

*MSAA* Spring 2005  
*The* **MOTIVATOR**

Bringing Information to People with Multiple Sclerosis

Employment  
Strategies



★ 35<sup>th</sup> ★  
Anniversary  
Edition

# The *MSAA* MOTIVATOR

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Vice President for  
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Andrea Borkowski, Editor  
& Advertising Manager  
Susan Wells Courtney, Writer  
Peter Damiri, Contributing Writer  
Amanda Bednar, Contributing Writer

## MSAA National Headquarters

706 Haddonfield Road  
Cherry Hill, NJ 08002  
(800) 532-7667

[www.msaa.com](http://www.msaa.com)

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

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**Breaking Down Barriers  
Building Up Hope**



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Spring is a time of renewal and growth. With this in mind, it is fitting that during the months of April, May, and June, MSAA is involved with several exciting

events that serve to commemorate, communicate, and plan for the future.

Highlighting MSAA's yearlong recognition of its 35 years of service is MSAA's 35th Anniversary dinner. This is taking place in Philadelphia, Pennsylvania on May 19th and raises funds for MSAA.

MSAA will highlight the contribution made by Dr. Jack Burks, MSAA's vice president and chief medical officer, who has dedicated himself to the care, treatment, and quality of life for individuals diagnosed with MS. Since the time that I arrived at MSAA in 1999, Dr. Burks has been a source of strength and support, as well as a valued professional colleague. MSAA owes much to the time, expertise, and credibility that he has brought to the organization.

Moving on to other events, the annual meeting of the American Academy of Neurology (AAN) was held in Miami, Florida in mid-April. We take part in this conference to learn about the latest findings in research and treatments, and interface with representatives of the different pharmaceutical and other medical companies. Each year we receive many visitors at our MSAA

booth in the exhibit hall.

The annual meeting of the Consortium of MS Centers (CMSC) will be held in early June in Orlando, Florida. This meeting provides the opportunity to speak with doctors, nurses, therapists, social workers, and researchers, all of whom specialize in the MS field. During this conference, an emphasis is placed on day-to-day living, quality-of-life issues, emotional health, family wellness, and specific client needs.

Our MSAA Board of Directors will also meet during this conference. This year concludes our previous five-year strategic plan, with all of our goals having been met – and many exceeded. Before a new plan is put into place, MSAA will focus on evaluating needs and services.

Robert Rapp, MSAA's vice president for programs and services, is overseeing two projects with this goal in mind. The first project is a comprehensive assessment of the needs of MS clients and the community. The second project is aimed at evaluating the success of our current programs and services. These projects are particularly important because we have a responsibility not only to the people we serve, but also to our donors, to ensure that money is being spent in the most effective ways possible.

I hope that everyone is enjoying the spring season and finding an opportunity for growth and renewal. Beginning in this issue we will highlight our Board members, starting with our wonderful treasurer:

Francisco "Pancho" Ramirez. ♦

*Douglas G. Franklin has been President and Chief Executive Officer of MSAA since April 1999. Mr. Franklin has 25 years experience in senior association management in the nonprofit sector and is an internationally published expert in the field of social marketing. A former national trainer*

*for the Peter Drucker Foundation, Mr. Franklin has conducted workshops in strategic planning and marketing development in more than 15 countries worldwide. He is a firm believer in the benefits of social investment for both the private and public sector workplaces.*

## ***MSAA Board Member and Treasurer, Francisco J. Ramirez***

Francisco J. Ramirez joined MSAA's Board of Directors in October, 2001. Known to everyone as "Pancho," Mr. Ramirez went on to become the Board's treasurer in May, 2002, and also serves as head of the Board's audit committee.



Mr. Ramirez came to MSAA with an extraordinary background. Born in Chile (and now a United States' citizen), he attended two universities in his home country, where he studied subjects from business to medicine. He is also fluent or has a working knowledge of five languages.

His job history is very impressive, holding top executive positions with large nonprofit agencies. These include the International Planned Parenthood Federation, the International Youth Foundation, and the Rural School and Community Trust, where Mr. Ramirez now works as the director of finance and administration/chief financial officer.

Mr. Ramirez is affiliated with several financial and nonprofit organizations, including the Ethics and Standards Committee of the Maryland Association of Nonprofit Organizations (with over 1,300 members), where he has served as both a member and director. This is one of the top organizations in the country for developing standards for non-

profit organizations – and Mr. Ramirez has been able to incorporate these high standards into MSAA's work.

According to Mr. Ramirez, "Belonging to this other organization has given me access to the 'best in the business' in relation to standards.

With this background and with the support and commitment to high standards from both MSAA's Board and staff, I have been able to develop several policies that have been adopted and implemented by MSAA in the last few years. For example, the Ethical Standards and Whistle-Blower Protection Policies, Fundraising Standards, Document Retention Policies, Salary Administration Program, Conflict of Interest Policies and Annual Disclosure, and Terms of Reference of the Audit Committee."

Through his efforts, MSAA is constantly improving its policies and procedures, in full compliance with the best practices, which are not yet mandatory for nonprofits. Mr. Ramirez has taken MSAA to new levels of performance, and we are extremely fortunate to have his valuable guidance. Everyone affiliated with MSAA is grateful to Mr. Ramirez and others like him, who have volunteered their time to help MSAA provide vital assistance to others.

# Employment Strategies

By Christine Norris

**M**any people choose to work for reasons greater than money alone. The interaction with others, the feeling of completing a well-done task, and the human need to feel valued in society, all make a paycheck so worthwhile. But when an illness strikes, individuals cannot always perform their jobs in the same way as they did in the past. Individuals with MS may find that symptoms such as increased fatigue, limited mobility, and visual changes may impact their ability to work. While the symptoms of MS can often be managed, job accommodations may be necessary to continue to work productively.

Some people with MS remain in their jobs with little or no modifications to their present working situation, while others may decide to leave their current position to be retrained to do something else. Fortunately, government funding is available for individuals with disabilities to receive the help they need to enter, re-enter, or remain in the workforce. This assistance enables men and women with



MS to find the right occupation, work environment, work schedule, and game plan for their unique circumstances.

Once diagnosed with MS, some individuals may go through the process of rethinking their life, but finding the necessary help to achieve new goals can be difficult. These individuals may take comfort in knowing that a good deal of assistance is available to help with determining the best employment path to take. Several sources have been listed in this article for anyone interested in more information.

### Determining What's Needed

Jamie Cahill was diagnosed with MS at age 27 while traveling with her husband on the professional tennis circuit in 1979. She spent the next 10 years trying in vain to find a treatment that might keep the disease from progressing. After moving from Memphis to Atlanta, she found a doctor at the Shepherd Center who treated her with one of the approved, long-term medications for MS. So far, the medication has been effective in slowing her disease activity.

According to Cahill, “The staff at the Shepherd Center works with the whole person. After I had been stabilized for enough time, I told them that I really wanted to work. The vocational rehabilitation people there helped me every step of the way.” She continues, “I love to work. I begged everybody from one end of the planet to the other to let me work. I’m skilled. I’m motivated. I love being around people. I have some gifts that I can share.”

Cahill went on to work for five years at a large insurance company in the claims department and as a motivational speaker for the company’s long-term disability recipients. Now she works from home as an ESL (English as a Second Language) instructor and in customer service monitoring fuel delivery all over the country.

The mother of two children, now ages 22 and 24, Cahill at 53 exemplifies the “can do” attitude that people with MS need to possess in order to enter, rejoin, or remain in the workforce. Armed with an

elementary education degree and plenty of determination, Cahill and the staff at the Center for Assistive Technology and Environmental Access (CATEA) at the Georgia Institute of Technology developed strategies for her to work both in a corporate environment and a home-office environment. They implemented assistive technology in both spaces to accommodate her physical disabilities.

“Since I’m in a wheelchair and cannot use my hands or my legs, I had to have a voice-activated computer and a work station that accommodates my wheelchair. They set it up for me and trained me to use it,” she recalls.

Cahill also was able to take advantage of government-funded vocational rehabilitation (VR) programs administered through the state of Georgia’s Vocational Rehabilitation Agency. “They sent me, free of charge, to California to take three courses in order to be certified to teach ESL,” she says. “Also, all of my office equipment and its set-up didn’t cost me anything because I qualified for assistance. People with MS need to know that there’s government money available for people who are disabled. You have to network to find the particular government agencies that have the funding.” For a list of state vocational rehabilitation agencies with links to their websites, readers may click on [www.jan.wvu.edu/sbses/vocrehab.htm](http://www.jan.wvu.edu/sbses/vocrehab.htm).

“I often work with employers to help them develop strategies to keep people with MS and other disabilities at work,”

says Carrie Bruce, MA, CCC-SLP, ATP, research scientist at CATEA and speech therapist at the Shepherd Center. “In most cases, it’s a lot easier and a lot less expensive to make accommodations for an employee with a disability, than it is to hire someone new and have to train that person. It’s an issue of awareness and education. There’s a lot more to it than physical access.”

### Understanding Your Rights

Also referred to as the “Emancipation Proclamation” for those with disabilities, the Americans with Disabilities Act (ADA) prohibits discrimination in employment



and in providing goods and services to individuals with disabilities. Federally mandated in 1990, it guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications.

To be protected under the ADA, the law reads: “A person must have a physical or mental impairment that substantially limits one or more of the major life activities of such individual, a record of such an impairment, or be regarded as having such an impairment.” People who have been clinically diagnosed with MS are covered.

The Title I employment nondiscrimination requirements of the ADA prohibit discrimination in all employment practices, including job application procedures, hiring, firing, advancement, compensation, training, and other terms, conditions, and privileges of employment. Its reach includes recruitment, advertising, tenure, layoff, leave, fringe benefits (such as access to the executive dining room, club memberships, etc.), and all other employment-related activities. For a copy of “The ADA: Your Employment Rights as an Individual with a Disability,” readers may call (800) 514-0301(voice) or (800) 514-0383 (TTY); readers may also visit [www.ada.gov](http://www.ada.gov) and go to “frequently asked questions.”

“The laws covering disabilities do not establish quotas for hiring as do those laws associated with affirmative action. Many agree that the hiring of those with disabilities has not gone nearly far enough,” writes Sharon F. Kissane, PhD, on page 209 of her book, *Career Success for People with Physical Disabilities* (VGM Career Horizons: 1997). “But you can make the difference by being hired on your abilities, making a successful career, and becoming a role model for others.”

### Disclosure Issues

One of the most difficult decisions to make is whether or not to disclose an MS diagnosis to an employer. Many individuals are afraid to share the information because of the risk of being fired, even though it's against the law to terminate employees for their disabilities.

Counselors and vocational rehabilitation (VR) professionals stress that this is a very sensitive subject, one that should be dealt with on a case-by-case basis.

