

MSAA

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The *MOTIVATOR*

Bringing Information to People with Multiple Sclerosis



When
Children
Have **MS**

The *MSAA* **MOTIVATOR**

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The Motivator's purpose is to inform and educate those with MS and their families.

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Cover Story

When Children Have MS 7

By Susan Wells Courtney

Despite very limited research, MS specialists work to diagnose, treat, and monitor pediatric MS, while helping kids and teens pursue their goals.



When Children Have MS, p. 7

Departments

Up Front 2

By Douglas G. Franklin

MSAA's president and CEO talks about MSAA's high level of activity. This issue's Board Sidebar (written by Amanda Bednar) features Board member Bob Manley.

Ask the Doctor 24

By Jack Burks, MD

MSAA's chief medical officer answers questions sent in by readers.

Research News 28

By Jack Burks, MD

Important study results presented at the ECTRIMS conference in Prague.

Program Notes 30

By Amanda Bednar
and John Masino

MSAA's new website offers many new features, providing easier access to information, programs, volunteering, and making donations.

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

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Thoughts about Giving 34

By Bruce Makous

Inspiring stories of generosity and MSAA's President's Circle reception are highlighted.

Symptom Awareness 38

By Susan Wells Courtney

Swallowing dysfunction is a common and challenging symptom of MS.

Health and Wellness 40

By Shelley Peterman Schwarz

Tips and recipes are available for individuals with chewing or swallowing problems.

Stories to Inspire 45

By Barbara P. Marchant

A reader of *The Motivator* talks about overcoming challenges to fulfill her dream.

Spread the Word 48

Two informative books and one video from MSAA's Lending Library are featured.

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Douglas G. Franklin

I am pleased to see such a high level of activity every day at MSAA.

Among many recent achievements are several awards we have received for our educational materi-

als. I am proud to announce that MSAA's web video, *A Closer Look at Multiple Sclerosis Symptoms, Part 1*, has won a Silver Telly Award (top honors). Additionally, MSAA's quarterly magazine, *The Motivator*, along with our children's book, *Mommy's Story*, received two National Health Information Awards, an APEX Award, and a Grand APEX Award (top honors).

I would also like to mention that MSAA meets the twenty rigorous standards of the Better Business Bureau Wise Giving Alliance, one of the leading charity evaluators. The Alliance's standards were applied to our organization's finances and solicitations, effectiveness, governance, and informational materials. Meeting these standards makes MSAA eligible to participate in the Alliance's Charity Seal Holder program. MSAA has elected to join the nearly 200 other charities who participate, and we will proudly display the Charity Seal.

My enthusiasm carries over to the MS Coalition as well. This affiliation of several independent MS organizations was recently honored for outstanding leadership in the MS world at The Heuga Center for Multiple Sclerosis Benefit, a gala event held in New York

City on October 23rd. As president of the MS Coalition, I was pleased to speak on its behalf.

MSAA has also begun a social marketing program to encourage adherence to disease-modifying therapies, which have been shown to slow MS disease activity. We have produced a public service announcement for broadcast on national TV, as well as a new publication. I am very excited for the opportunity to share this vital message with the MS community.

On September 28th, we held our President's Circle reception, where MSAA's generous supporters were honored. This inspiring event was attended by regional donors and volunteers, along with MSAA's Board members, Healthcare Advisory Council (HAC) members, regional directors, and senior staff.

On the following day, MSAA Board and HAC members, along with directors and senior staff, all convened to focus on developing a three-year plan for MSAA's programs and services. The overall goal is to optimize what we do in a complementary way, so that no one is left behind. We will build on these discussions for January's meeting, when we hope to have a clear consensus on our signature services and core programs, based on what clients want – as determined through a national assessment conducted by MSAA.

As the winter months quickly approach, I would like to wish all of our readers a very happy holiday season. May everyone enjoy much health and joy throughout the coming New Year. ♦

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

four universities. He currently serves on the National Board of the Key Philanthropic Organizations Committee of the American Society of Association Executives and serves on the Executive Committee of Health First – America’s Charities Board in Washington, DC.

Meet MSAA Board Member Bob Manley

Bob Manley, one of MSAA’s newest Board members, was looking for a way to give back to the community. After a lengthy conversation with his friend, MSAA Board member Tom Vassallo, Bob came to the decision that MSAA might be the right organization for him to join. Bob explains, “Once Tom described the mission of MSAA and told me how the programs and dedicated staff change lives, I thought this could be the one for me. I have been very blessed in my life, and I believe that when you are given a lot, you should give back.”

After attending his first Board meeting in June 2007, Bob knew he had made the right choice. He was greatly impressed by the accomplishments of the staff at MSAA. “The high quality of work that is produced by such a small staff is amazing. Numerous awards have been received for MSAA’s publications as well as its new educational video,” says Bob. “Everyone I have met at MSAA is extremely passionate about his or her job and it shows.”

Bob was also inspired by the numerous ways MSAA impacts so many people in so



many different ways. “When I received my first packet of information from MSAA, I was surprised by all of the different programs and services offered,” states Bob. “There are many different ways that MSAA touches the lives of people affected by MS, and I like that.”

During his tenure on the Board, Bob would like to see MSAA continue to grow and roll out new programs, such as the life-coaching program presently under consideration. “Many times you can get great medical advice and treatments,” Bob points out, “but the human touch is missing – the person who puts his or her arm around your shoulder and says, ‘You’re not alone. Let’s put some plans in place for feeling your best and reaching your goals.’ For individuals who are newly diagnosed, that is the emotional support they need. MSAA can be there to help.”

Bob resides in Westchester County, New York with his wife Karen and three teenage daughters. Professionally, Bob owns a home-healthcare company and is a registered nurse (RN).

— Amanda Bednar

When Children Have MS

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Diagnosis and Research

Multiple sclerosis (MS) has long been identified as a neurological disorder affecting young adults. For many years, when young children or teens would show signs of MS, their family doctor or neurologist would explain that children “don’t get MS.” They were thought to be too young, and were assumed to have another condition that mimics MS.

Even in recent years, with the knowledge that children could develop MS, this was never an easy diagnosis to make. Many doctors continued to steer away from a diagnosis that would be difficult to confirm, was a chronic and potentially disabling condition, and until the 1990s, had no effective treatments.

