The same balance of protein, fat, and fiber should make up dinner. Goodfriend continues, "When MS causes fatigue, people can't stand each night in the kitchen to cook. They can make a large pot of soup or chili Sunday and divide it into containers for the week. A soup or chili made with vegetables, beans, and lean ground turkey is ideal. These foods are good for losing weight, depending on portion size."

Yet, portion sizes can be tricky. Most people eat an entire can of soup, while one-half can is a serving. A large banana or large apple provides two servings, although many people think of any fruit as one serving. Goodfriend notes, "At first, people should weigh and measure how much they eat until they can eyeball it. It's surprising how we pour ourselves a double portion of cereal without realizing it."

At a time when "super-sizing" is the norm, Cindy Richman, senior director of services at the Multiple Sclerosis Association of America, says that education about portion control is more important than ever. "On TV commercials and in restaurants, portion size is so large. When people go out together, they should think about sharing their portion."

In order to help control portion size, Savard reminds readers to avoid buffet restaurants. She also advises to put extras back in the refrigerator before serving the meal, and to buy small packages of snack food to control serving size.

The Massachusetts Institute of Technology has a guide to portion sizes at their website, which can be helpful to those battling skyrocketing weight: **http://web.mit.edu/athletics/sportsmedicine/wcrservings.html**

With all of the diet books on the market, how can someone with MS know which diet is best? Richman points out that a balanced diet recommended by a specialist familiar with MS is best. "Weight is an individual issue. People need to make complete lifestyle changes, since they won't be able to follow fad diets for any length of time. It's better to consult a nutritionist or take courses about food groups and different choices at health and wellness centers. It's all about balance. If ordering chocolate cake when out with friends Saturday night, eat less the next day."

Counting calories is helpful for many people with weight loss. To lose weight, people should shoot for 20 to 25 calories per kilogram each day. To determine kilogram weight, divide weight in pounds by 2.2. To maintain the same weight, 25 to 30 daily calories per kilogram is appropriate. To gain weight, consume 35 to 40 daily calories per kilogram. This translates to roughly 10 calories per pound to lose weight; 12 calories per pound to maintain weight; and 17 calories per pound to gain weight. Using **www.fitday.com** or **www.sparkpeople.com** makes it easier to track calories.

EDITOR'S NOTE: Readers are strongly advised to consult their physician before making any changes to their diet. A doctor can also help determine the exact number of daily calories that are specifically appropriate for an individual.

I lost 126 pounds using techniques recommended by my doctor's nurse practitioner. To prevent cravings caused by blood sugar surges, I replaced simple carbohydrates (such as white rice, white bread, and sugar) with complex carbohydrates (including brown rice and whole grain bread). I maximized fruit and vegetables to increase my fiber and feel full. To lower both weight and cholesterol, I decreased animal fats (red meat, full-fat dairy). I gave up second helpings and limited portion sizes. To track my food and calorie intake, I used fitday.com as a journal. I removed junk food from my kitchen, planned my menus one week in advance (in writing), bought only the items listed on the menu, and found new, tasty recipes to prevent boredom. I also relied on my grocery store's online delivery service to prevent fatigue.

Some people with MS have the opposite problem – they lose too much weight. Goodfriend says that weight gain and weight loss stem from many of the same reasons. “The biggest factor is loss of muscle from lack of movement and pain. Decreased muscle mass leads to decreased strength and energy. Fatigue can cause inability to go shopping for food or to prepare complete meals. Medications, stress, or depression can also cause lack of appetite.”

To gain weight in a healthful way, eating three balanced meals a day plus snacks is important. Goodfriend recommends taking a balanced multiple vitamin (one that includes no more than 100 percent of the recommended daily allowances). Underweight people should also eat healthy foods, but in larger portions. The following strategies, with a doctor’s approval, may help put on weight:

- Add healthful fats, such as olive oil, olives, avocadoes and nuts
- Include calorie-dense, nourishing foods, such as dried fruit and fruit juices
- Add dry powdered milk to a casserole or a cup of milk
- Try a nutritious protein or meal-replacement drink, such as Carnation Instant Breakfast® or Ensure®, between meals (please note that these types of drinks may be high in sugar; some sugarless varieties are available)
- Combine milk, yogurt, and fruit in the blender as a snack

If someone takes in more calories than he or she burns, weight gain occurs. If a person burns more calories than he or she eats, this causes weight loss. Exercising helps the body burn calories while promoting balance and flexibility in people with MS, so it’s good for both people needing to lose and gain. Physical activity with most disabilities can be complicated, and MS is no exception.