In general, if MS symptoms are mild and do not interfere with a person's ability to perform the essential functions of a job, the employee is under no obligation to reveal the diagnosis to the employer. However, if an individual's symptoms are interfering with his or her ability to complete job tasks and remain productive, disclosing the diagnosis might be in his or her best interest.

When sharing the diagnosis with an employer, taking a positive approach and emphasizing skills rather than limitations may be a good plan. One might discuss specific needs for modifications and how these modifications will contribute to the success of the operation.

Relatively inexpensive accommodations

can make a significant difference in an employee's productivity. For example, a parking space closer to the building may lessen fatigue, a computerized pocket planner/recorder can help with memory deficits, and dictation of reports may assist with

decreased dexterity.

For more information on "reasonable accommodations" and how to implement them, readers may refer to the EEOC's

"Enforcement

Guidance:

Reasonable

Accommodation and

Undue Hardship



under the ADA" at [www.eeoc.gov/policy/docs/accommodation.html](http://www.eeoc.gov/policy/docs/accommodation.html).

"We advise our clients to review the human resources' manual before meeting with the company representative. It's important to review what was signed (in terms of a contract when beginning the position) and what tasks one thinks can still be accomplished," advises Cindy Richman, director of client services for MSAA. "It's also a good idea to bring a vocational rehabilitation counselor along to show the employer how certain tasks will be performed with certain accommodations."

Under dictates of the ADA and other employment discrimination laws, an employer cannot address these accommodation issues unless the employee is willing to



openly discuss his or her needs. Someone who chooses to keep an employer in the dark may risk receiving a poor performance evaluation.

CATEA's Carrie Bruce has worked with more than 100 individuals with disabilities to help them remain in or enter the workforce. She has found that disclosing information on a disability to employers isn't always necessary; but if accommodations may need to be made later on, obtaining them might be easier if the diagnosis has been shared.

"If any job modifications or accommodations have been agreed upon, it's very important to document what's been decided, especially in large companies where there can be a lot of supervisor or human resources turnover," Bruce stresses. "By having documentation, the employee and employer can go back on a yearly basis and determine if the situation is still meeting the needs of everyone."

Bruce also recommends discussing what she calls "nontraditional accommodations" to help relieve MS symptoms. "For example, an employee experiencing pain or fatigue may need to take frequent breaks, while a person with fluctuating vision may need to move from one work station to another." For a discussion of reasonable accommodations and how to implement them at work, readers may refer to the EEOC's document mentioned earlier.

### **Assistive Technology**

The explosion of advances in assistive technology (AT) has helped many people



with MS continue to work productively. Bruce explains, "Computer access and telephone access have really opened up employment options for people with MS. Many large firms are moving to phone services over the computer. This is really big because phone access through the computer can be adapted for a variety of needs. For example, if a person has trouble seeing, the screen can be enlarged. If the person has trouble hearing, the speakers can be made louder. If the person can't physically dial a telephone, voice dialing can be added."

Bruce notes, "In fact, most office equipment can now be accessed via a computer, including the copy machine and fax

machine. As long as a person has a consistent movement, an eye blink for example, he or she can have full access to the computer.”

The term “assistive technology” (AT) refers to any product that is employed to increase, maintain, or improve the functional capabilities of an individual (as defined in PL 100-407, the Technology-Related Assistance for Individuals with Disabilities Act). Such AT may be considered for reasonable accommodations; AT products provide solutions for mouse access, typing, viewing information, reading, and many other computer-related tasks.

Specific information on minimizing the “digital divide” for individuals with MS is available in three articles recently published in *The Motivator*. The first article published in the Fall 2004 issue features various seating, table, and workstation systems to increase function and comfort for the computer user. The second article published in the Winter 2005 issue highlights different types of computer hardware AT, including monitors, keyboards, and mouse/cursor control. To request issue copies, please call MSAA at (800) 532-7667. To view or download a copy of the articles (or the entire issues), readers may visit MSAA’s website at [www.msaa.com](http://www.msaa.com). The third part of the series covering computer software AT is found on page 27 of this issue.

Studies also indicate that 41 to 44 percent of the MS population experiences some type of speech or voice dysfunction. Augmentative and alternative communica-

tions (AAC) can help those with this type of impairment to communicate more effectively with others. In “Speech Solutions,” published in the Fall 2003 issue of *The Motivator*, various AAC products are discussed. To request or view a copy, readers may call MSAA or log onto the website, as mentioned in the previous paragraph.

### The Telework Boom

Some individuals with MS are afraid to suggest flextime (also referred to as flexible hours) or telecommuting (also known as telework) to their employers because they fear rejection or loss of status. According to an article in the March 2003 issue of *TechConnections* (published by CATEA, the

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United Cerebral Palsy Association, and the Southeast Disability and Business Technical Assistance Center), telework has become a viable job accommodation. The ADA includes telecommuting as a reasonable accommodation when a person's disability prevents the successful performance of the job in the standard working environment.

During the past several years, employers have shown an interest toward applying this approach to work activities conducted by all employees, not just for those with disabilities. In some states, vocational rehabilitation agencies have been moving to some form of telework in order to reduce administrative and facility costs, while promoting increased efficiency for rehabilitation counselors, job placement specialists, and others.

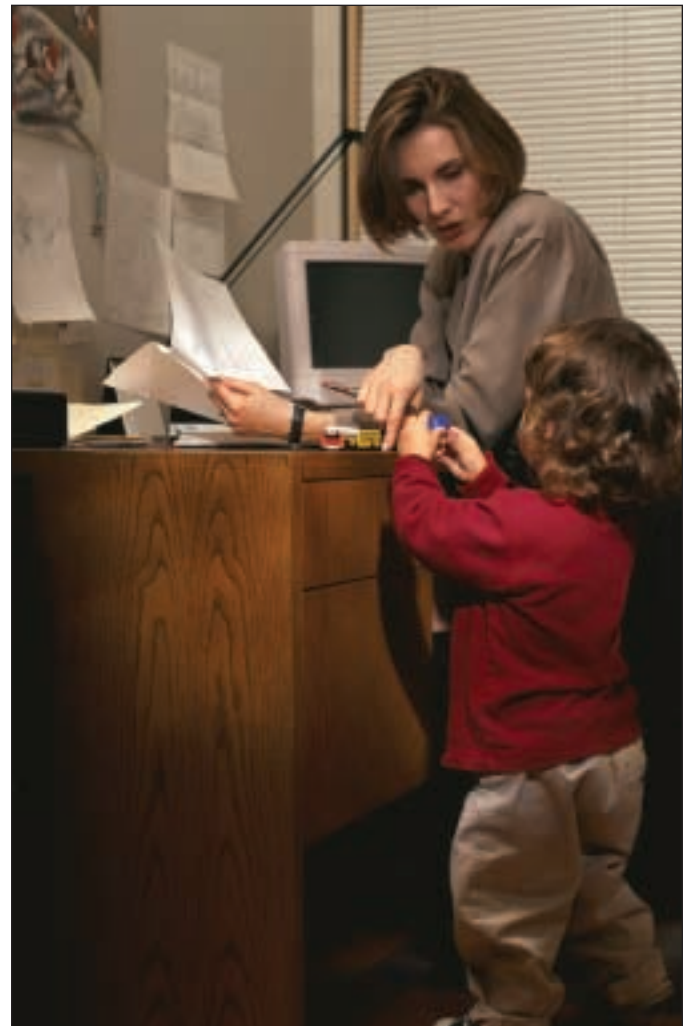
Recent studies on the subject of telework and improved corporate and individual performance support these views. Findings include:

- According to research conducted in October 2000 by the International Telework Association & Council (ITAC), a teleworker can save an employer approximately \$10,000 per year in reduced absenteeism.
- Teleworking can improve employee performance due to working peak hours, uninterrupted work time, and other factors, according to a Colorado Telework Study. The study found that American Express teleworkers produced 43 percent more business than office workers; results also showed that Compaq teleworkers increased productivity by 15 to 45 percent.

- According to an article published in the magazine *Telecommuting Review*, IBM reduced its real estate costs by 40 to 60 percent after implementing a corporate-wide telework option. The savings resulted from more people working from home, requiring less office and parking space at the business location.

### Telework Success

Michael Dziak, author of *Telecommuting Success: A Practical Guide for Staying in the Loop While Working Away from the Office* (Park Avenue: 2001), lists the following tips to avoid common telecommuting traps and



to make telework a success.

- Avoid the “do-it-all” trap by prioritizing your daily duties and organizing your schedule to focus on a single work task at a time.
- Avoid the “sloppy surroundings” trap by establishing a defined office environment and make the commitment to keep it organized and secure. A separate room that is used only as an office is best.
- Avoid the “nosy neighbor” trap by setting work hours and maintaining strict adherence to the schedule. Everyone, from family to friends to repairmen, needs to understand which periods of your time should be free from interruptions.
- Avoid the “housekeeping trap” by refraining from multitasking when it comes to doing the laundry, the dishes, and the housework. Some people make rules that these activities can be done only at certain times of the day.
- Avoid the “secluded trap” by staying in touch. Make the effort to keep in regular contact with the office, especially your immediate supervisor so that you don’t fall into the “out of sight, out of mind” routine. This concern is often prevented by making periodic visits to the office.

Other experts recommend different strategies to help make working from home a success. For instance, to combat feelings of social isolation, teleworkers may schedule time to be with others. Some at-home workers make lunch dates with friends, while others take an exercise break. Sometimes even a brief phone call during lunch to a friend can make one feel connected to the outside world.

Not allowing work to interfere with family life is important as well. After putting in the required time, a teleworker should leave the work area and not think about it again until the following work day.

### Vocational Rehabilitation

Many individuals with MS can benefit greatly from vocational rehabilitation (VR). VR provides a wide range of services to help individuals with disabilities succeed with their work. These services may include:

- vocational guidance and career counseling
- evaluation of rehabilitation potential
- restoration of physical and/or mental skills
- vocational and other training services
- rehabilitative technology, including assistive technology services, assistive technology devices, and rehabilitation engineering
- occupational tools and equipment
- transportation to access other vocational rehabilitation services
- job placement into suitable employment
- financial assistance to cover additional costs incurred during the period of vocational rehabilitation
- personal assistance services, such as a personal care attendant, scribe, reader, and interpreter
- assistance with making the transition from school to work
- guidance in starting a business

According to section 102(a) of the Rehabilitation Act of 1973 (with amendments), to be eligible for state-funded VR services, a person must be able to benefit from VR services in terms of achieving employment, including supported employ-

ment (programs to assist individuals with severe disabilities). The person must also:

- have a physical or mental disability which constitutes or results in a substantial impediment to employment
- be able to benefit from VR services in terms of employment
- require VR services to prepare for, enter, engage in, or retain gainful employment

The Rehabilitation Services Administration (RSA) of the federal government oversees the grant programs that fund the VR programs in each state. The services are free of charge. Unfortunately, due to the number of cases, not everyone who is eligible can receive services. Individuals with the most significant disabilities are given a priority over those with less significant disabilities. For more information on how the state VR programs work and how to apply, readers may log onto the Office of Special Education and Rehabilitative Services' website at [www.ed.gov/about/offices/list/osers/rsa/research/html](http://www.ed.gov/about/offices/list/osers/rsa/research/html). Information on other options for VR, which are free of charge or provided at a reduced fee, may be obtained by calling the Georgia Tech Center for Assistive Technology and Environmental Access (CATEA) at (800) 726-9119 (toll-free voice/TTY).