Jayne Ness, MD, PhD, is the director of the Center for Pediatric-Onset Demyelinating Disease at the Children’s Hospital of Alabama University in Birmingham. Dr. Ness explains, “Ten to twenty years ago, there was reluctance amongst neurologists to diagnose children with MS and ‘label’ them with a life-long disease without a treatment. However, MS in childhood and adolescence is now being diagnosed more frequently, due in part to an increased awareness that children can get MS and there are available disease-modifying therapies. Thanks to advanced neuroimaging techniques and the publication of diagnostic criteria, the diagnosis of MS in childhood has become more straightforward, but extra

When Children Have MS

caution is still needed when diagnosing pediatric MS, particularly in young children.”

Diagnosis in children is still extremely involved. A recent report listed more than 40 of the more commonly known diseases that may initially behave similarly to early MS. Many variables come into play when a neurologist is faced with the task of diagnosing MS in adults, but the task of diagnosing MS in children can be even more daunting.

A common disorder that can initially be difficult to distinguish from MS is acute disseminated encephalomyelitis (ADEM). This is found more often in children than adults, and is frequently linked to a recent vaccination or viral illness. As many as 27 percent of patients initially diagnosed with ADEM are later diagnosed with MS.

Over time, MRI data and clinical symptoms can differentiate the two disorders. A correct diagnosis, however, will allow for early treatment of a clinically isolated syndrome (CIS), which is the first MS-like episode experienced by a patient, and typically leads to a diagnosis of MS.

Neuromyelitis optica (NMO) is another condition that may be difficult to distinguish from MS, involving recurrent demyelination of the central nervous system. Found in both adults and children, NMO affects the optic nerves and spinal cord, causing symptoms that include visual loss and weakness.

Daniel Kantor, MD, is an assistant professor and director of the Comprehensive MS Center, Department of Neurology, at the University of Florida & Shands Jacksonville. According to Dr. Kantor, “There are many other conditions which may be more likely than

MS in kids, so it is important not to jump to conclusions, and to seek advice from your doctor, if pediatric MS is a possibility. Parents and doctors are getting better at recognizing kids who may be having difficulties, and the availability of MRIs makes diagnosing kids with MS much easier than it used to be.”

Dr. Ness continues, “With a first-time demyelinating event in childhood, we try to carefully characterize the event. Similar to adults, CIS in childhood can include one or more symptoms, such as optic neuritis (ON), transverse myelitis (TM, resulting in weakness or numbness in half of the body, or bowel and bladder problems), or brainstem syndrome with difficulty moving the eyes, problems swallowing, facial numbness, or weakness.

“In CIS, there should be no alternation in mental status. However, children often experience their first episode of demyelination as ADEM. This often presents as persistent lethargy, irritability, or even coma, along with one or more neurologic abnormalities.

“The MRI in ADEM frequently shows large, patchy areas of abnormal white matter, while an MRI in children with CIS (who often go on to be diagnosed with MS) has multiple small scattered abnormalities in the white matter. An MRI doesn’t always distinguish ADEM from CIS, but a repeat MRI several months later will show improvement with ADEM, while there is no change in CIS or even worsening. If there are more MRI lesions following an episode of CIS that are consistent with McDonald diagnostic criteria, we will recommend starting disease-modifying therapy. However, in children who have

ADEM as their first episode, we are much more careful about making the diagnosis of MS, as ADEM patients can experience additional episodes of demyelination that may not progress to MS.”

A confounding factor to understanding MS in children has been the lack of consistent studies and terminology in the area of pediatric MS around the world. In response to this issue, the National Multiple Sclerosis Society (NMSS) formed the International Pediatric MS Study Group, which initially met in 2004 and 2005. The study group’s goals are to review published studies, improve diagnosis and care, along with promoting international collaborative research in pediatric MS.

The NMSS has also named six Pediatric MS Centers of Excellence. These are: the Center for Pediatric-Onset Demyelinating Disease at the Children’s Hospital of Alabama, University of Alabama at Birmingham; the Pediatric MS Center of the Jacobs Neurological Institute, State University of New York at Buffalo; the Mayo Clinic, Rochester, Minnesota; the National Pediatric MS Center at Stony Brook University Hospital, in Long Island, New York; the Partners Pediatric MS Center at the Massachusetts General Hospital for Children in Boston; and the University of California, San Francisco Regional Pediatric MS Center.

According to the NMSS, “The centers have committed to sharing critical resources and collecting standardized data so that each family at every center will get the same access and information. Center directors will meet in person two-to-four times annually to discuss advancements and share best practices.”

Maria Milazzo, MS, CPNP, is a nurse practitioner for the National Pediatric MS Center at the Stony Brook University Hospital & Medical Center in Long Island, New York. As one of the six Pediatric MS Centers of Excellence, Ms. Milazzo notes that many children are referred in for evaluation. “Some come in with other disorders or diseases, such as ADEM, recurrent optic neuritis (ON), or leukodystrophies. A number of kids have NMO. Knowing the right diagnosis is important, since the treatments are different for MS than for other conditions.”

She continues, “We see local children, from Long Island, New York City, and the tri-state area, as well as kids from across the country and around the world. Children from as far away as Japan, Indonesia, and Central America have come to us for evaluation. After they return to their country, we continue to consult with their local physicians and family members so they may continue with their treatment.”

Facts and Figures

Up to five percent of individuals with MS are believed to have experienced their first symptoms by the age of 15. In the United States, as many as 10,000 children and teens have MS. These figures present a number of challenges, in that little or no research is available for MS in these age groups, and most doctors have little or no experience caring for children with MS.

While estimates vary, pediatric MS and adult MS appear to have some differences. Some general findings about these differences are listed on the following page.

When Children Have MS

- A larger percentage of children with MS begin with the relapsing-remitting form of MS (RRMS), with estimates ranging from 90 to 98 percent (versus 80 percent of adults).
- Few children have primary-progressive MS (PPMS), although some very young children can have an aggressive form of MS, which may cause permanent and severe psychomotor deficits.
- Children with MS will typically have a second relapse sooner than adults, but their symptoms are more transitory and remit sooner, with symptoms lasting approximately four weeks versus six to eight.
- MS in children tends to progress more slowly, with more time to reach a certain level of disability, as measured by the Kurtzke Expanded Disability Status Scale (EDSS).
- MS in children takes several more years to convert to secondary-progressive MS (SPMS) than for adults, although given that children are diagnosed at an earlier age, the median age of conversion to SPMS is also at an earlier age than adults.
- A higher percentage of girls may develop pediatric MS than boys, with varying ratios as high as three or four to one.
- In published descriptions of pediatric MS populations worldwide, totaling more than 1,000 children with MS, the average age of onset was between eight and 14 years.
- While adult MS is primarily diagnosed in Caucasians, a higher-than-expected percentage of other ethnic populations, notably Latin Americans, appear to have an increased incidence of pediatric MS.
- MRI findings are less understood in pediatric MS; children have fewer lesions than adults; lesions in children do not show up as well following gadolinium injection (a dye given prior to the scan).