Richman recommends having a physical therapist create an exercise plan. “Most health club programs are not designed for people with MS. For example, a trainer may possibly do more harm than good. Personal trainers may tell people to do more repetitions, which may add to a patient's fatigue. Unless the personal trainer is experienced in working with MS, the ideal option is to consult with a physical therapist. If insurance won't pay for the ongoing therapy, the therapist can explain how to do exercises at home.”

Since fatigue is a major factor, the exercise plan for someone with MS must be flexible. People who nap after lunch could exercise in the morning. Late sleepers might prefer evening strolls. Wheelchair users might like aquatic therapy. People with MS should listen to their bodies. Richman explains, “When a person is very tired or in pain, exercise may be skipped for that day. Most of all, people with MS should consult a physician before embarking on a diet and exercise program. A condition unrelated to MS, such as a thyroid disorder, could cause weight change. A doctor, an occupational therapist, a physical therapist, a nutritionist, and the patient all need to be part of a team working together.” ◆

For some healthy ideas for balanced meals, snacks, and recommended serving sizes, please see the accompanying sidebar on page 38.

What Do I Eat?

Whether a person with MS needs to gain or lose weight, it's important to eat healthful foods. Some healthy, balanced ideas for breakfast, lunch, dinner, and snacks – with recommended serving sizes – have been included in the following list. Be sure to eat larger portions if trying to gain weight. *Please note that any changes to one's diet and exercise regimen should only be made under the supervision of a qualified physician.*

BREAKFAST OPTIONS:

- A small apple with 8 ounces low-fat yogurt
- ½ cup low-fat cottage cheese with ½ banana
- A bowl of high-fiber cereal (at least 5 grams of fiber per serving) with soy/skim milk and a peach
- Whole-grain toast topped with 2 tbsp. peanut butter
- Scrambled egg white/egg substitute and 1 ounce low-fat cheese sautéed with tomatoes, mushrooms, and onions; and a pear
- Oatmeal (⅓ to ½ cup before cooking) with ¼ cup nuts and 1 cup berries

LUNCH OPTIONS:

- A salad should contain many vegetables, a protein source like beans or chicken, and only a small amount of cheese
- A serving of low-fat yogurt increases protein
- A slice of whole-grain bread provides extra fiber
- Avoid ranch or blue cheese dressings, as they contain saturated fats. Use balsamic vinaigrette or Italian, which emphasize healthful fats
- An open-face sandwich cuts calories. Good toppings are tuna salad with fat free mayonnaise; low-fat cheese and vegetables; and sliced turkey or chicken

DINNER OPTIONS:

- Baked, grilled, or broiled salmon and chicken breast are good main dishes
- Add grilled chicken to whole-grain pasta with vegetables and sauce
- One-pot meals like stir-fried vegetables and tofu with brown rice make preparation easier

SNACK OPTIONS:

- Carrots dipped in 2 tbsp. hummus
- Part- skim string cheese stick with ¼ cup nuts
- Air-popped popcorn
- Fat-free pudding in individual serving containers
- Low-fat yogurt with one fruit serving

— Maryann B. Hunsberger

THE PHILANTHROPY CIRCLE

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

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

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

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

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

RESOURCE DETECTIVES℠ NEEDED

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

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

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

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

DRESS TO FEEL YOUR BEST

by Shelley Peterman Schwarz

I've always taken pride in the way I look. Perhaps it is because my mother and my grandmother did too. There was even a family joke that no matter what ailments my grandmother had in her final years, whether hospitalized or sick in bed, she always put on lipstick, earrings, and a pretty bed jacket.

Even today, at 85, my mother doesn't leave the bedroom without "her face on," and I've never seen her wear a sweatshirt or sweatpants. Me? Every day I dress as if I'm going to work or to a meeting; a fashionable outfit, makeup, and jewelry. You'll never see me in a pair of torn jeans and a faded T-shirt. Psychologically, if I look "schlumpy," I feel "schlumpy." When I am confident about my appearance, I just feel better.