A VR counselor works with an individual to set realistic goals and to develop strategies to assist an individual in the workplace or other vocation. As dictated by a person's specific needs, additional professionals may be involved. For example, a speech-language pathologist (SLP) or speech therapist (ST) may be consulted to

help solve speech or communication problems that may affect someone's job performance. Several other professionals can be involved to assist in other aspects, such as setting up the office area for easy access, selecting proper furniture and custom-fitting it for the individual, and training to develop specific job skills. For more information on the role of rehabilitation in helping individuals with MS, readers may call MSAA at (800) 532-7667 and request a copy of the Winter 2004 issue of *The Motivator*. To view or download a copy of the article (or the entire issue), MSAA's website may be visited at [www.msaa.com](http://www.msaa.com).

Bruce advises her clients to "chunk" their problem of how to return or stay in the workforce. "By chunking, I mean breaking down what has to be done into small pieces or chunks. You don't have to solve every problem at one time," she says. "It's better to figure out what the biggest problem is and take care of it. Then move down the ladder to address each of them."

Contacting the local Medicare office is also a good idea for anyone planning to enter or return to the workforce after taking time off to be treated for MS. Medicare has different rules regarding employment and benefits, and clarification may be necessary in order to fully understand one's options. The Center for Medicare and Medicaid Services can be reached at (800) 633-4227.

### **Starting a Home-Based Business**

After examining their career choices and symptoms, some people with MS choose to

start their own home-based businesses. The federal government can assist people in need of VR to achieve this goal. According to the Rehabilitation Act Amendments of 1998 regarding self-employment, each state's VR office must include this option as part of a person's overall evaluation.

The Region VI Rehabilitation Continuing Education Program also maintains a website on self-employment and entrepreneurship with disabilities at [www.rcep6.org/business.htm](http://www.rcep6.org/business.htm). The program publishes *Getting Down to Business: A Blueprint for Creating and Supporting Entrepreneurial Opportunities for Individuals with Disabilities*. To obtain a copy of this helpful publication, individuals may log onto the website for the United



States Department of Labor Office of Disability Employment Policy at [www.dol.gov/odep/pubs/business/toc.htm](http://www.dol.gov/odep/pubs/business/toc.htm); readers may also contact this office at (866) 633-7365 (voice), or (877) 889-5627 (TTY). Ideas for home-based businesses abound. Entrepreneurs with MS work in many fields and find that running home-based businesses offers the flexibility they need to manage their

symptoms while remaining productive and successful at work. Here are some home-based business ideas to consider:

- massage therapy
- aromatherapy (using fragrance to promote healing)
- interior decorating
- telephone or website sales
- graphic design
- writing/editing
- headhunter (matching candidates with high-level job opportunities)
- tutoring children or adults on basic skills or school subjects
- selling dried flowers or other craft items
- bookkeeping
- personal shopping (helping others do errands and shop)
- personal coaching (helping others achieve goals in life through motivation and goal setting)
- family and individual therapy or counseling



### Happy and Productive

Armed with this information and a positive attitude, individuals with MS can often find meaningful work. MS may change one's life, but it doesn't have to keep one from finding new and fulfilling career opportunities.

“With most job fields wide open to people with ability who happen to have a physical disability, there is no longer any excuse not to select a career based on what you truly wish to do for the rest of your life,” writes Sharon F. Kissane in her book, *Career Success for People with Physical Disabilities*. “This is not to say the path is easy. But, the path is there, if you choose to follow your dream.”



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### About the Author

A former editor of *The Motivator*, Christine Norris is now a freelance writer specializing in health and wellness issues.

### Helpful Resources

The following publications are available through MSAA's Lending Library. Please see page 60 for more information.

Kissane S.F., *Career Success for People with Physical Disabilities*, VGM Career Horizons, 1997.

Perkins L., Perkins S., *Multiple Sclerosis: Your Legal Rights*, second edition, Demos Medical Publishing Inc., New York, 1999.

Rumrill Jr., P., *Employment Issues and Multiple Sclerosis*, Demos Vermande, New York, 1996.

Stolman M.D., *A Guide to Legal Rights for People With Physical Disabilities*, Demos Publications Inc., New York, 1994.

Listed below are some additional publications that readers may find to be helpful:

Abrams R., *Six-Week Start-Up: A Step-by-Step Program for Starting Your Business, Making Money, and Achieving Your Goals*, The Planning Shop, San Francisco, 2004.

Abrams R., *What Business Should I Start: Seven Steps to Discovering the Ideal Business for You*, The Planning Shop, San Francisco, 2003.

Dinnocenzo D.A., *101 Tips for Telecommuters: Successfully Manage Your Work, Team, Technology, and Family*, Berrat-Koehler Publishers Inc., 1999.

Dziak M., *Telecommuting Success: A Practical Guide for Staying in the Loop While Working Away from the Office*, Park Avenue, 2001.

Please note: Some of these books may be ordered through [www.amazon.com](http://www.amazon.com) or Barnes & Noble at [www.bn.com](http://www.bn.com). Barnes and Noble may also be reached by calling (800) 843-2265.

### For More Information

For information on the Vocational Rehabilitation System and assistive technology, readers may click on [www.techconnections.org/legislation/RehabAct/Q1-1.cfm](http://www.techconnections.org/legislation/RehabAct/Q1-1.cfm). Readers may also consult the following agencies.

ADA Information Line  
United States Department of Justice  
(800) 514-0301 (voice) or -0383 (TTY)  
[www.ada.gov](http://www.ada.gov) (website)

Georgia Tech Center for Assistive Technology and Environmental Access  
490 Tenth Street, NW  
Atlanta, GA 30332-0156  
(800) 726-9119 (toll-free voice/TTY)  
[www.catea.org](http://www.catea.org) (website)

United States Architectural and Transportation Barriers Compliance Board  
(800) 872-2253 (voice)  
(800) 993-2822 (TTY)  
[www.access-board.gov](http://www.access-board.gov) (website)

Disability and Business Technical Assistance Centers  
(ADA and IT Centers)  
(800) 949-4232 (voice/TTY)  
[www.adata.org](http://www.adata.org) (website)

United States Department of Labor  
Job Accommodation Network  
(800) 526-7234 (voice/TTY)  
[www.jan.wvu.edu](http://www.jan.wvu.edu) (website)

United States Department of Transportation  
(888) 446-4511 (voice)  
[www.dot.gov/accessibility](http://www.dot.gov/accessibility) (website)

United States Equal Employment Opportunity Commission  
(800) 669-4000 (voice) or -6820 (TTY)  
[www.eeoc.gov](http://www.eeoc.gov) (website) ◆

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## Tools and Techniques for MS Teleworkers

By Grant Olsen

Both employers and members of the MS community stand to benefit from the continued interest in telework. This term refers to individuals working outside of the office through the help of telecommunications and other technology, including the personal computer, internet, and fax.

Jane Anderson, Director of the Midwest Institute for Telecommuting Education (MITE), testified before the United States House Committee on Small Business in 2002 and specifically cited a growing demand for telework from individuals with MS. To capitalize on this trend and to work effectively from home, individuals with MS may opt to use a number of additional tools to complement their “digital” (computer-related) appliances. Such devices may include:

- Cooling vest
- Fan and/or air conditioner
- Writing (grip) aids
- Tape recorder (to take notes)
- Page holder or book holder
- Adjustable lamps and other lighting

- Mouth stick (to turn pages or turn tape recorder on and off)

Furthermore, various strategies and techniques may be employed by members of the MS community to develop an accommodating telework environment:

- Situate the work area in close proximity to the restroom to reduce travel time
- Minimize the amount of travel by combining trips away from the work area
- Take scheduled, frequent breaks throughout the workday
- Adjust the work schedule to avoid hot weather
- Utilize reminders, such as notes, calendars, and organizers, to assist with memory
- Acquire written instruction regarding duties and tasks to aid memory
- Obtain large-print material when available
- Receive a copy of co-workers’ notes when necessary
- Rely on written communication, including email and faxes, if speech is impaired

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This information was adapted from: The Region 7 Rehabilitation Continuing Education Program (of the Rehabilitation Services Administration), *Handbook of Disabilities*; The Job Accommodation Network, *Accommodating People with Multiple Sclerosis*; The Cornell University Program on Employment and Disability, *Workplace Accommodations for People Living with Multiple Sclerosis*; and Tech Connections, *Case Study Bulletin - Spring 2003*. Readers may go to the following web addresses to find additional information on teleworking with MS.

[www.mite.org/Small Business Use of Telework.htm](http://www.mite.org/Small Business Use of Telework.htm)

[www.rcep7.org/projects/handbook/msclerosis draft.pdf](http://www.rcep7.org/projects/handbook/msclerosis draft.pdf)

[www.jan.wvu.edu/media/MS.html](http://www.jan.wvu.edu/media/MS.html)

[www.ilr.cornell.edu](http://www.ilr.cornell.edu) (search for multiple sclerosis)

[www.techconnections.org/resources/News/BulletinSpring03.cfm#case1](http://www.techconnections.org/resources/News/BulletinSpring03.cfm#case1)

# Minimizing the Digital Divide for Individuals with MS:

## Computer Software Assistive Technology

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

**By Carrie Bruce, MA, CCC-SLP, ATP**

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

This is the final article in the series about assistive technology for the computer. The first article appeared in the Fall 2004 issue of *The Motivator*, and talked about strategies and equipment to increase computer accessibility. The second article appeared in the Winter 2005 issue of *The Motivator*, and covered the different types of computer "hardware" (such as the monitor, keyboard, and mouse). To request copies of these articles or issues, readers may call MSAA at (800) 532-7667. Copies may also be viewed or downloaded by going to MSAA's website at [www.msaa.com](http://www.msaa.com).

Assistive technology software options exist for assorted computer tasks and to meet an array of skill levels. Individuals with disabilities may use word processing, accounting, spreadsheet, organizational (addresses and calendar), email, and/or game programs. These standard programs may require modifications, supplementary programs, or simplified substitute programs to accommodate for physical, cognitive, and/or sensory issues.