Dr. Ness' center is also a Pediatric MS Center of Excellence. She explains, "We see patients with acquired pediatric onset demyelinating disease ranging from infancy to 18 years of age. We may follow these patients until they are 21 years of age or out of college, unless they are ready to transition to adult care before then."

Dr. Kantor's center sees both children and adults. According to Dr. Kantor, "Five percent of all MS patients are under the age of 18 years. The youngest patient we have diagnosed at our center was six years old, but usually pediatric MS is teenage MS."

Ms. Milazzo adds, "About half of the children we see have been diagnosed with MS. The youngest children we have evaluated for MS have been two four-year-olds. The one was diagnosed with MS within a few months at age five; the other was diagnosed with MS about two years later, at age six. The good news is that MS in children this young is very rare. Typically, pediatric MS affects children 12 to 13 and up; the older the children, the higher percentage of those diagnosed with MS."

“Regarding ethnic background, we may see more variation. At our center, we have a higher incidence than expected of children with MS who are Hispanic; another center reports seeing more African-Americans than expected. Kids are presenting earlier, and they are not necessarily Caucasians. These statistics are being looked at by researchers.”

Similar to adults with MS, the risk for pediatric MS is thought to be largely influenced by a combination of environmental, genetic, and viral factors. Sunlight and vitamin D may play a role in the development of pediatric MS, and antibodies to the Epstein-Barr virus (EBV) are significantly higher in children with MS versus matched controls. Researchers do not know if this suggests a causative factor, or if children with MS have an increased propensity for viral reactivation.



Treatments

Correctly diagnosing MS in children is important for the early initiation of disease-modifying therapies (DMT), the identification and management of symptoms, as well as attention to disease impact that may be affecting quality of life. The fact that early initiation of DMT in adults has beneficial effects on disease activity, combined with the assumption that these drugs may work similarly in children, adds to the urgency of diagnosing MS

as soon as possible in young individuals.

Since studies with pediatric MS are extremely limited, much emphasis is placed on continual monitoring of safety, side effects, and efficacy issues. Children are different from adults in a number of ways, including how their bodies and immune systems respond to medications. How children absorb medications, their distribution of fat, the amount of available tissue for subcutaneous

injections, and the functioning of their liver and kidneys, are among the many challenges of treating pediatric MS.

Additionally, physicians need to be watchful for any impact that a medication may be having on overall body growth and organs that are still developing. With pediatric MS, inflammation and demyelination are occurring in areas of the brain and spinal cord

at a time when the body is still furnishing the protective myelin to insulate the nerves. These are also vital years in a child's academic development.

Treating Relapses

No rigorous studies have been conducted with pediatric MS and the treatment of relapses. As mentioned earlier, disease flare-ups in children with MS tend to resolve more quickly than in adults and their symptoms tend to be more transitory.

When Children Have MS

In adults, mild exacerbations may go untreated – reserving the use of steroids for more severe flare-ups in the future. When relapses need to be treated in children with MS, the short-term use of corticosteroids at established doses appears to be well tolerated. Long-term use can affect growth and cause other serious side effects. Plasma exchange and IV immunoglobulins (IVIg) are two possible alternatives to corticosteroids.

Disease-Modifying Therapies

With very limited research data available on the treatment of children with MS, treating physicians must rely on the published results of small, uncontrolled, and sometimes retrospective studies; personal experience; and assumptions from treatments with adults. None of the DMTs have been approved by the Food and Drug Administration for use in children, so neurologists must prescribe these “off label” to their pediatric MS patients.

This raises the question of dose amounts in individuals who have not reached full adult size. With the differences in weight and body surface, trials have yet to be conducted to determine the ideal dosages for children. Optimum dosing means that it is not only the most effective dose, but that it is also one which can be safely tolerated. Other questions concern the long-term safety issues for the patient. Trials have not yet been conducted to see if any of the DMTs affect growth, puberty, or the immature immune system of a child.

At the moment, physicians may derive some useful information from the results of a few small studies for safety and tolerability

with the interferons (Avonex[®], Betaseron[®], and Rebif[®]) as well as glatiramer acetate (Copaxone[®]) in children with RRMS. In general, no unexpected adverse events occurred, and side effects appear to be similar to those experienced by adults.

With the interferons, liver function is of concern, particularly in children under the age of 10, and must be monitored regularly. Other side effects from the interferons include flu-like symptoms and injection-site reactions; depression has also been reported. To minimize side effects, interferons are given at smaller amounts and slowly build to a full dose.

Copaxone does not affect liver function and does not tend to cause the flu-like symptoms observed with the interferons. The most commonly reported adverse events are injection-site pain and a transient systemic reaction, also occurring in adults. Copaxone may be given at full dose from the start; dose escalation is not needed.

The authors of some of these published studies have reported a reduction in relapse rate for children taking a DMT. While this is encouraging, these observations, however, are compared to a patient’s baseline and not a matched placebo control. Efficacy will need to be established through future, well designed, placebo-controlled trials.

“It may seem depressing to think of kids having MS,” notes Dr. Kantor, “but I think that they have opportunities available to them which were not around just a few years ago. Although it is considered off-label, I think that kids with MS should be treated with disease-modifying therapies, just like adults.”

Dr. Ness comments, “We have not

When Children Have MS

observed an adverse event in children on a DMT that differs from those experienced by adults, although children are at a higher risk for abnormalities in liver function tests. Children are typically started at a lower dose of DMT which is gradually increased over several weeks, and all but the smallest children end up on a full adult dose.

“A child’s level of maturity and lifestyle may mean that a parent or other adult is given primary responsibility for administering the medication. The timing of when the DMT is given may be adjusted so that children miss fewer days at school. For example, a parent may give a weekly injection on Friday evening, so that the child will recover from side effects by Monday morning.”

Ms. Milazzo explains, “We usually recommend treatment immediately for kids who meet the diagnostic criteria for MS. As with the treatment recommendations in adults, in the past, we would monitor children with CIS closely. Now we may recommend starting treatment, with the goal of increasing time to the occurrence of a second event. Treating right away is almost a relief for some people – not having to wait for treatment. Very rarely does a child or parent deny treatment.

“We tend to get a much better adherence to the treatments with children compared to adults. Parents care for their children and want to do the best for them; the children listen to their parents and follow their instruction.

“We give recommendations and explain options. We work closely with the families, and try to optimize treatment adherence. Kids feel that MS is not what they are; it’s just a piece. While we have very high rates of com-

pliance, we want to know if anyone is missing doses, in which case we might change medications, change the routine, or take a vacation from medication. We work with the kids to make decisions and to make adjustments at any time.