For 20 years or more, as a result of strength and mobility issues with MS, I've needed lots of help getting dressed. I've had to make compromises and adaptations to the way I dress to make it easier, safer, and less tiring. To follow are some of my personal, energy-saving tips, which you may find to be helpful.

Dressing Tips to Make Life Easier

Assess your morning rituals. Is it easier to get dressed before or after you take your medication, shower, or eat breakfast? Everyone is different, so experiment with the order of your morning routine to find what works best for you. For me, I always drink a glass of juice before my husband helps me out of bed. This gives me the little energy boost I need to get dressed.

Make sure your home thermostat is set to a comfortable temperature when you get out of bed. Avoid getting overheated from a house that feels too warm, or becoming stiff and clumsy from a house that feels too cool.

Each night, select and gather all of your clothing items for the next day. This will not only save time and energy in the morning, but if you need assistance with buttons or zippers, you may be able to enlist the aid of a family member before he or she leaves the house.

Choose what you wear based on the day's activities. If you plan on swimming, for example, choose an easy-on, easy-off outfit with few buttons, zippers, or ties. If you will be traveling, wear something that is a little looser, in a smooth fabric that makes it easier for you to change positions or get in and out of an upholstered seat.

Dressing in front of a mirror can be of assistance to some people. It may help you to find the sleeves and match-up buttons with buttonholes. Also, if you button garments from the bottom up, you're less likely to skip a button. If your balance is an issue, sitting on the edge of the bed or on a chair can be of help when dressing.

For individuals with strength or mobility problems, dressing the weaker arm or leg first is a good idea. When undressing, the garment should be taken off the stronger arm or leg first.

Easy-on, Easy-off Clothing

Loose-fitting clothes, particularly those made of knit fabrics, are easier to pull on and take off. When I find a garment that I like, in a style and size that fits, I try to purchase several in various colors. This can save a lot of time and trouble.

I also recommend wearing lightweight clothing. Heavier fabrics may actually wear you out just putting them on.

Some individuals may find that wearing nylon underwear, instead of cotton, helps with pulling slacks on and off. For the same reason, when purchasing wool slacks, I always make sure they are lined.

Clothing that opens in the front is easier to put on and take off than garments which open in the back. One strategy is to partially button the lower portion of a shirt, and then slip it over your head. If you choose clothing that slips over your head, make sure it has enough stretch to make it easy to get on and off.

Once started, zippers can be easier to use than buttons. If you have trouble grasping a small zipper pull, enlarge it by attaching a decorative charm, bead, or key ring.

Wearing shawls instead of coats or jackets can make life easier. Pre-knotted ties are helpful as well. In general, I try to find clothes and accessories that make dressing easier. Try not to worry so much about what is in style; you can create your own style.

If you are less active, then you may be more likely to feel cold. Dressing in layers will help to give you better control over your body temperature. The spaces between the layers of loose-fitting clothes trap warm air, and you can take off or put on layers as needed to stay comfortable.

If you use a wheelchair or spend a great deal of time sitting, you may want to consider purchasing garments which are one size larger than you normally wear. Clothing is more comfortable for sitting, and easier to get on and off, if it is not too snug. Wearing clothes that are too tight may actually cause you to feel tired.

Individuals who wear an orthotic device may try slipping a section of nylon stocking over it before getting dressed. This can help clothing to slide on more easily.

Dressing Aids

Some people may find a dressing stick to be helpful. This extends your reach, and may be made from a wooden hanger. To make one, I first remove the hanger hook on top, and then screw a small hook into one end of the stick, while putting a finger thimble made of rubber on the other end. The hook may be used to grab onto garments, and the rubber tip can help to slide clothing into a comfortable position. You may also make a dressing stick by untwisting a wire coat hanger with a pair of pliers.

Earlier, I mentioned attaching a decorative charm, bead, or key ring to a zipper tab to make it easier to pull up. Of course, you can't do this with every zipper. To pull up a zipper on a pair of trousers, you can slip a large paper clip through the hole in the zipper tab. Once in position, you can remove the clip and keep it in your pocket when not in use.

To locate adaptive equipment (such as reachers, dressing sticks, and buttoning aids) in your community, you may contact the hospital or clinic's occupational therapy departments, medical equipment and supply stores, and pharmacies. These businesses may also carry other helpful dressing aids, which include: sock aids to help you put on and take off socks or stockings; long handled shoe horns; and elastic shoe laces that allow you to slip shoes on and off without tying and untying them.