### Built-in Features with Windows and Macintosh Operating Systems

Both Windows and Macintosh operating systems have built-in features that can be customized to accommodate for vision, hearing, and mobility impairments. The operating systems include several basic options that users can set and adjust without installing any extra programs. These include:

#### StickyKeys (Win) or Sticky Keys (Mac) –

This feature enables a user to press any modifier key (Ctrl, Alt, Shift) and have it remain active until a non-modifier key is pressed. Certain commands do require the user to press more than one key at a time (such as capitalizing letters), so a person who has dexterity issues or types using only one finger, one hand, or a pointing device (such as a mouthstick) may benefit. Other examples of commands requiring more than one keystroke at a time are Ctrl+C (copy), Ctrl+V (paste), and Ctrl+Alt+Delete (used for terminating program or shutting computer down). Sticky

Keys tells the computer that the first key in a series is being held down, similar to how the shift lock works to capitalize the first letter of a word.

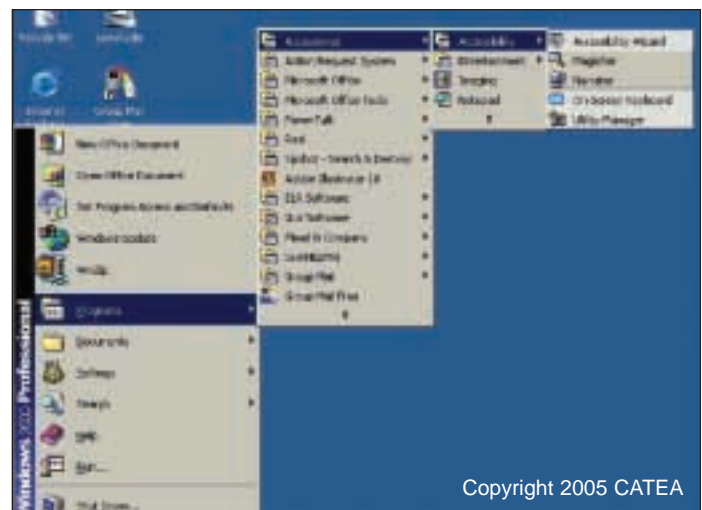
**Filter Keys (Win) or Slow Keys (Mac)** – This feature is designed for people with motor difficulties who are unable to consistently hit the correct letter. In essence, it “filters” out repeated or sudden keystrokes. It only accepts a character after the key has been held down for a specified time period.

**Toggle Keys (Win)** – An auditory feedback feature useful to individuals who have reduced visual skills, finger sensitivity, or fine motor coordination. When the “Caps Lock,” “Num Lock,” or “Scroll Lock” buttons are used, the computer will beep to announce that it is being turned on or off.

**MouseKeys (Win) or Mouse Keys (Mac)** – This is a feature that enables the user to make mouse movements with the numeric keypad to move the cursor around the screen. This is useful to individuals who have difficulty using a standard mouse due to tremors, dexterity issues, fatigue, or weakness. (This was also mentioned in the previous article on computer hardware.)

In addition to these features, the user can adjust screen colors, contrast, resolution, text and icon size, visual sound alerts, cursor size, and cursor speed. The operating systems may also include an onscreen keyboard, screen reader, text-to-speech, and magnifier programs. These additional

accessibility programs may be found in Windows Me, 2000, and XP, as well as Macintosh OS X. Previous versions of Windows and Macintosh operating systems have more limited accessibility features, but may contain some options. To explore what your system has already built in, find the “Accessibility” (Windows), “Easy Access” (Macintosh), or “Universal Access” (Macintosh) menu or file.



*Windows accessibility*

### **Additional Programs Available**

If an individual has accessibility needs that cannot be met with the software that is included with the computer, additional programs may be purchased and/or downloaded. These programs are often categorized according to their function and include the following features (among others).

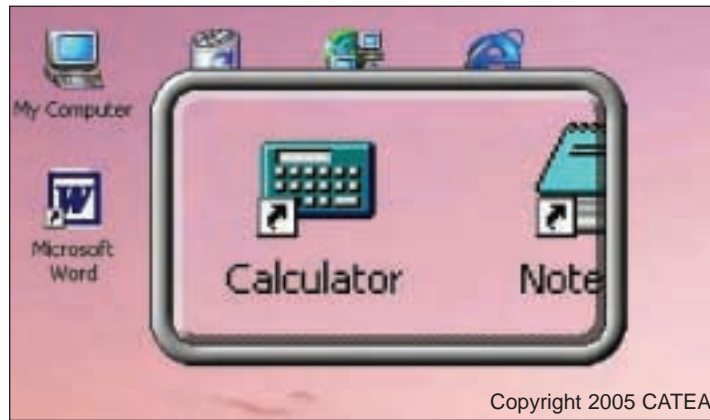
#### **Products that Help with Reading Information on the Screen**

**Screen readers** – This program reads the text, and sometimes graphic information, aloud. Many times, the voice speed and

gender can be modified to suit the user's preference. This type of program is useful to individuals who have visual problems, learning disabilities, cognitive impairments, or literacy issues. Minimal to moderate training may be required, depending on how extensively the program will be used and the complexity of the particular program.

### **Screen magnifiers** –

This program magnifies a portion of the screen, so that it can be more easily viewed, and may include some screen reading capability. This is used primarily by individuals with low vision. Little or no training may be required, depending on the complexity of the program.



*Screen magnifier*

**Text-to-speech** – This program converts typed text into spoken letters, words, or sentences. As with screen readers, the voice speed and gender can be modified to suit the user's preference. Text can be typed in or inserted through copy and paste. These programs can also be used to help an individual hear what he or she is typing, enabling the person to make corrections as needed. This type of program is useful to individuals who have visual problems, learning disabilities, cognitive impairments, or literacy issues. Little or no training may be required, depending on the program.

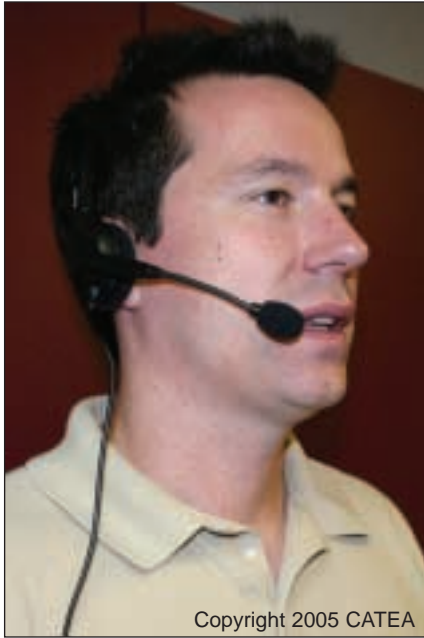
### **Products That Help With Typing and Spelling Issues**

**Word prediction/completion** – This program offers the user a list of words after a letter (completion) or word (prediction) has been typed. Word completion offers word choices to help the user complete the word based on the sequence of letters already typed. For example, if a user types

“t-o,” the choices that might be offered are “to,” “today,” “tomorrow,” and “top.” The user can simply choose the desired word from the list, without typing the rest of it. Word prediction is based on the

sequence of previous words rather than on the basis of letters, and attempts to follow grammatical structure. Word prediction/completion programs are used by individuals who have fine motor difficulties (such as pain, fatigue, or reduced range of motion), cognitive impairments, literacy issues, or learning disabilities. Minimal to moderate training may be required, depending on the program.

**Voice or speech recognition** – This program identifies spoken words and converts it into text on the computer. An individual uses a microphone to input or dictate text and may do so through discrete (one word at a time) or continuous (full sentences) methods. This type of program may also



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*Voice recognition*

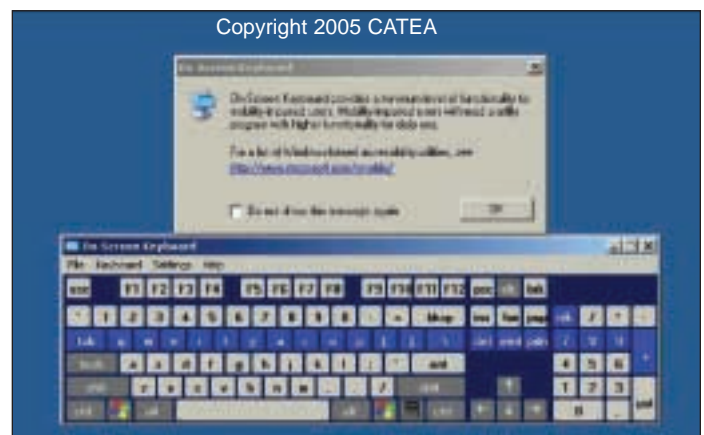
include functionality for controlling the cursor. Voice or speech recognition is frequently used by individuals who are not able to type, who type very slowly, or who fatigue quickly while typing.

Moderate to extensive training is required to become proficient in using most of these types of programs. Learning how to effectively dictate is a key training point if the program will be used for extensive document creation.

### Onscreen keyboard (or virtual keyboard)

– This program emulates a keyboard on the user’s screen. The user can select keys by moving the cursor (by standard mouse or alternative option; referred to in the previous article on computer hardware) and clicking or selecting the desired choice. Most of these keyboards can also be set to a scanning mode that highlights each row, then each key in the row, until the user selects one. Many of the keyboards include a “dwell” or “hover” selection mode that enables a user to select a key by placing the cursor over it. By keeping the cursor on the key for a designated amount of time, it is automatically selected by the dwell feature. Some of these programs have additional

features such as the ability to customize the keyboard layout, utilize word prediction/completion, adjust letter size, and create pre-stored phrases or sentences. Onscreen keyboards are typically used by individuals who are not able to type on a standard keyboard due to weakness, fatigue, immobility, tremors, or literacy issues. Little or no training is required to use these programs,



*Onscreen keyboard*

however, some initial setup may be required, depending on the user’s preferences.

**Abbreviation expansion** – This program enables the user to assign a series of letters, words, or sentences to one or more key-strokes. When the assigned keys (the abbreviations) are entered, the program will automatically insert the expanded text. For example, the user can assign “HHY” to expand and type “hello, how are you today?” into a document, email, or text-entry field. A macro program also has this capability, but includes more functionality (information is given on macro programs in the following section). Some other programs

include abbreviation expansion as a feature, but this can be purchased as a stand-alone program that will work with the user's existing internet pages, email, documents, spreadsheets, and other programs.

Abbreviation expansion is typically used by individuals who fatigue easily while typing or who have difficulty with spelling. Minimal training is required to learn how to use these programs. The user is only limited by the number of abbreviations that he or she can remember!