“We haven’t found that any of the DMTs work better than another. The decisions are up to each individual, and the drugs used may change over time. The small kids may prefer the once weekly injection, while the pre-teens, from about 10 to 13, may opt for the daily injection. This is because the daily injection does not require blood monitoring for liver function, and also, because it is taken every day, it’s something they can do after brushing their teeth before they go to bed.

“Once in college, we see some of the older kids switch to a weekly injection. They can take this when home on the weekends, and they don’t need to store or administer any medication while on campus. I know of one mother who meets her child in the college parking lot every Saturday to give the injection. It’s interesting to watch how different kids adapt their schedules to the medications.

“With the interferons, we start at a low dose and titrate very slowly to a higher dose. We give Tylenol® or Advil® before and after each dose to reduce side effects. We continue to monitor the situation monthly, and then every three-to-six months. We have tricks for dealing with injection-site reactions, and most of the kids like the auto-injectors. It’s all individualized.”

With regards to the auto-injectors, Dr. Kantor sees a special young boy. “I have a six-year-old patient who presses the button on

his own auto-injector while it is held by his parents. When I first showed the auto-injector to him, he was excited because his auto-injector was ‘cooler’ than his dad’s (who has diabetes). I encouraged him to decorate it and make it ‘his own.’ This has helped a lot in keeping him on the medication and keeping him running around.”

Symptom Management

The symptoms experienced by children with MS often parallel those experienced by adults with MS. While no trial data is available for symptom management in pediatric MS, physicians can use treatment guidelines from other conditions that affect children and share certain symptoms. For example, spasticity in pediatric MS is treated similarly to children with severe spastic cerebral palsy.

Common symptoms experienced by children with MS include fatigue, spasticity, tremor and ataxia (loss of muscular coordination), paroxysmal symptoms (sudden recurrence of symptoms, or a spasm or seizure), bladder and bowel issues (although these symptoms are more common in adults with MS), visual changes, and cognitive impairment. With children, symptoms can be transient and resolve more quickly than in adults.

Ms. Milazzo points out, “Fatigue is a huge and life-changing symptom for the kids. They need to go to school, have friends, and have a life. It really causes difficulty and impacts their quality of life. We work on planning their school days, which might include putting ‘heavy’ classes in the morning. Examples of work-saving strategies (which must be arranged by the school) include doing fewer

math problems, doing less writing, using a PC, and having a scribe take notes. Many things can be done. Medications are also available to help with fatigue.

“Cognitive problems are very common as well. School modifications can help. Being 15 and having cognitive issues is frightening. They sometimes need to transition career choices and modify their plans for college. We let the kids know that they have a good future with great potential, but they need to be realistic in their goals.”

Dr. Ness explains that symptoms can vary among age groups. “Preteens may experience cognitive problems, and as a result, academic issues can be more severe because of early-disease onset. Emotionally, they can become more dependent on parents and have difficulty transitioning to normal independence in adolescence.”

She continues, “With teens, we see visual changes, difficulty with mobility, fatigue, sleep disturbances, and muscle weakness as common physical symptoms. Seizures fortunately are rare. Cognitive symptoms can include attention difficulties, short-term memory loss, and problems with processing information. Emotionally, we see depression, general anxiety, injection anxiety, and withdrawal from others. In terms of social/economic concerns, teens with MS are more difficult to insure, they have limited career paths available, and their future can be unpredictable.”

The Impact of MS on Children and Teens

The psychosocial effects of MS can impact many aspects of a young person’s life.

When Children Have MS

School, family, friends, activities, and quality of life can all be greatly affected. Healthcare professionals, parents, and teachers (among other educational specialists) can all play a role in helping a child and family adjust to the symptoms and implications of a chronic illness.

When children or teens have MS, they typically feel different and socially isolated, as though they don't "fit in." Unlike some other, better known disorders (such as asthma or juvenile diabetes), not many children are diagnosed with MS. Parents and children feel alone without others to identify with and provide support. Given that pediatric MS is a relatively rare condition, family members may feel frustrated over a lack of information available and a lack of understanding from others who are not familiar with MS.

Children with MS must cope with a number of issues, such as:

- **Ongoing doctor appointments**, which may include various types of therapies, in addition to periodic exams and tests
- **Ongoing treatment**, including injections at home (from once per week to once per day), as well as any symptom-management drugs needed, and side effects from these treatments
- **Missed school** as a result of not feeling well or having a relapse
- **Specific symptoms**, which can limit the child's ability to participate in school and activities, affect his or her performance, and can be embarrassing or a source of teasing from peers

Many symptoms can negatively impact a child or teen's performance and behavior at school. Cognitive and/or visual deficits can increase the difficulty of class work, taking tests, and completing other schoolwork. Gait and movement issues can limit the amount and speed of walking necessary to go from one classroom to another; these issues can also prevent a child from participating in a sport or activity that he or she previously enjoyed. Bladder or bowel problems can require several embarrassing trips to the lavatory. Severe fatigue can prevent a child with MS from going to school full time, or socializing with friends after school. Some of these symptoms may be misinterpreted by teachers as ways to get out of doing work.

Mood and behavioral problems are also a part of the equation. So much can weigh on a young person's mind when he or she has MS. The unpredictability of the disease along with the potential for disability is always in the back of one's mind. This not only impacts the present, but also the plans one has for college and career, creating worries over insurance, healthcare, family planning, and long-term financial security. Children, as well as family members, may feel anxious and depressed about their situation and their future. Symptoms of depression can include crying spells, withdrawal from others, and even self-injury or suicide. Seeking psychological counseling, and if needed, anti-depressive or other medications, is vital to good mental and emotional health, and for some, can be life-saving.

Similar to young people with other chronic conditions, such as diabetes or

epilepsy for example, adjusting to a chronic illness can be a very difficult process. The fact that a young person is diagnosed with a chronic illness is simply not fair, and the individual can feel angry and frustrated. Emotions can show in different ways, and in addition to tensions at home, some children may become uncooperative and even disruptive in class. Other examples of poor behavior can include cutting classes, incomplete assignments, and becoming physically aggressive toward other children. Some children and teens may involve themselves in risk-taking behavior, possibly running away, experimenting with drugs and alcohol, becoming sexually permissive, and even getting into trouble with the law.

To minimize and ideally avoid these types of troubling behaviors, health-care specialists use a team approach. Professionals, such as neuropsychologists, physical and occupational therapists, social workers, and other specialists, can work together to make sure that the disease, symptoms, and side effects, as well as mental and emotional health, are all being proactively addressed. The team also involves the parents and family members, along with teachers and staff at the child's school, to provide important information about MS and to put problem-solving strategies into place.