No Need to Shop 'Til You Drop

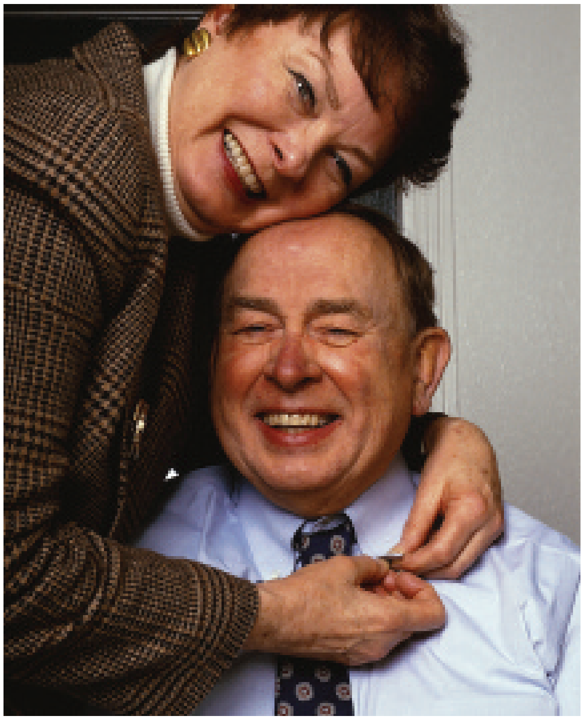
Even when I still had the strength and energy to try on clothes, I shopped at small clothing stores. Large department stores were too overwhelming and impersonal. In addition, I always found that in small stores, clerks helped coordinate outfits and helped me in the fitting room. The clothing may have cost a bit more, but for me, the special service was worth the added price.

Shopping on weekdays and early mornings can help you to avoid crowds and long lines. Surveys indicate that Tuesday is the least busy shopping day of the week. When the women's or men's department registers are busy, I always pay for items in lower traffic areas – such as the infants' department or the cosmetics counter.

At large department stores, checking out the floor plan and plotting your course is a good idea. You may want to stop by the service desk for directions or to get a map of the store. At shopping malls, the information center will have a map to help you locate the stores you're looking for as well as rest areas, food courts, and accessible bathrooms.

I try to conserve energy by sitting in a chair in the dressing room whenever I try on clothes. If there isn't a chair, I ask the salesperson to get one for me. If you do not have the energy to try on clothes at stores, make sure that the store does not have any limits on returns. Some stores may only offer credit rather than a cash return for certain items. In smaller boutiques, I ask to take the clothes home "on approval," so I may try them on at my leisure. I have even shopped with a friend who is about the same size as I am. By asking her to try on the clothes, I can get an idea of whether or not the garment will work for me.

Wearing classic styles rather than the latest fad helps to keep the number of shopping trips (and the need to try on all those clothes) to a minimum. Then I simply update outfits by changing jackets, blouses,



and different accessories, such as jewelry, scarves, belts, purses, and shoes.

Buying outfits, as opposed to buying a pair of slacks here and a blouse there, makes it easier to build a well-rounded wardrobe. I try to choose coordinated garments that provide greater flexibility; you can purchase different tops and bottoms and mix and match different style garments to suit your needs.

If you know exactly what you want, you may be able to call ahead and ask the store to have it ready for you. One option is to pay for the item(s) by credit card and have someone else pick up your purchases at his or her convenience. This can save much time and energy.

I also like to take advantage of extra services that some stores offer, such as personal shoppers and bra fitters. Once they know your personal preferences and sizes, these store employees can save you a great deal of time and energy by pre-shopping before you arrive at the store.

Resources for Modified Clothing

People with active lifestyles, and who are looking for ready-to-wear garments that have been designed with easy dressing in mind, need not despair. Today you can find a multitude of store, catalog, internet, and TV-shopping sources that carry modified clothing. You'll find everything from sleepwear to evening wear, and shoes to accessories, for men, women, and children. To follow is a list of a few popular sources:

Multiple Sclerosis Association of America's (MSAA's) Equipment Distribution Program offers a number of items to assist individuals with MS who are experiencing strength and mobility issues. These are provided at no cost (certain income and distribution limits apply). Dressing aids offered by MSAA include button hooks, dressing sticks, sock aids, and metal shoehorns. An application may be requested by calling **(800) 532-7667, extension 130**, or by visiting **www.msassociation.org**