### Optical character recognition (OCR) –

This program translates a printed

document into electronic text that can be edited, saved, read aloud, or sent in an email. For individuals who need to fill out forms or add additional text to a previously printed document, they can scan in the document and use OCR to enable editing. A scanned and OCR-translated document can also be

read aloud by a screen reading or text-to-speech program for individuals who have vision or literacy issues. A scanner is required in addition to the software. Minimal to moderate training may be required, depending on how extensively the program will be used and the complexity of the particular program.

### Products that Help with Moving the Cursor on the Screen (Mouse Movements) Scrolling or scanning mouse emulator –

This program enables a user who has minimal movement (switch access or finger) to control where the cursor moves. A horizontal, vertical, or rotary line moves across the screen until the user presses a switch or hits a designated key on the keyboard. The cursor then moves along the stopped line until it reaches the target. The user presses the switch or key again to “click” on the target. This type of program can be used by individuals who have a consistent, voluntary movement anywhere on his or her

body. For example, if an individual is in bed and is only able to move his or her head, a switch can be positioned and connected to the computer to enable that person to control the movement of the line on the screen. Little or no training is required to use these programs. An evaluation for switch access may be needed to determine

where the best location is for the switch and what body action will accurately activate the switch.

Expanded features – This program offers additional features for cursor movement, speed, and/or appearance. Many of the programs have adjustments for the size, color, contrast, and design of the cursor to suit the visual needs and preferences of the



*Windows control panel*

user. A few programs have adjustments for speed and movement to enable a user with fine motor difficulties (due to mild tremors or spasticity, weakness, and/or fatigue) to compensate for reduced range of movement or uncontrollable movements. Some setup is required to ensure that the settings are properly adjusted. Little or no training is required to use these programs.

**Dwell clicking** – This program offers an alternative way to perform mouse clicks and drags. Once the user stops moving the cursor, the software waits a predetermined amount of time before initiating a click. This makes it easier for individuals who have difficulty coordinating the movement and clicking of the mouse. Those with sensitivity issues or reduced strength in their fingers will also benefit. These programs can be used in conjunction with onscreen keyboards and some of the previously discussed hardware options. Some setup is required to ensure that the settings are properly adjusted. Little or no training is required to use these programs.

**Macro** – This program enables users to “record” a long series of commands and assign them to a function key, combination of keys, menu item, or on-screen button. Macros are typically created for frequently performed actions. Once a macro is recorded, the user can execute a complicated task exactly as recorded simply by typing the assigned key(s), selecting from the menu, or clicking the button. For example, with one or two keys, the user may open a word

processing program, enlarge the text, and enter a name or address. Another macro may be created to save and print a document in one keystroke. This is useful to individuals who are able to access keys on the keyboard but have difficulty moving the cursor, or for users who fatigue easily. This may also be useful for individuals who have difficulty remembering multi-step processes. Minimal training is required to learn how to use macro programs.

### Products that Help Keep in Touch With Friends and Family

**Simplified email** – This program provides a simplified interface for email. Such programs reduce the amount of visual clutter and make the steps for composing email more



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<b>Lightweight &amp; Comfortable</b>		For Additional Information, Visit Our Website <a href="http://www.polarsoftice.com">www.polarsoftice.com</a>	
<b>Worn Under or Over Clothes</b>		<b>Polar Products Inc.</b> <b>1.800.763.8423</b> 	

apparent. Several of these programs can be configured to include graphics for both reading and composing emails. Some of the programs enable the user to record a spoken message instead of having to type an email. Individuals can also use text-to-speech programs to have received email read aloud.

**Telephony** – This program enables an individual to make phone calls using the computer as an interface. Telephony can work in several different ways. A user can make and receive calls via phone-to-phone, computer-to-phone, or computer-to-computer transmissions, with some additional hardware. Two main advantages of using some of these programs are lower phone bills and access to a computer interface. The computer interface is flexible for most individuals and this can make it easier for a person with

minimal movement to make calls. The computer can also store all of the contact information for callers and can be configured to record calls for playback at a later time. These programs vary in the complexity of setup and user-friendliness. Some telephony programs may not require any training, while others may involve extensive training.

**Video** – These programs enable a user to transmit and receive video (picture), either with or without audio (sound). These programs can record video for sending via email or can be connected with another user for conferencing. These programs require a small computer camera in addition to the software. Video programs vary in the complexity of setup and user-friendliness. Required training varies from none to moderate.

## In Conclusion

This series of three articles on assistive technology for the computer has been an overview of the many ways the computer can be made accessible to individuals with varying abilities. Identifying, obtaining, and setting up the work station, hardware, software, and peripherals are significant steps (and may feel like the most difficult) in the process. The importance of training, however, should not be downplayed.

Consumers need to remember that when starting out, forgoing the bells and whistles, while focusing on simple and low-tech solutions, is a smart plan. This will save money and frustration in the long run. With some of the more complex and expensive equipment, contacting a profes-



sional who is familiar with computer access is recommended, and he or she may possibly give an evaluation. Many programs around the country are available that provide options for equipment evaluations, demonstrations, and loans. Readers may see the resource list below for further contacts.

### Resource Websites:

Information on Microsoft (Windows) accessibility:  
[www.microsoft.com/enable/](http://www.microsoft.com/enable/)

Information on Apple (Macintosh) accessibility:  
[www.apple.com/accessibility/](http://www.apple.com/accessibility/)

Information about state Assistive Technology projects:  
[www.resna.org/taproject/at/statecontacts.html](http://www.resna.org/taproject/at/statecontacts.html)

Information on products listed here:  
[www.assistivetech.net](http://www.assistivetech.net)

### Programs for recycled or free computers: ReBoot

(770) 934-8432  
[www.gatfl.org/reboot/default.htm](http://www.gatfl.org/reboot/default.htm)

### Beaumont Foundation of America

(866) 546-2667  
[www.bmtfoundation.com/bfa/us/public/](http://www.bmtfoundation.com/bfa/us/public/) ♦

## MAKING A GIFT TO MSAA ONLINE IS: *FAST, EASY, AND SECURE*

MSAA depends on individual gifts to provide the funds that pay for all the meaningful programs and services it provides to the thousands of people who call for our help each year. More than 400,000 Americans live with MS, along with their families and care partners. Through vital donations, MSAA is able to reach as many of these people as possible.

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2. Fill in the form on the secure server.
3. Add credit card information, and the transaction is complete.

Donors receive an acknowledgement and receipt immediately via e-mail. MSAA accepts Visa, MasterCard, American Express, and Discover. You can also make memorial donations or gifts in honor of a special person or event. And because you're online, 100 percent of your gift comes directly to MSAA!

**BE GENEROUS. BE THOUGHTFUL. BE EFFICIENT.**

**Make your voluntary gift to MSAA online  
today by visiting [www.msaa.com](http://www.msaa.com).**

The MSAA logo is written in a stylized, white, cursive font with a slight shadow effect, set against the red background of the box.

# MSAA Commemorates

# 35 Years



Everyone affiliated with the Multiple Sclerosis Association of America (MSAA) is proud and pleased to be a part of its 35th anniversary commemoration. This milestone year marks three-and-a-half decades, from 1970 to 2005, of serving individuals whose lives have been affected by MS.

## 1970s

Founded on June 6, 1970, the Multiple Sclerosis Association (MSA) began as a small, grassroots organization where MS clients and their families banded together to offer care and service to those in need. Armed with first-hand knowledge of the disease and its effects on the family, the all-volunteer Board and staff were eager to reach out and bring a new level of hope, service, and support to the MS community.

In its first few years, MSA aggressively worked to establish several core services which addressed the needs and day-to-day challenges of individuals with MS. These included: the Equipment Loan Program, where clients could receive a wide array of items for safety and mobility; monthly support groups; and a peer-to-peer telephone support line which offered information,

referrals, and, most importantly, encouragement to those who called.



*MSA purchases its own office and activity center in Oaklyn, New Jersey.*

In 1976, MSA secured a sizable grant from a local foundation to purchase its own office and activity center in

the small town of Oaklyn, New Jersey. With this new office, MSA was able to increase visibility and fundraising efforts. This led to the development of new services including a 12-page bimonthly newsletter, a local transportation program, exercise and therapy classes, and increased client events such as workshops, seminars, and holiday dinners.

## 1980s

As MSA entered its second decade of service, program delivery spread across the Greater Delaware Valley. This included New Jersey, Pennsylvania, and Delaware, and eventually



*MSA establishes the Barrier-Free Housing Program.*

carried over to many of the states throughout the Northeast.

Recognizing the necessity for accessible housing, MSA established the Barrier-Free Housing Program. MSA then secured two million dollars in funding through the United States Department of Housing and Urban Development for the construction of a 41-unit, fully accessible apartment complex. The facility, which promotes safe, independent living, opened its doors in early 1986. The success of this program initiative led to the funding and construction of four additional housing complexes. Of these five apartment complexes, four are located in New Jersey and the fifth is in North Carolina.

In 1988, MSA became a national non-profit organization and incorporated “of America” into its name. MSA was now officially renamed the Multiple Sclerosis Association of America (MSAA).



*MSA incorporates “of America” into its name, adopting this new logo.*

## 1990s

The decade began with the opening of two regional offices to help meet the ever-growing

demand for services. MSAA’s first regional offices were the Mid-Atlantic Region in Washington, DC and the Midwest Region in Cleveland, Ohio. A few years later MSAA opened the Northwest Region in Great Falls, Montana. By the late 1990’s, MSAA added the Mid-South Region in Little Rock, Arkansas, the California Region in Beverly Hills, California, and the Southwest Region in Phoenix, Arizona.

In the early 1990’s, MSAA collaborated with many prominent MS medical centers and established a partnership with the National Aeronautics and Space Administration (NASA) to further advance the use of microclimate cooling (a spin-off technology from the Apollo missions) as a therapy for MS. Through the success of these studies, MSAA established the Cooling Program, which provides clients with a variety of cool suits, vests, and other garments that help counteract the devastating effects of heat stress on individuals with MS.

The MRI Diagnostic Fund and the Home Ramp Program were added to MSAA’s increasing list of services. The MRI Diagnostic Fund covers the expense of a magnetic resonance imaging (MRI) test for those who are suspected of having MS but cannot afford the exam. The Home Ramp Program provides clients with light-



*The Home Ramp Program is added to MSAA’s increasing list of services.*

weight, portable ramps for home access.

As rapid growth and expansion continued toward the decade's end, MSAA's Board of Directors used this opportunity to re-examine, re-evaluate, and recommend changes, ensuring that the organization would achieve the greatest success possible for the new millennium and beyond. These changes enabled MSAA to improve its operational procedures to maximize efficiency and provide the highest quality of service possible to its MS constituency.