Studies show that families can cope better if members can communicate openly with one another. A positive family environment with caring support is important, as is support from friends and healthcare professionals. Family members should acknowledge the disease, but at the same time, try to keep things as normal as possible, acting in ways that demonstrates this to others.

Cognitive changes can be particularly concerning and require specialized evaluation and treatment plans. Estimates range from 30 percent to as high as 60 or 70 percent for the number of adults with MS affected by neuropsychological deficits. Common issues include problems with memory, visual-spatial functioning, processing speed, and executive functioning (problem solving, planning, etc.).

Children also experience cognitive problems, and a small study identified potential deficits in the areas of general cognition, language,

visual-motor integration, as well as verbal and visual memory. Cognitive problems can occur in MS without any physical symptoms. While they can affect school performance, studies show that a child experiencing cognitive deficits can still have test grades within normal expectations for that age group, so specialized testing with a neuropsychologist or similar professional is needed to identify

When Children Have MS

areas of difficulty. Listening to instruction, organizing assignments, and idea generation, are examples of problem areas that may affect schoolwork.

A number of strategies at school can help address some MS symptoms. For cognitive problems, cognitive intervention can be done with a specialist to develop areas of strength – which in turn will help improve memory and compensate for any deficits. Sitting closer to the front of the class can assist with listening and following instructions. Increased time for testing can help as well.

Fatigue and weakness issues can be helped through fewer assignments, reduced distances to walk, and fewer classes during times of greater fatigue (maybe in the afternoon). Visual evaluation and tracking strategies can help with visual problems, and some students may have a scribe to take notes. An occupational therapist is able to prescribe and fit adaptive equipment to minimize the effects of certain physical symptoms, which may affect writing, walking, etc.

Teens with MS often experience fear about the future and taking treatments. While most individuals feel an initial shock over the diagnosis, this can frequently turn into determination. The following strategies and activities may be helpful to teens who are coping with a chronic illness.

- **Stay active** and continue with other activities, including hobbies, sports, music, walking, and exercise.
- **Stay socially active**; join a group, go out with friends or on dates.

- Some find **prayer and meditation** helpful.
- Look for **support from family and friends**; **share feelings**; talk openly to those close to you.
- **Consider other support systems**, such as support groups, chat rooms, and pen pals; connect with other teens with MS or those with another chronic condition.
- **Keep a positive attitude** and a sense of humor; don't feel sorry for yourself; remember that everyone has his or her own set of problems and issues that are different.
- **Find choices to exercise free will**; you can't control having MS or taking treatments, but you can choose certain activities, such as entertainment, clothes, decorating your bedroom, etc.
- If feeling depressed or anxious, **talk with a family member** and get help from a health-care professional; therapy and/or medications can greatly improve how you feel and your outlook for the future.

Dealing with the normal stresses of being a teenager, such as dating, peer pressure, self image, body shape and complexion, school, and parents, is challenging for anyone that age. Adding the stress of a chronic illness can affect one's formation of identity, feeling as if he or she is flawed, sick, or doesn't fit in with others. Teens with MS should work to move MS to the side, understanding that it is something they must deal with, but it does

not define who they are. Instead, take care of the MS, but focus on other activities, including friends, family, school, and special interests, such as cars, animals, sports, and music.

Teens need to understand that some friends may not be able to handle the burden of their MS, but most will not find it to be a burden – and are happy to give their support. If symptoms become severe or if home-schooled... family, friends, and the teen with MS, need to make extra efforts to stay involved with outside social activities – to avoid feeling alone.

“We’ve found that several of our teens with MS want to do everything they can to not set themselves apart from their peers,” notes Dr. Ness. “To remain ‘normal,’ some don’t tell others they have MS, they don’t accept school accommodations recommended by our staff (so that other teens will not see they are getting special treatment), and they may not tell their parents about symptoms they are experiencing, in order to participate in school and social activities. Teens with MS may experience isolation and ‘being the only one’ more so than adults, because the disease is very rare in people their age.”

She continues, “A multi-disciplinary team cares for the pediatric demyelinating disease patients in our center. All patients see a pediatric and adult neurologist, a physical therapist, occupational therapist, neuropsychologist, child psychiatrist, and school psychologist. Depending on the needs that these specialists find, referrals to other specialists and further outside therapy or counseling will be recommended. This could include referral to urology, neuro-ophthalmology,

additional physical therapy, occupational therapy, rehabilitation, and psychiatric therapy.

“We also recommend that all of our patients complete a neuropsychological evaluation as part of the baseline testing with the neuropsychologist. All of our MS patients undergo repeat neuropsychological evaluation every two years for on-going evaluation, follow-up, and recommendations. In addition, our school psychologist will assist families with implementation of accommodations or modifications at school as necessary.”

Ms. Milazzo agrees, “I always encourage ongoing psychological care with a psychologist or social worker – some type of psychological help – for both the parents and the child. Like anyone else, things can be going well, and then you have periods of crisis, where things get unadjusted.

“We also talk about alcohol and drugs. We tell them if they already have symptoms from MS – whether a limp, balance problems, etc. – taking alcohol or drugs may make things worse. They need to make wise lifestyle decisions.”

Dr. Kantor lends more support to the need for ongoing psychological care. “We are trying to raise the awareness among pediatricians and pediatric neurologists, that pediatric MS should be given extra consideration. Life for adults with MS can be rough, but imagine being at school and being teased that you look pregnant because you gained weight on IV steroids; or missing school because of a hospitalization and being teased that you must have been taken to jail. Kids can be mean and they tease other kids who look different or have any type of difficulty. That is

When Children Have MS

why it is very important to make sure that kids with MS have not only a medical and nursing support system, but psychological and social support as well.

“M*STAR is the Multiple Sclerosis Team Approach we use at our center, and it is especially important for our kids with MS to realize that they are in charge of their own care, their own destiny. We have found that our pediatric MS patients tend to mature faster than other kids because they are forced to realize the importance of taking care of their health to maximize their future.”

MS Camp and Shining Stars

Ms. Milazzo is thrilled with the success of her center’s summer camp. “I feel so lucky to be at a center where we’ve developed a camp for kids with MS.

“Each session goes for four-to-five days, and during that time, the kids stay in the retreat center. This is like a college dorm with a dining room... more of a ‘luxury camp,’ since we’re not in tents. The kids do a lot outside – sailing, kayaking, high ropes course, going to the beach (many are from areas that do not have a beach), and many other fun things. They learn to work together as a team, building a connection, being together, doing very physical types of activities. We also do activities involving music, movement, and performing arts therapy.