Professional Fit Clothing purchases regular clothing from manufacturers and adapts it for people with disabilities. They will custom fit and alter almost any item to fit your needs. Shop online and order by phone. Professional Fit Clothing; **(800) 422-2348**; **www.ProfessionalFit.com**

American Health Care Apparel works directly with manufacturers to design traditional and adaptive clothing and footwear, which are both functional and attractive. These provide dignity and comfort without sacrificing style. Call for a catalog or order online. American Health Care Apparel, Ltd.; 302 Town Center Blvd; Easton, PA 18040; **(800) 252-0584**; **www.ClothesForSeniors.com**

Wear Ease® offers bras, loungewear, and other garments for women who have trouble dressing due to wrist injury, arthritis, fibromyalgia, spinal cord injury, paralysis from stroke, or other disabilities. These products can help enable individuals to return to independent dressing and reduce the amount of work for caregivers. Wear Ease® Bras are constructed with Naturexx® fabric, which transfers moisture away from the body. They are designed to be cooler in warm weather and warmer in cold weather. The bra offers full back support and an adjustable fit, in a pullover shirt design, which requires only a one-hand grasp to remove. They are cold-water washable and available in a variety of band and cup sizes. Wear Ease, Inc.; P.O. Box 8831; Boise, ID, 83707; **(866) 251-0076**; **www.wearease.com**

Dressing Tips and Clothing Resources for Making Life Easier is a book which offers additional tips for shopping and making dressing easier. Numerous resources are listed by category, making your search for adaptive shoes, clothing, and wheelchair accessories easier. This book may be ordered from Attainment Company; PO Box 930160; Verona, WI 53593-0160; **(800) 327-4269**; the book may also be ordered by visiting **www.AttainmentCompany.com** and doing a search for the book's title.

AdaptiveOutlet.com offers discount prices on everything from clothing to wheelchair accessories, including options for people with more severe disabilities. To keep prices lower, their catalog is only available online. Adaptive Outlet; 1701 E. Hennepin Ave; Minneapolis, MN 55414; (866) 331-1122; **www.adaptiveoutlet.com**

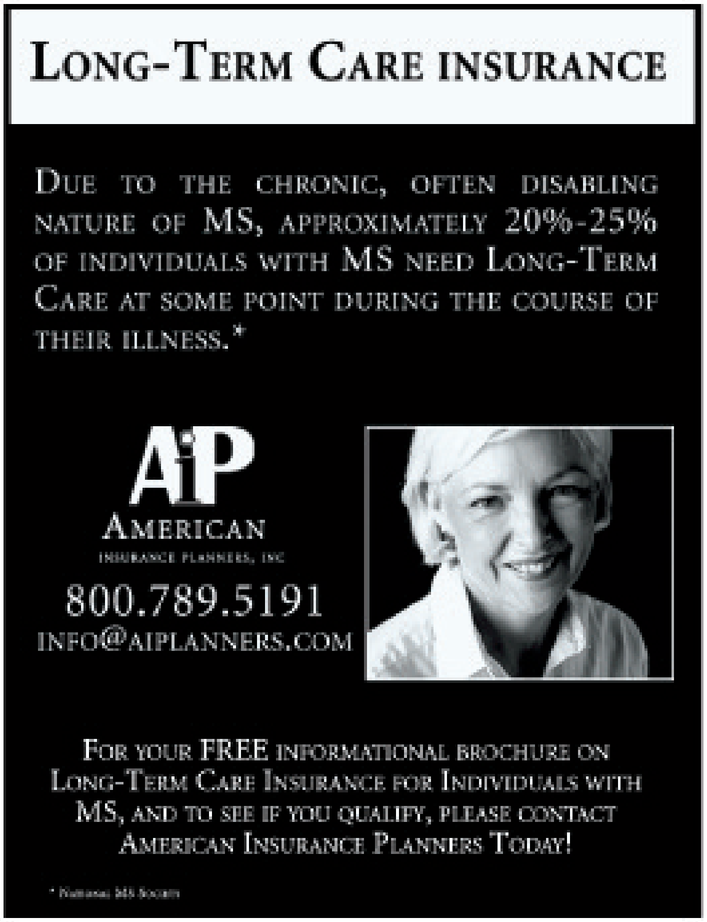
Silvert's, who has been providing adaptive clothing options for 78 years, offers a full line of clothing and accessories especially designed for people with limitations and disabilities. Shop online or call for a catalog. Silvert's, 3280 Steeles Avenue West, Suite 18; Concord, Ontario L4K 2Y2 Canada; (800) 387-7088; **www.silverts.com**