*MSAA updates and expands its published materials, including *The Motivator*, which is now a four-color, quarterly magazine.*

## 2000s

With the arrival of the new millennium, MSAA developed a five-year strategic plan and a working blueprint for improvement in all departments. MSAA revised its formal mission statement to fully describe the role which the organization plays in the MS community. MSAA's mission "to ease the day-to-day challenges of individuals with multiple sclerosis and their care partners" is considered in all aspects of the organization's initiatives.

MSAA expanded the scope of published materials in an effort to provide comprehensive, educational literature in an attractive and easy-to-understand format. MSAA's bimonthly newsletter, *The Motivator*, evolved into a 52-page, four-color, quarterly magazine. New editions of MSAA's publica-

tions, *The Process and Medical Treatments* and *Managing Symptoms*, were produced. MSAA published two new booklets titled *All About Multiple Sclerosis* and *MSAA Programs and Services Guide*. Another booklet titled *Multiple Sclerosis and Cooling* was redesigned and a new edition was published. New programs were created. These included the Home Modification Program, the Networking Program, MSAA's Lending Library, the MRI Institute, as well as upgrades to the Equipment Loan, Cooling, and MRI Diagnostic Programs.

The number of regional offices was increased, with the addition of the Northeast, Southeast, and Western Regional Offices (located in Cherry Hill, New Jersey; St. Petersburg, Florida; and San Francisco, California, respectively). Field offices were opened in Connecticut and Chicago. The Mid-South Region moved to Mesquite, Texas and was renamed the South-Central Region, while adding a field office in Hot Springs, Arkansas. The reach and number of support groups, educational events, and service delivery were increased as well, while the services were expanded to better meet the needs of those affected by MS.

In 2001, neurologist and MS specialist Jack Burks, MD joined MSAA as part-time

staff in the role of chief medical officer. Dr. Burks oversees all medical information written and distributed by MSAA, in addition to writing a column for MSAA's magazine, *The Motivator*.

Also in 2001, the Healthcare Advisory Council (HAC) was formed. Headed by Dr. Jack Burks, the HAC is a group of healthcare professionals from several disciplines. This group is dedicated to addressing MSAA's work as it relates to the different areas of medical treatments, information, and the development of an optimal overall healthcare plan.

During these years, MSAA also developed private-sector fundraising by establishing successful relationships with pharmaceutical and other medical companies. This led to open discussion of how to best help individuals with MS, and ultimately brought financial grants to help fund vital client programs and services.

During this time the client services department increased its professional staff. In 2003, the department extended Helpline hours, providing evening access for individuals in the eastern portion of the country, as well as availability until 5:00 pm for clients on the west coast. In 2004, a bilingual consultant was added to assist with calls received from the Spanish-speaking community.

MSAA redesigned its website, [www.msaa.com](http://www.msaa.com), and launched a new and

improved site in June of 2004. The new site includes descriptions and applications for each MSAA program, important research information, MSAA publications (which can be downloaded), regional events and support groups, ways to support MSAA through volunteering and donating online, and is easily navigated and linked to multiple other sites.



MSAA approached other MS organizations with the intention of developing positive working relationships to benefit the entire MS community. Discovering how each organization can best serve individuals affected by MS, as well as avoiding a duplication of services, are two of MSAA's goals. MSAA continues to meet regularly and hold valuable discussions with other national organizations such as the

National Multiple Sclerosis Society (NMSS), the Consortium of Multiple Sclerosis Centers (CMSC), and the Multiple Sclerosis Foundation (MSF).

Until a cure is found, MSAA is steadfast in its efforts to help as many in need as possible, and to find new and better ways in which to assist people affected by this challenging disease. The year 2005 is a milestone for MSAA and the people it serves. As this important anniversary is commemorated, everyone at MSAA continues to look to the future for even greater accomplishments ♦

# Ask the Doctor



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

**Q:** I am a 43-year-old Navy veteran, diagnosed with MS in 1996. I wanted to know if a connection has been found between MS and exposure to asbestos.

**A:** As you may know, a number of environmental toxins

have been considered as suspects in the search for the cause of MS. Mercury and formaldehyde are two examples. Despite several investigations, no link has ever been found between such toxins and MS. As with these other studies, after researching this subject, I could not find any direct evidence associating MS with asbestos.

**Q:** Can you give an update on the status of stem cell research?

**A:** Stem cell research using embryonic, fetal, or placenta blood stem cells have not been reported in scientific MS clinical trials to date. I am still optimistic, however, that these types of stem cells may have the potential to one day help individuals with MS. On the other hand, research using bone marrow transplant (which also goes by the name of “stem cell” research) is ongoing, but long-term efficacy and safety have not been established. This procedure is considered “experimental.” Research is

impeded by the fact that this procedure has a five to ten percent mortality rate, as well as a risk for toxic effects to the brain from the drugs used to “cleanse” the cells. For more information, readers may refer to the “Ask the Doctor” column in the Spring 2004 issue of *The Motivator*. Copies may be obtained by calling MSAA at (800) 532-7667 or by logging onto [www.msaa.com](http://www.msaa.com).

**Q:** Are any specific medications available to improve balance?

**A:** No medications are specifically designed to improve balance problems with MS. Medications are available, however, to treat vertigo and dizziness, which can certainly impact one’s balance. These include antihistamines (such as Antivert®, Benadryl®, Dramamine®, and a scopolamine patch), as well as benzodiazepines (which include Klonopin®, Ativan®, Xanax®, Serax®, and Valium®). Patients should consult a physician before taking any of these over-the-counter or prescription drugs. Aside from treating vertigo and dizziness with medication, balance may sometimes be helped through rehabilitation techniques, which can be especially effective in decreasing one’s risk of falling. Assistive equipment such as walkers, canes, feeding devices, and other tools may help individuals with balance problems to feel and function better, as well as increase safety. Biofeedback may also be helpful for some people. ♦

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

## To Submit Questions to Ask the Doctor...

Many of these questions were submitted by readers. If you have a question that you would like to ask, please submit your question to:

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

Readers may also send in questions via email to [aborkowski@msaa.com](mailto:aborkowski@msaa.com). Please be sure to write "Ask the Doctor" in the subject line.

## MSAA IS ONLINE!

Visit MSAA's website at  
**[www.msaa.com](http://www.msaa.com)**  
for resources, program information,  
news updates, and much more!

# MSAA Needs Volunteers!

## Volunteering assignments include:

- Public Education Ambassadors
- Support Group Leaders
- Professional Volunteers (including lawyers, occupational therapists, and physical therapists)
- Independent Volunteer Fundraisers
- Resource Detectives

Please contact **Malcolm Friend at MSAA**

Phone: (800) 532-7667, ext. 8

Email: [volunteering@msaa.com](mailto:volunteering@msaa.com)

Website: [www.msaa.com/volunteer.html](http://www.msaa.com/volunteer.html)

(When sending an email, please include areas of interest for volunteer work and any contact information)

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# Research News

## Tysabri® (Natalizumab) Update

### Tysabri is Released and Subsequently Suspended From the Market

Tysabri is the latest drug approved for the treatment of MS, having been released for use in the United States in November 2004<sup>1</sup>. Tysabri is a humanized monoclonal antibody and is designed for patients with relapsing forms of multiple sclerosis. It prevents the inflammatory phase of MS by blocking activated leukocytes from crossing the blood-brain barrier (BBB).

Biogen Idec and Elan Pharmaceuticals, the companies licensed to manufacture and commercialize Tysabri®, voluntarily suspended marketing of the drug<sup>2</sup> on February 28, 2005. The decision to voluntarily suspend the marketing of Tysabri was based on reports of dramatic events occurring in two patients who were treated with both Tysabri and Avonex (interferon beta-1a). Both patients were confirmed as having Progressive Multifocal Leukoencephalopathy (PML), and one of the patients died.

PML is a viral disease occurring in immuno-suppressed patients. Both patients were enrolled in a long-term clinical trial, receiving Tysabri in combination with Avonex for more than two years. More recently, a third person who was a patient in an open label Crohn's disease clinical trial was diagnosed with PML postmortem. This latter case is still under investigation. Biogen Idec and Elan Pharmaceuticals are currently conducting an extensive evalua-

tion of all patients treated with Tysabri in clinical trials for multiple sclerosis, Crohn's disease (an inflammatory disease of the small intestine and colon), and rheumatoid arthritis. The result of this analysis will decide Tysabri's future. Biogen Idec and Elan could reconsider the dosage of Tysabri, change the elective patients for the treatment, or remove the drug from the market. The pharmaceutical companies reported no cases of PML in patients treated only with Avonex.

### Progressive Multifocal Leukoencephalopathy

Progressive Multifocal Leukoencephalopathy (PML) is a fatal viral disease of the Central Nervous System (CNS), which consists of the brain and spinal cord. PML is characterized by demyelination in white matter, or destruction of the oligodendroglial cells which make the myelin sheath covering of the nerve cells of the brain. This demyelination occurs at the same time at numerous locations in the brain (multifocal).

Symptoms of PML include vision loss, speech disturbances, ataxia (inability to coordinate movements), paralysis, and ultimately coma. PML affects patients with suppressed immune systems, including patients with cancers such as leukemia or lymphoma.

The cause of PML is the activation of the polyoma virus known as "JC Virus." As many as 80 percent of healthy adults could be carriers of the inactivated (latent) form of the JC Virus. When a carrier becomes



immuno-compromised, the virus has the opportunity to become activated.

### What is Tysabri?

Tysabri is an immunomodulator, which is an agent that reduces the body's immune responses. It was the sixth disease-modifying treatment approved by the FDA to treat the inflammatory phase of multiple sclerosis.

Tysabri is a humanized monoclonal antibody, engineered and produced in the laboratory. Originally derived from a mouse antibody, Tysabri is 80 percent human in sequence. Tysabri is also known as a laboratory-produced immunoglobulin (Ig).

Naturally occurring immunoglobulin is a protein that is manufactured in the blood by lymphocytes (a type of leukocyte, which is a white blood cell that helps to fight disease).

Immunoglobulins function as antibodies, which are molecules that react only to a specific substance called an antigen.

Antigens are present on the surface of bacteria and toxins that enter the body. Each antigen induces a specific immune response.

The monoclonal antibody Tysabri specifically identifies a region of the integrins alpha4 beta1 (a4b1) known as the alpha4 (a4) subunit. Alpha4 integrin is a cell-surface protein present on the surface of all leukocytes (except a type called neutrophils).

### How does Tysabri work?

Tysabri's strategic design is based on the following observation: during MS exacerbations, lymphocytes and monocytes (two types of leukocytes) from the blood stream

cross the blood-brain barrier (BBB) and enter the central nervous system (CNS). With MS, these leukocytes migrate into the CNS, where they begin an attack on the body's own myelin (nerve covering) and nerves, causing inflammation.