“Over the years, we’ve been adding to the program. At first, we wanted the kids to enjoy themselves and not think about their illness. As it turns out, the kids want to talk about their MS, including things like lifestyle choices, deciding how to grow up, what they’ll be, their feelings about MS, and being different in some ways while being the same in other ways.



“It’s incredible to listen to kids about their diagnosis. Often they are relieved that it was not a brain tumor; they thought things would be much worse; there’s almost a sigh of relief. Of course, there is also despair over having an unpredictable, chronic illness, that not a lot of kids have, and with treatments that have not yet been proven in children. They are even given a hard time; everyone says that ‘kids don’t get MS.’ They definitely feel isolated. This is why the

camp is so important. Both kids and parents meet other kids with MS and their parents; both groups realize they are not alone.

“The NMSS has a wonderful program for kids. It includes a quarterly phone program for parents, where they talk about things like school, fatigue, financial planning, and other important topics. They also have a networking program through email, for both kids and parents. This develops a virtual community of children with MS and their parents.

“At camp, some of the kids who have

been writing to each other finally get to meet in person. They already know each other – which is ‘really cool.’ New kids feel welcome as they join the others. Some of the kids know everybody, and they are the ‘celebrities.’ Kids don’t want to feel different; they want to be like everyone else. Being around so many other kids who also have MS and have the same challenges is just powerful.

“During the camp’s two sessions, kids come from all over the country and Canada. We are developing a new pilot program this winter. It is for the older kids as they transition into adulthood. We will be working on the next step; kids have a different perspective of MS than an adult – different needs, school, future family plans, etc.”

Ms. Milazzo continues, “Our kids are amazing. One of the camp kids had two full scholarships offered for soccer. She does a lot of public speaking, serving as a mentor to many.

“Another girl in Boston is working to

raise awareness at the high schools. In Pennsylvania, one of the children wrote a book for kids with MS, talking about symptoms and how friends can help.

“Every one of these kids is special. They are all really nice, and all really driven. They are ‘A’ students, athletic, healthy, well-rounded, doing great, and motivated.

“There are tons of people around who are ready to help; people who really care. I see an international outpouring of interest in research for pediatric MS. Things are going to continue to get better in a very short time, as we learn more about MS and develop new treatments.

“The important thing for people to realize is that kids with MS are just like everybody else. We all have individual issues – some of us wear glasses or some of us may have one leg shorter than the other – but these things are just one piece of who these kids are. When we can put everything in perspective... we’re good!” ♦

FOR MORE INFORMATION

For details about the camp (for ages 11-18), readers may visit www.pediatricmscenter.org. Readers may contact Maria Milazzo via email at mcmilazzo@notes.cc.sunysb.edu or phone at (631) 444-7802. In addition to camp information, Ms. Milazzo is happy to take calls with general questions about pediatric MS, or to discuss coming in for an evaluation.

To reach Dr. Daniel Kantor, readers may call (904) 244-3961 or email mstar.mspn@gmail.com. Readers may visit the MS center’s website at <http://jax.shands.org/hs/multiple-sclerosis>.

Dr. Jayne M. Ness may also be contacted for questions or pediatric MS evaluations.

Dr. Ness may be reached via email at jness@peds.uab.edu, or via phone at (205) 996-7633. Readers may visit www.uab.edu/cpodd for more information.

Readers may also speak with one of MSAA’s Helpline consultants at (800) 532-7667 for more information or for a full list of resources used for this article.

Ask the Doctor

By Dr. Jack Burks
Chief Medical Officer for MSAA



Dr. Jack Burks

Q: I am taking Avonex and a statin. Should I stop my statin because it may interfere with my Avonex?

A: The definitive answer is not known for certain, but I will give

you the data available at this time.

The good news is that interferons, including Avonex[®], Betaseron[®], and Rebif[®], have been proven effective in treating MS. In addition, a pilot study demonstrated that MRI lesions decreased after MS patients were given statins alone. However, statins are not yet approved by the Food and Drug Administration (FDA) for the treatment of MS. More definitive MS studies are underway with statins in MS patients.

The theory is: if two drugs are presumed effective in MS, why not combine them and get even better results? This hypothesis is so attractive, that some individuals with MS may want to combine drugs, even before FDA approval.

The troubling news is that two recent studies reported at the American Academy of Neurology meeting (2007) have cast some doubt on combining interferons with statins. First, a basic research study, which used immune cells from MS patients, found that statins interfered with a crucial biochemical step in interferon action. A second small study showed an increase in MRI lesions when a statin was added to an interferon. These small clinical trials

raise the question of potential statin interference with interferon effectiveness.

The encouraging news is that at the latest international MS conference (ECTRIMS), held in Prague, Czech Republic, data were presented that indicated statins may not be linked to reduced effectiveness of interferons in MS patients.

For more information, readers (as well as medical professionals) may visit the American Academy of Neurology's website at www.aan.com, and search within the site for "statins and interferons." The ECTRIMS data is in the journal *Multiple Sclerosis* in Vol. 13, Supp. 2, 2007.

What to do? I recommend that you discuss the results of these scientific papers with your doctor.

The following are my current recommendations to my patients. These may change as more information becomes available.

Until clarification, I do not recommend adding statins to interferons with the desire to receive additional MS benefits. For patients currently taking an interferon plus a statin for their MS, I recommend reviewing the status of your MS with your neurologist to determine if interference (or benefit) may be occurring, (Copaxone[®] is not affected by this statin action).

If a statin is being taken to help lower your cholesterol or for another (non-MS) medical purpose, I recommend that you review all options with both your neurologist and other treating physician. If indicated, other cholesterol-lowering treatments may be considered if statin interference of interferon therapy is detected.

Again, I recommend talking with your doctors about these controversial and conflicting data.

Q: I have MS and am experiencing attacks of severely itchy skin. Doctors have referred to this as “neuro itch.” What on earth can be done about these attacks? I take Neurontin, but not a high dose (to avoid weight gain).

A: As you realize, this can be a difficult problem. If your skin is also dry, I recommend a moisturizer cream. Cool baths may help. If a medication is indicated, Neurontin® (as you are already taking) may be helpful. As always, your doctor can give you the best advice.

If you have issues with Neurontin, Lyrica®, a new but related drug, is an alternative to Neurontin. Benadryl®, which is an allergy medication, is another possible aid. Each of these medications has side effects to discuss with your doctor. A dermatologist may have other suggestions.