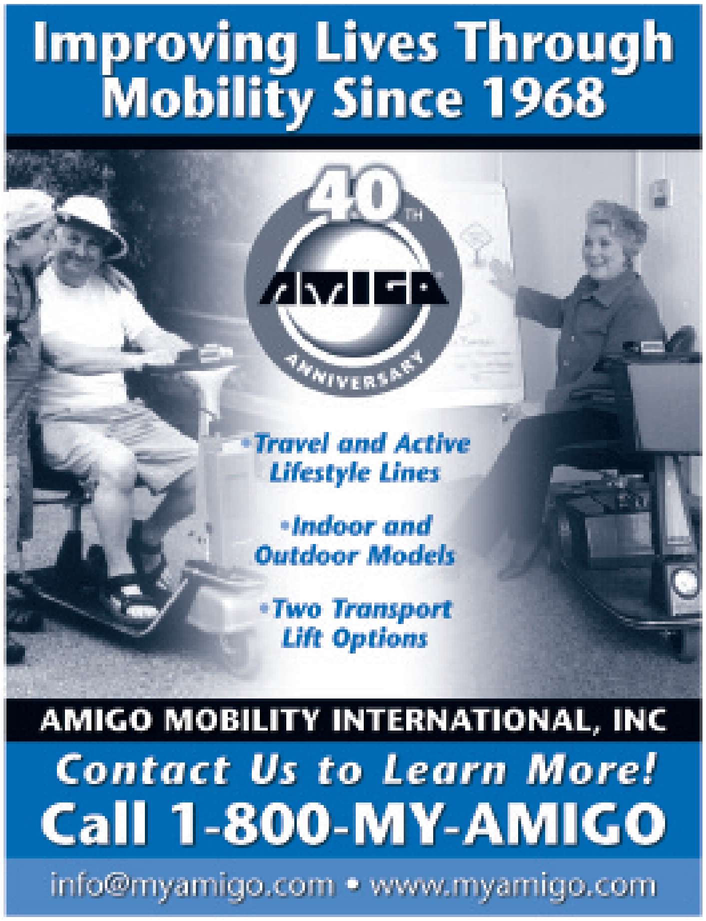
continued from page 28

meet its primary endpoint for individuals with primary-progressive MS (PPMS), as measured by the time to confirmed disease progression. **Rituxan** continues to show encouraging results in reducing disease activity in individuals with RRMS.

The oral drug **FTY720** is also showing encouraging results. A phase II study extension shows that 68 to 73 percent of the participating MS patients remain relapse-free, and 89 percent are free from active brain lesions, after three years of treatment. ◆

— Information summarized by Susan Wells Courtney and reviewed by Dr. Jack Burks





Stories to Inspire

Strength, Courage, and Wisdom

Written by Dr. Valecia D. Barber

I am a living testimony to how all trials and tribulations can be overcome through prayer, encouragement, motivation, and the will to succeed. In the summer of 1988, I was diagnosed with multiple sclerosis (MS) while in my junior year of Pharmacy school at Florida AM University (FAMU). Never knowing what was going on with me, I suffered through many obstacles and wanted to give up many times. As I look back, I realized that God was holding my hands the whole time.

While in undergraduate school, I struggled to walk around campus during my daily activities and attending classes. It became increasingly difficult for me to keep my balance. The left side of my face and my tongue became completely numb. One day, I saw a TV commercial that said MS was a terribly debilitating illness, and the commercial mentioned the signs and symptoms associated with the disease. I can remember thinking to myself, this is so sad and I felt sorry for the individuals who would be facing this dreadful illness. I never knew this was happening to me.

Dr. Valecia Barber, left, with her mother, Mary.

During the latter part of the same year, I was a bridesmaid in my sister's wedding. This was supposed to be a happy and joyous occasion for all involved. However, when it was my turn to walk down the aisle, I could not put one foot in front of the other. As two hundred well wishers waited anxiously for me to enter the sanctuary, I felt hot and flushed, as if I had no lower extremities.