In order for lymphocytes and monocytes to cross the BBB, they need to recognize a specific site on the wall of the blood vessel. Among them is the "vascular cell adhesion molecule-1" (VCAM-1). By binding a4-integrin (located on the leukocytes' surface) and VCAM-1 (located on the vascular endothelial cells' surface), leukocytes are able to latch onto and then penetrate through the BBB.

By analogy, a4-integrin is the key and VCAM-1 is the lock. Working together, they open the door from the blood stream, across the BBB, and into the CNS. Once in the CNS, the leukocytes initiate an inflammatory cascade leading to the release of inflammatory molecules and the recruitment of additional lymphocytes and monocytes. This subsequently causes an increase in inflammation and eventual demyelization.

The mission of Tysabri is to block the key (a4-integrin) on the leukocytes' surface. By doing so, Tysabri prevents the disease-fighting cells from crossing the BBB to the brain and spinal cord. Instead, the leukocytes remain in the blood stream and therefore the inflammatory cascade is interrupted. As a result, this process may reduce or prevent the formation of new sclerosis (or damage to the nerves).

### How Tysabri Differs from Other Disease-Modifying Agents Approved for MS

Before the release of Tysabri, five drugs were available to the practitioner to prescribe to his or her patients. Four are immunomodulatory drugs: Betaseron® (interferon beta-1b), Rebif® and Avonex® (interferon beta-1a), and Copaxone® (glatiramer acetate).

The immunomodulators, by various approaches, regulate the immune activation involved during the inflammatory process of an attack. In contrast to Tysabri, these drugs are not pharmacologically focused on one event of the attack, but rather contribute to affect several aspects of the exacerbation and immune responses to the disease.

The fifth drug available for MS is Novantrone® (mitoxantrone), which is a chemotherapeutic agent. As a chemotherapeutic drug, Novantrone indiscriminately destroys all rapidly dividing cells in the organism, including those in the immune system. It is seen as an immunosuppressant; usually prescribed for worsening disease in spite of treatments with the immunomodulating drugs.

Tysabri's action is quite different from the other immunomodulator drugs. Tysabri was designed to reduce new lesion formation and to limit the progress of evolving lesions, acting before the irreversible destruction of the CNS tissue occurs. Tysabri is a pharmacological agent specifically targeting the lymphocytes and monocytes involved in inflammation, by preventing them from reaching the CNS. More specifically, Tysabri is targeting the alpha4 beta1 integrin present at the lymphocytes surface.

### The Consequences of Tysabri's Withdraw

While the contribution of Tysabri remains unknown on the development of PML, Tysabri's withdraw jeopardizes the future of eleven other drugs under development which use alpha4 beta1 integrin as a target. Five of these are designed to fight MS.

Drugs targeting the alpha4 beta1 integrin have been studied since 1995. This strategy seemed to be very promising and generated lots of excitement in the pharmaceutical industry. If the Tysabri withdraw becomes permanent, then the development and approval of other alpha4 beta1 integrin antagonists would be more difficult.

After the investigation, should Tysabri be shown to cause PML, Biogen Idec and Elan Pharmaceuticals may still ask the FDA if Tysabri may go back on the market with a "black box" on its label. This would warn doctors and patients that the medication could cause fatal complications in a certain percentage of patients. The black box warning allows doctors and consumers to decide what risks they are willing to take.

Written by Christian CD Poncet, PhD

Email: christianponcet@hotmail.com.

Comments and questions are welcome.

### References:

1. The FDA is reporting this suspension at [www.fda.gov](http://www.fda.gov) (search for natalizumab)
2. Tysabri's Website: [www.tysabri.com](http://www.tysabri.com); Biogen Idec help line: (800) 456-2255 ♦

# Program Notes

## New Items Available through MSAA's Equipment Programs

Striving to continually meet the needs of MS clients and their care partners, MSAA is pleased to announce the addition of several new and very useful items to the equipment programs. Two of these new products are highlighted below, along with program, application, and catalog information.



MSAA's Equipment Loan Program now features a new, lighter manual wheelchair that has removable side arms as well as adjustable and removable wheels. Manufactured by Pride®, the "Stylus" weighs 23 pounds and has a weight capacity of 300 pounds. The wheels have an easy push-in/pull-out feature that allows the chair to adjust to three different heights of low, middle, and high. Additionally, when both wheels are removed, the chair folds down to fit into most car trunks or back seats.

MSAA's Equipment Distribution Program, which offers a wide array of safety and daily-living aids, recently added a heavy-duty walker to its comprehensive inventory. The "Rollator Four Wheels" walker features a seat, basket, and nine-inch wheels which allow a weight capacity of 450 pounds. Clients who are interested in this walker should include their height and weight on the application.

As spring temperatures begin to rise, so will requests for cooling vests, accessories, and other products through MSAA's Cooling Distribution Program. Individuals who are heat sensitive and feel they could benefit from MSAA's cooling products don't need to wait until the summer sun is blazing down upon them. Interested readers may request cooling equipment at any time throughout the year.



Readers interested in applying for any of the equipment or cooling products may call MSAA at (800) 532-7667 to request an application. To assist with the selection of cooling equipment, a cooling catalog with photos and product descriptions is

included with each application mailed. Applications, as well as the cooling catalog, may also be downloaded from MSAA's website at [www.msaa.com](http://www.msaa.com). ♦

# Symptom Awareness

## Treating Pain through Complementary and Alternative Medicine

Some individuals with MS are using alternative treatments to help ease their pain. Known as complementary and alternative medicines (CAMs), this type of therapy often has multiple benefits. While more research is needed before the advantages can be fully known, studies as well as participant reports often show positive responses to various CAM therapies.

Anyone considering CAM therapy is strongly advised to consult and gain approval from his or her physician in advance.

According to Allen C. Bowling, MD, PhD, and author of *Alternative Medicine and Multiple Sclerosis*, a plan should be developed before beginning any type of CAM therapy. This book is available through MSAA's Lending Library as book #130; please see page 60 for ordering information. A copy may be purchased through [www.amazon.com](http://www.amazon.com) and Barnes & Noble at [www.bn.com](http://www.bn.com). A copy may also be purchased by calling Barnes & Noble at (800) 843-2665.

To follow are some of the tips that Dr. Bowling offers when beginning a CAM therapy:

- Consider conventional medicine first
- Obtain accurate information about effec-

- tiveness, safety, cost, and effort involved.
- If CAM is chosen, discuss it with your physician, monitor your response, and discontinue the treatment when appropriate
- Use caution
- Realize that information about most forms of CAM is incomplete
- Be aware of the “telltale” signs of unreliable forms of CAM. Warning signs include:

- A heavy reliance on testimonials
- Strong claims about effectiveness – terms such as “amazing” and “miraculous” should raise suspicions; if it sounds too good to be true, it probably is
- The composition of a therapy is “secret”
- The unwillingness of a CAM practitioner to work cooperatively with a physician
- Recognize that MS is a disease that involves increased immune system activity
- Avoid misconceptions about supplements (many are not FDA approved and do not have sufficient clinical studies to support their claims; some may even be harmful or cause dangerous interactions with other medications)

CAM(s) should not be a replacement for a treatment recommended by a physician. To follow is a listing of some of the more common CAM therapies that may help some individuals with MS to reduce pain. Much of the information was derived from Dr. Bowling's book.

Listed below are three examples of CAM therapies which require direct, hands-on work by a professional. The patient does not play an active role in the treatment.

### Acupuncture

Acupuncture is a therapy of traditional Chinese medicine. Slender needles are inserted into the skin at particular points, which (according to theory) helps to balance the chi energy. Acupuncture may help ease MS-related pain and reduce the severity of muscle spasms for some individuals.

### Massage

Various types of massage include Shiatsu, Swedish massage, and acupressure. The skin is the largest organ of the body and is packed with nerve endings that respond to touch. Massage works by soothing the skin and relaxing tense muscles. Regular massage may help someone with MS to better manage muscle pain.

### Chiropractic

Back pain is common for many individuals with MS, and weakened leg muscles may exacerbate this. The basic principle behind chiropractic care is the idea that spinal manipulation can help musculoskeletal problems, such as back pain, as well as improve a person's general state of health. Individuals should be carefully examined before chiropractic care is begun to make sure the pain is not caused by some other type of injury (such as a herniated disk or vertebrae damage).

Please note that while chiropractic

practice is viewed by many as an effective treatment for back pain and injury, not all traditional doctors agree on its effectiveness and safety, particularly for those with MS. Dr. Jack Burks, MSAA vice president and chief medical officer comments, "Some physicians are concerned that neck manipulation in MS patients with active disease in the cervical spine may actually aggravate disease activity. Please be sure to consult your physician for his or her guidance before beginning chiropractic treatment."

The five CAM therapies listed below are overseen by a professional, but do not require any physical contact by the professional, other than to assist with instruction or apply sensors or other equipment (as with biofeedback). The patient plays an active role in these therapies, learning relaxation techniques to calm nerves, reduce muscle tension, become more mentally focused, and even slow heart rate and breathing.

### Yoga

While many different types of Yoga are practiced, they all have a common goal in mind, which is to rely on structured poses timed with breathing. Yoga helps to relieve stress, since concentrating on the postures and breathing acts as a powerful form of meditation. The gentle, sustained stretches also help improve flexibility, reduce muscle stiffness, and even reduce fatigue.

### Meditation

Meditation can be a powerful stress-management therapy for some individuals. It is

the deliberate clearing of one's mind in order to promote a sense of calm and heightened awareness. During meditation, the brain produces alpha waves, which have been found to promote relaxation of the entire nervous system.

### Tai Chi

Using slow body movements, Tai Chi can provide some of the physical benefits of exercise and the relaxation of meditation. Studies have shown that it may increase strength while reducing fatigue, depression, and anxiety.

### Biofeedback

Using technology to monitor bodily functions (such as heart rate, pulse, or muscle tension), body activity is translated into images or sounds. A biofeedback therapist usually administers the test and also develops a treatment plan. Participants are given physical and mental exercises that help control body functions. Measuring muscle tension, electromyography is a type of biofeedback used to help control pain triggers. From this, the therapist may develop a treatment program that focuses on relaxation, progressive muscle relaxation, or visualization. (Information derived from WebMD at [www.webmd.com](http://www.webmd.com).)

### Progressive Muscle Relaxation

Used to reduce muscle tension which can affect pain, progressive muscle relaxation works by tensing one muscle group for eight to ten seconds and then relaxing the

muscle. Based on muscle physiology, when a muscle is tensed and then released, the muscle relaxes. Further resting of the muscle will allow even greater muscle relaxation. This can have a ripple effect, as other components of the relaxation response will follow naturally, causing slower breathing and a reduced heart rate. (Information derived from Lessons for Living at [www.lessons4living.com](http://www.lessons4living.com).)