Q: I have relapsing-remitting MS and I would like to ask two questions:

First, since diagnosed about five years ago, I have been prone to startling. I even jumped at the sight of my own shadow. Coworkers must ring a bell on my cubicle wall because I jump right off my chair at the slightest hello. It's not guilty conscience, I assure you. Does this sound like a byproduct of MS?

Second, heat really affects me. Even an hour in mid-70-degree weather makes my hands feel especially swollen and prickly.

What is the neurological reason for heat exacerbations?

A: (1) MS and startling: This is a very unusual MS symptom. Your approach (ringing a bell) is creative. If the problem becomes disabling, Neurontin, Lyrica, or tricyclic anti-depressants such as Elavil® might be worth discussing with your doctor. Does anyone else who reads this column experience this symptom?

(2) MS and heat: Nerve impulses deliver messages from the brain to different parts of the body. These impulses travel along nerves (also known as “axons”), which act like electrical wires. Increased heat can reduce the nervous system’s ability to transmit nerve impulses (messages) in MS due to reduced insulation (myelin) of the nerves (wires). A treatment to increase nerve conduction (Fampridine-SR®) is not yet FDA approved, but may be helpful if the current clinical trial proves successful.

Q: What is the difference between symptoms of primary-progressive MS and those of hereditary spastic paraparesis? The neurologists I have seen disagree with my diagnosis and these are the two runners up.

I am 54 years old, my MRIs and spinal-fluid analysis have been negative, and I have had optic neuritis with continuing deficits and nystagmus. Exams show balance problems, hyper-reflexes, babinski sign, and clonus. I have been using a cane since 2002 and forearm crutches for the past year. I also have hearing loss, cognitive problems, extreme fatigue, weakness

and pain in my legs (and sometimes arms), vertigo, and bladder/bowel problems.

I know that many of the symptoms for these two diagnoses are the same. Could you tell me how they differ?

A: Hereditary spastic paraplegia (HSP) has similar symptoms to primary-progressive MS (PPMS). Both can cause progressive weakness in the legs during adulthood. Complicated HSP is a rare form (10 percent of HSP patients), which can be associated with additional problems such as optic neuritis (decreased vision), dementia, speech problems, incoordination, peripheral neuropathy, epilepsy, and other neurological symptoms. More information is available through the Spastic Paraplegia Foundation (www.sp-foundation.org) in Falls Church, Virginia.

A major distinction is that HSP has a genetic link. Some genes have already been identified. The mechanism of how HSP genes cause damage is under intense investigation. If in doubt, I recommend an evaluation at a major MS center with experience in both diseases.

To find an MS center near you, please visit the Consortium of MS Centers' website at www.mscares.org. Readers without internet access may call MSAA's Helpline at (800) 532-7667 for assistance. ♦

To Submit Questions to Ask the Doctor...

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

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

Readers may also send in questions via email to aborkowski@msassociation.org. Please be sure to write "Ask the Doctor" in the subject line.

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



¿Habla Usted Español?

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

(800) 532-7667, extensión 108

Research News

News from the European Committee on Treatment and Research in MS (ECTRIMS)

Held in Prague, Czech Republic, October 2007

by Jack Burks, MD

Additional New MS Treatments May Prove to be Helpful

Several trials with potential new treatments were presented at the conference. For example, a small study found a trend toward effectiveness in treating relapsing forms of MS (relapsing-remitting MS, [RRMS], and secondary-progressive MS [SPMS] with relapses) with a common antidepressant, Prozac®. This drug appears to have an effect on modulating the immune system, which may help MS. More studies, however, are needed before a final determination is possible.

The Future Looks Good

One example of a promising new potential MS treatment is the drug, Campath®. Three years of data on Campath (a potent monoclonal antibody treatment being tested in MS) were presented at the prestigious Charcot Lecture by Professor Alistair Compston from England. He presented data that showed continued benefit at three years in patients treated with Campath, even though patients had received no new treatment for two years. Most were only treated at baseline and at one year. The data after three years from treatment onset continued to show substantial benefit over Rebif® (please note that Rebif also showed an effective response). Remarkably, with Campath, disability was actually less at three years compared to the beginning

of the trial. In other words, people with MS on Campath improved with treatment. No new, toxic effects were detected in the last year of observation. However, in the first two years, thyroid problems, low platelets, and infections were detected. Toxicity will be carefully screened in the next trial, which is starting soon. Campath is not approved by the United States' Food and Drug Administration (FDA) for the treatment of MS. Other monoclonal antibody treatments, including Rituxan® and Zenapax®, are also showing encouraging efficacy results.

The New Rebif Formulation Data are being Evaluated by the FDA

The new, reformulated Rebif was associated with less injection-site reactions and pain, compared to data from a previous Rebif clinical trial. In addition, 30 percent fewer patients developed neutralizing antibodies with the new formulation. However, flu-like side effects occurred in 71 percent of patients, but 50 percent reported these side effects to be mild. The relapse rate per year (Annualized Relapse Rate) decreased from an average of 1.8 at the beginning of treatment to 0.7 after two years of treatment. A total of 53 percent of the treated patients were free of attacks during the two-year trial. The FDA has not yet approved the new formulation. Therefore, we await their decision.

Early Treatment Shows Reduction of Risk for MS Progression

Treating patients with Betaseron® after the initial attack of neurological damage (also referred to as a clinically isolated syndrome, or CIS), reduced the risk of disease progression at three years by 40 percent, compared to those who were treated after the second attack or at two years after the CIS. This was among the findings from the BENEFIT trial. Cognitive performance was also better in early-treatment patients. Neutralizing antibodies in treated patients were often transient and did not appear to have any negative effect on the clinical outcome, including disability progression. In another study of Betaseron, a short-term increase in disability appears to be related to long-term disability 16 years later. Therefore, the trend to treat MS patients as early as possible will likely increase, due to this demonstration of reduced disability with early treatment.

Class I Comparison Trials with Interferons and Copaxone

REGARD TRIAL: At ECTRIMS, a study comparing Rebif with Copaxone® found that no differences were noted in the primary clinical outcome, which was the time to first attack after beginning treatment. Furthermore, no differences were detected in relapse rates between the treatments. Some MRI outcomes favored Rebif. The best news for MS patients is that both treatments had very good results, which were even better than in previous trials. A low attack rate with both treatments may (or may not) have contributed to difficulty in detecting any

differences in the treatments. In any event, in this group of patients, we can be pleased that these two drugs worked very well.