After this traumatic event, my mother and I decided it was time for me to seek medical attention. I went to several physicians and finally a neurologist sent me for a magnetic resonance imaging (MRI) scan, which ruled conclusively that I had MS. Under the suggestion of my physician, I changed my major from pharmacy to something less stressful.

What motivated me to go forward were a strong family and a will to succeed! I had remembered an Abnormal Psychology class, where the professor told the class of his struggles to become a medical doctor. He was allergic to formaldehyde, so he had to change his major; he became a doctor of psychology. This was a sign to me that I could become a doctor also. I continued to pursue my studies and later I graduated in the summer of 1991 from FAMU, with a bachelor's degree in psychology and a minor in sociology.

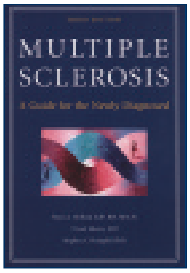
I felt a need to stay in the helping profession, although several well-meaning individuals tried to discourage me, saying that I could not go on to get a graduate degree because of the difficultly of pursuing a master's degree. They felt I would not be able to perform because of the stress of the disease. However, I did not listen to those naysayers. Instead, I kept focused, pursuing and receiving a master's of science degree in human growth and development in 1995 from Troy State University.

A few years later, the learning bug kept biting and I had a strong desire to continue my education by completing another advanced degree. After checking out local universities and talking to professors, I decided to pursue my PhD. During my course of study, I ran into all sorts of obstacles and challenges that could have easily derailed my course.

For example, I was in and out of the hospital, and I discovered that the disease was progressing. One of the biggest problems I faced was my optic neuritis, which began worsening from all of the reading that a doctoral degree requires. Here is the wonderful part of my story. God made the seemingly intangible, tangible! Through the prayers of my mother, Mary Barber, her diligence, tireless support, encouragement, and the support of other family and friends, I was able to work through the entire process. Together we conquered a major obstacle, the completion of a PhD! These individuals knew my desire to achieve and willingness to never, ever give up.

I graduated in 2005 with a PhD in counseling from Barry University. Presently, I work as a psychotherapist counseling individuals both with and without disabilities. I am also a motivational speaker. My life is a testimony to all individuals who are living with MS, as well as others who are experiencing adversities. I never would have made it without God in my life. My words of wisdom are, "Do not let your loss make you lost. Stay motivated and find the strength, courage, and wisdom that already exist within you to help you succeed." ◆

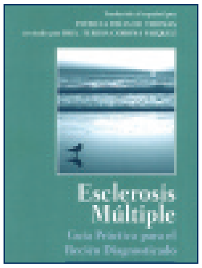
Spread the Word



Multiple Sclerosis, A Guide for the Newly Diagnosed, 3rd Edition

Written by Nancy J. Holland, EdD, RN, MSCN; T. Jock Murray, MD; and Stephen C. Reingold, PhD
Published by Demos Medical Publishing
MSAA Book #234

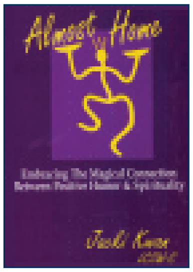
This book was designed to serve as a guide for learning about MS, how the disease may impact one's life, and the medical treatments now available for managing it successfully. Other vital topics include how MS is diagnosed, strategies for coping with the disease, employment issues, and research.



Esclerosis Múltiple, Guía Práctica para el Recién Diagnosticado

Elaborado por Nancy J. Holland, EdD, RN, MSCN; T. Jock Murray, MD; y Stephen C. Reingold, PhD. Traducido al español por Patricia Frías De Thomas Revisado por Dra. Teresa Corona Vázquez
Publicado por Demos Medical Publishing
MSAA Book #55

Este libro fue elaborado para servir como guía para aprender sobre la EM, sobre cómo afecta la vida de uno, y sobre los tratamientos que existen para controlarlo con éxito. Otros temas importantes que se incluye son cómo se diagnostica la EM, cuáles son las estrategias para bregar con la enfermedad, temas sobre el empleo y la investigación.



Almost Home, Embracing The Magical Connection Between Positive Humor & Spirituality

Written by Jacki Kwan, LCSW-C
Published by Cameo Publications
MSAA Book #160

Almost Home explains how humor can have a profound influence on one's quality of life, as well as one's physical, mental, and spiritual wellbeing. The author is a clinical social worker, master practitioner of Neuro-linguistic Programming, and a "registered laughter leader." Author Jacki Kwan has been leading "Laughter Club" sessions since 1994.