### For More Information

For more information on managing pain, readers may contact or visit the websites of the resources listed below. Individuals may also call MSAA's Helpline at (800) 532-7667.

American Academy of Pain Management  
Phone: (209) 533-9744  
Email: [aapm@aapainmanage.org](mailto:aapm@aapainmanage.org)  
Website: [www.aapainmanage.org](http://www.aapainmanage.org)

American Pain Foundation  
Phone: (888) 615-7246  
Email: [info@painfoundation.org](mailto:info@painfoundation.org)  
Website: [www.painfoundation.org](http://www.painfoundation.org)

American Pain Society  
Phone: (877) 734-8758  
Email: [info@ampainsoc.org](mailto:info@ampainsoc.org)  
Website: [www.ampainsoc.org](http://www.ampainsoc.org)

Consortium of MS Centers  
Phone: (201) 837-0727  
Email: [info@mscare.org](mailto:info@mscare.org)  
Website: [www.mscare.org](http://www.mscare.org) ♦

- Amanda Bednar

# Health and Wellness

## Food Pyramid Updated

In the article, “Healthcare Beyond MS,” appearing in the Winter 2005 issue of *The Motivator*, proper diet and good health practices were discussed. As a follow-up to this article, details from the government’s new food pyramid are presented in this issue’s Health & Wellness column.

Recently released by the United States Department of Agriculture (USDA), the updated pyramid has a new look and a full day’s supply of important food and health information. The former “Food Guide Pyramid” has been renamed as the “MyPyramid” food guidance system.

The website, [www.mypyramid.gov](http://www.mypyramid.gov), shows the pyramid’s new design, explains the features, and provides numerous options for determining the optimal diet plan. Website visitors are given the opportunity to get individualized diet programs by typing in their height, weight, food intake, and exercise levels.

The food groups are given according to their advised ratio in a person’s diet. Grains (in orange), vegetables (in green), and milk products (in blue) are given the larger sections to denote more servings. Fruits (in red) and Meat & Beans (in dark blue) have a smaller

area than the first three, to denote a smaller number of servings. Oils (in yellow) have a thin space on the pyramid, and this refers to fewer and smaller servings being recommended.

The new pyramid symbolizes a personalized approach to healthy eating and physical activity. The new graphics and slogan, “Steps to a Healthier You,” represent the importance of activity, moderation, personalization, proportionality, variety, and gradual improvement. This pyramid works with the “Dietary Guidelines for

Americans 2005,” which was highlighted in MSAA’s “Healthcare Beyond MS,” article mentioned earlier.

To learn about the MyPyramid food guidance system, readers may visit [www.mypyramid.gov](http://www.mypyramid.gov). Individuals without internet access may contact MSAA at (800) 532-7667 for assistance. Readers may also call that number to request a copy of the Winter 2005 issue of *The Motivator*, which is also available for viewing or downloading at [www.msaa.com](http://www.msaa.com). As always, readers are strongly cautioned to consult their physician before making any changes to one’s diet, exercise, or other health-related issue. ♦



# Regional News

For information on events and newly formed support groups, please call the phone numbers listed. When specific numbers are not given, please contact the MSAA Regional Office appearing below each listing. Established support groups are held in many other cities; please call the nearest MSAA Regional Office for details. All activities are free of charge unless otherwise noted. Times listed are in the local time zone for the region or location of the event.

## Northeast Region

### Upcoming Events:

- June, Care Partners Educational Workshop, Boston, Massachusetts (date and location to be determined)
- Saturday, June 18th, 9:30 am to 12:00 pm, Patient Education Outreach for the Hispanic Community, Bethesda, Maryland; please contact Richard Palacio at (800) 532-7667, ext. 108 for more information

### Newly Formed Support Groups:

- Holbrook, New York; contact Jaime Cummings at (613) 472-5045
- Scranton, Pennsylvania; contact Debbie Niehuus at (570) 961-2268

### Support Groups Coming Soon:

- Lehighton, Pennsylvania
- Staten Island, New York
- Washington, DC

### *MSAA Northeast Regional Office:*

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

### *MSAA New Hampshire Field Office:*

John Robinson  
Client Services Coordinator  
13 Elwood Road  
Londonderry, New Hampshire 03053  
(603) 434-0176  
(800) 532-7667, ext. 151

## Southeast Region

### Upcoming Events:

- Friday, June 24th, 6:30 pm to 9:00 pm, "Be Cool," a presentation on cooling and MS; Pasco County, Florida
- Saturday, August 13th, educational talk with a doctor; Asheville, North Carolina

### Support Groups Coming Soon:

- Charlotte, North Carolina
- Chatham, Virginia
- Gainesville, Florida
- Greenville, South Carolina
- Salem, Virginia

### Therapeutic Groups Coming Soon:

- Leesburg, Florida
- Palm Coast/Flagler County, Florida



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

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### Midwest Region

#### Upcoming Events:

- Saturday, July 16th, MSAA Day at the Zoo, Columbus, Ohio; Dr. Kottil Rammohan will speak at this event, which also features a small animal exhibit
- Saturday, August 13th, MSAA Day at the Zoo, Cleveland, Ohio; Dr. Randall Schapiro will speak at this event; an animal demonstration will also be given
- Wednesday, September 21st, MSAA Day at the Comedy Club, Cleveland, Ohio; in addition to entertainment, an MS specialist will speak at this event
- Saturday, October 29th, MSAA Halloween Party, Cleveland, Ohio; in addition to the party, an MS specialist will speak at this event

#### Newly Formed Support Groups:

- Brookfield, Illinois; contact Nancy Stanger at (708) 209-6944
- Park Forest, Illinois; contact Coni Howard at (708) 747-2129
- Springfield, Illinois; contact Debi Slater at (217) 522-3132

MSAA Midwest Regional Office:  
Renée Williams, Director  
13938A Cedar Road, #243

University Heights, Ohio 44118  
(216) 320-1838  
(800) 532-7667, ext. 140

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### South-Central Region

#### Upcoming Events:

- Saturday, June 11th, “MSAA Awareness Day,” St. Louis Public Library, St. Louis, Missouri
- Thursday, June 16th, “MS and Cooling,” Adam Roberts, South-Central Regional Director and MSAA Head of Cooling Research and Development, Denver, Colorado, 12:00 noon to 1:00 pm
- Saturday and Sunday, August 13th and 14th, “MS Sky Trek,” Denver, Colorado
- Friday through Sunday, October 7th through 9th, “Ruston/Monroe Retreat,” Lake D’Arbonne State Park, Farmerville, Louisiana. Space is limited, so please call early to check on availability

#### Newly Formed Support Groups:

- Ardmore in Carter County, Oklahoma; contact Jerri Ann Fick at (580) 223-7511
- Fort Worth in Tarrant County, Texas; contact Adam Roberts at (800) 532-7667, ext.153
- San Antonio in Bexar County, Texas; contact Wende Buchanan-Jones at (210) 691-9455
- St. Louis in St. Louis County, Missouri; contact Frances Lenoir at (314) 985-0820

#### Support Groups Coming Soon:

- Breckenridge, Colorado
- Mansfield/Arlington, Texas
- Tahlequah, Oklahoma

### *MSAA South-Central Regional Office:*

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

### *MSAA Arkansas Field Office:*

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

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## Northwest Region

### Upcoming Events:

- June, “Living with MS” with Dr. James Bowen, Yakima, Washington
- July, “MS Update” with Dr. Steven Pugh, Wenatchee, Washington
- August, “MS Update” with Dr. Steven Pugh, Walla Walla, Washington (dates for three events above have yet to be determined)
- Friday, August 12th, “35th Anniversary Luncheon,” Omaha, Nebraska
- Sunday, September 11th, “Celebration Picnic,” Sons of Norway Hall, Great Falls, Montana, 1:00 pm
- Saturday, September 24th and Sunday, September 25th, “Parade of Homes,” Great Falls, Montana

### Newly Formed Support Group

- Kellogg, Idaho; contact Diane Lamar at (208) 783-2725 or Teri Treckler at (208) 682-9484

### Support Groups Coming Soon:

- Bozeman, Montana
- Casper, Wyoming
- Meridian, Idaho
- Minot, North Dakota

### *MSAA Northwest Regional Office:*

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

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## Western Region

The Western Regional Office is hoping to start support groups soon in the following cities:

- Los Angeles, California (both Spanish and English-speaking support groups)
- San Francisco, California
- Portland, Oregon
- Las Vegas, Nevada

Anyone interested in joining a support group in any of these areas or starting a support group in another area should contact MSAAs Western Regional Office listed below.

### *MSAA Western Regional Office:*

Amanda Montague, Director  
1819 Polk Street, Mailbox #326  
San Francisco, California 94109  
(415) 260-6420  
(800) 532-7667, ext. 155 ♦

# Spread the Word



## ***Facing and Fighting Fatigue***

Written by Benjamin H.

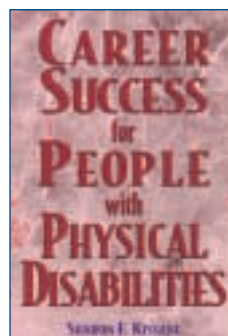
Natelson, MD

Published by

Yale University Press

MSAA Book #252

Dr. Natelson is a professor of neurosciences at the University of Medicine and Dentistry in New Jersey, as well as a director of the New Jersey Chronic Fatigue Syndrome (CFS) Center and principal investigator for CFS research. In his book, he discusses the different types of fatigue problems, explaining what causes fatigue and providing many useful strategies for fighting this sometimes overwhelming symptom.



## ***Career Success for People with Physical Disabilities***

Written by Sharon F.

Kissane, PhD

Published by

VGM Career Horizons

MSAA Book #54

Written by an author with a PhD in education, this valuable resource helps individuals with disabilities to identify their talents and needs to develop a career plan. From there, Dr. Kissane covers a wide range of topics, from education and career selection to creating a resume, networking in the job market, and preparing for job interviews.

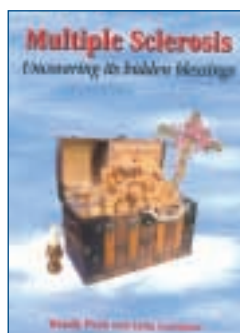
## ***Multiple Sclerosis: Uncovering its Hidden Blessings***

Written by Wendy Peck,

with Erika Coachman

Published by AuthorHouse

MSAA Book #100



Wendy Peck is a friend and neighbor of MSAA's Headquarters in New Jersey. Inviting readers into her own personal story, complete with friends and family, Ms. Peck talks about the many changes she has experienced along with the insight and inspiration she has gained. Counting her blessings, while inspiring others to find theirs, has become her mission.

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