MSAA Lending Library

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

MSAA Lending Library
706 Haddonfield Road
Cherry Hill, NJ 08002

(Please reference book number)

Solutions for Wellness

MSAA Programs and Services Provide Solutions to Enrich the Quality of Life!

Do you find your symptoms worsen with heat?
Solution: MSAA's Cooling Product Distribution Program

Do you have difficulty affording MRI exams for MS diagnosis or follow-up treatment?
Solution: MSAA's MRI Diagnostic Fund and MSAA MRI Institute

Are you unable to afford essential safety equipment, mobility devices, or daily living aids?
Solution: MSAA's Equipment Distribution Program

Do you need the most up-to-date MS information?
Solution: MSAA's website (www.msassociation.org) and quarterly magazine, The Motivator

Do you need information, support, or guidance provided by highly trained and compassionate professionals?
Solution: MSAA's Helpline at (800) 532–7667

Contact MSAA at:
(800) 532-7667
www.msassociation.org
for these and other MSAA services.

Program applications and MSAA publications may be downloaded at **www.msassociation.org**

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Multiple Sclerosis Association of America

National Headquarters
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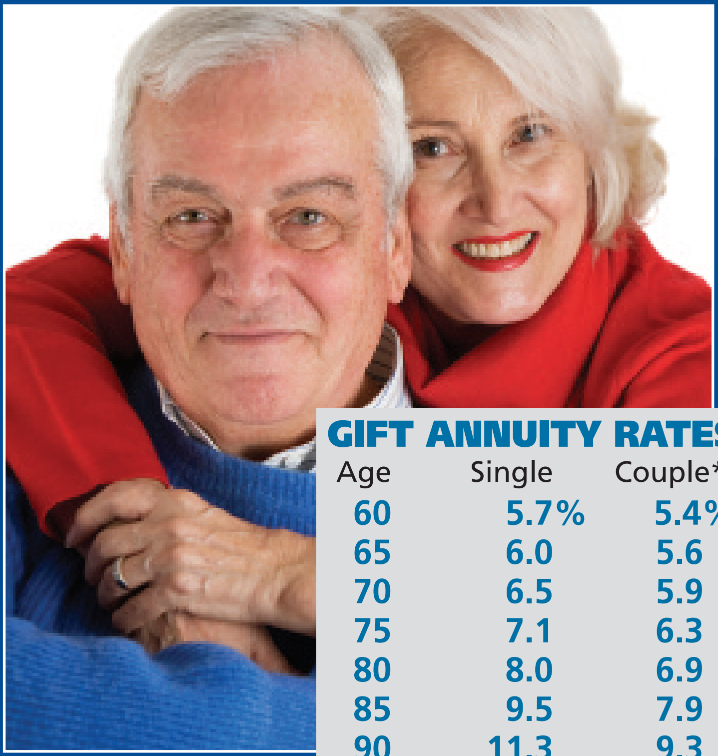
- Annual income for life. Income rates increase with age. Rates range from 5.4% for a couple age 60 to 9.3% for a couple age 90. (See *Gift Annuity Rate* table.)
- Peace of mind knowing that you are having a significant charitable impact on an organization that means so much to you—the Multiple Sclerosis Association of America.
- You benefit from your annuity, and MSAA benefits from enhanced financial security.

Ensure MSAA's Future while Securing Your Own

Support MSAA with a Charitable Gift Annuity

BBB ACCREDITED CHARITY



GIFT ANNUITY RATES

Age	Single	Couple*
60	5.7%	5.4%
65	6.0	5.6
70	6.5	5.9
75	7.1	6.3
80	8.0	6.9
85	9.5	7.9
90	11.3	9.3

* same age

To discuss establishing a gift annuity, please contact Bruce Makous, vice president of development at (800) 532-7667, extension 148 or bmakous@msassociation.org.

Gift annuities are not available in California. Please call Bruce Makous at the number above for more information.

MSAA™
Multiple Sclerosis Association of America

Multiple Sclerosis Association of America
706 Haddonfield Road
Cherry Hill, NJ 08002 USA

CHANGE SERVICE REQUESTED