BEYOND TRIAL: Following the ECTRIMS meeting, Bayer HealthCare Pharmaceuticals released a statement announcing that the BEYOND comparison trial showed that a double dose of Betaseron had no clinical benefit over the regular dose of Betaseron. These results indicate that patients taking Betaseron are on the optimal dose, which is good news for these patients. Additionally, Betaseron and Copaxone were shown to be equally and robustly effective in the BEYOND comparison trial. Betaseron patients had fewer injection-site reactions, and the regular dose of Betaseron had the lowest drop-out rate of the three treatment groups, indicating it was well tolerated.

MESSAGE FROM THE TWO COMPARISON STUDIES: We are fortunate to have the interferons and Copaxone as first-line treatment options for MS. The two studies show very robust results in those three drugs' abilities to reduce disease activity in those with relapsing forms of MS. These results show that the message of starting treatment early and staying on the treatment are helpful in treating relapsing forms of MS. New drugs may be available in the future, but these three current treatments have all shown remarkable benefit in these two head-to-head comparison trials.

To reduce the effects of MS, using disease-modifying therapies at the earliest signs of MS, combined with a healthy lifestyle and a good mental attitude, are reasonable to

continued on page 39

Program Notes

MSSAA Transforms Website with New Features, Functionality, and Enhanced Content

Visitors to msassociation.org may have noticed some changes in recent months, starting with the MSi Program, featuring a series of educational videos entitled, *A Closer Look*. The latest change to the MSAA website comes cosmetically, as a “face lift” has taken place. A new design scheme and layout add more functionality and features to help MSAA better serve the MS community. When visiting msassociation.org, you will find a website packed with MS information not just for the individual with MS, but for all who are affected by the disease, and for anyone interested in learning more.

“Our goal to help more people in more places is brought substantially closer to reality by this new website technology,” states MSAA President & Chief Executive Officer Doug Franklin. “We are very proud of our continued commitment to enrich the quality of people’s lives in every way possible.”

The enhancements made to msassociation.org help fulfill this goal by giving people the resources and tools they need to enrich their quality of life right at their finger tips. To follow are some highlights to the new website.

Become a Part of msassociation.org

One of the first changes visitors will see is the new **Login** and **Register Now** links on the red bar at the top of each page. By registering your name and email address online,



MSAA is able to communicate with you more effectively through web content, online surveys, and future e-newsletters – all tailored to your specific interests.

Once registered, you can receive personalized information about MSAA’s educational programs and events in your area as well as MSAA updates and medical news. Another added feature of joining msassociation.org is that online applications, surveys, event RSVPs, and donation forms will be “pre-populated” (filled in) with your contact information after registering for the first time and logging in whenever you visit the website. Your name, address, and other personal data are completely secure on msassociation.org, and no other website user may access this information in any way.

Programs and Services Online

All of MSAA’s signature programs and services are highlighted on msassociation.org in the **Programs and Services** section of the

website. Our new online capabilities allow visitors to review a particular MSAA program or service – such as the **Cooling Equipment Distribution Program**, **Lending Library**, and **MRI Institute** – download the application, print it, and then return it to MSAA via regular mail with the proper documentation (in some instances a doctor’s note is required).

Information for the Newly Diagnosed

A newly designed **About Multiple Sclerosis** section features such topics as, “What is MS,” “Types of MS,” and “Treatments of MS.” Visitors may also click on a **Newly Diagnosed** section, designed to provide answers and support to those who are new to the world of MS.

New Ways to Volunteer

Added web enhancements make volunteering easier, whether in your community, at your school or business, or from the comfort of your own home. All volunteer opportunities are broken down into age and interest groups on our new **Volunteer** section.

If you have a specific idea for a volunteer fundraising event, you can now click on **Fundraising Events** to fill out a form notifying MSAA about your idea and interest. Here you will also find links to MSAA’s **Resource Detectives Program**, where volunteers work from their home to identify local MS services for a national

database; and **Public Education Ambassadors**, MSAA’s public speaker program.

Other Ways to Give

A new section for donating to MSAA offers more ways to give than ever before. One of the most exciting new ways to give is through MSAA’s **Circle of Hope**, an online tribute web page created by you to honor a member of the MS community, or it may also be used as your own personal page. You may upload photos, share your story, and email friends and family, asking them to contribute. All funds generated will benefit MSAA’s programs and services.

For major donors, a new section is devoted to MSAA’s **President’s Circle**, where MSAA’s most loyal and generous donors are recognized. Information and instructions on **Planned Giving**, **Workplace Giving**, and **Corporation and Foundation Support** are also in this section. You can still make a general donation, honor donation, or memorial donation, however, our new online forms make the



MSAA Web Directory

You can navigate to any section on the website by going to MSAA's homepage and clicking on the various links at the top, left, and bottom of your screen. For direct access to key pages, please type the following addresses in your web browser as they appear:

MSAA's Homepage: www.msassociation.org

Programs and Services: www.msassociation.org/programs

About MS: www.msassociation.org/about_multiple_sclerosis/whatisms

Publications: www.msassociation.org/publications

Volunteer: support.msassociation.org/volunteer

Donate: support.msassociation.org/donate

Calendar: support.msassociation.org/calendar_of_events

Individuals without internet access may contact MSAA at (800) 532-7667 for more information about any of MSAA's programs and services, or to speak with a Helpline consultant.

process easier and more efficient... and as always, secure.

Support Groups, Activities, and Educational Events

MSAA's **Calendar of Activities and Events** lets you search any day of the year and can be seen in either "List View" (daily or monthly), or "Grid View" (similar to a typical calendar). When looking for a specific type of activity or event, you can filter the calendar by the following categories: **Community** (therapeutic classes, upcoming live chat sessions), **Public Education Events** (including patient, nurse, and physician events), **Self-Help Support Groups**, and **Volunteering** (special events organized by volunteers and other activities, including orientation teleconferences). Website visitors may access MSAA's Calendar by clicking on **Programs and Services**, then **Awareness Events and Therapeutic Classes**, found under **Branching Out** in the navigation bar on the left.

Publications

The publication section features *The Motivator*, MSAA's award-winning quarterly magazine, as well as booklets such as *Understanding and Treating Depression in Multiple Sclerosis*, *All About Multiple Sclerosis*, and MSAA's *Programs and Services Guide*; MSAA's two monographs, *Thinking about Complementary and Alternative Medicine* and *The Confusing World of Clinical Trials*; plus *Mommy's Story*, MSAA's award-winning children's book. All of these publications may be viewed online through your web browser or as a PDF file. MSAA publications may also be ordered online; MSAA will mail a copy of the publication anywhere in the United States.

MSAA welcomes you to log onto the new msassociation.org to personally experience all of the new features and information that is now at your finger tips. ♦

— Amanda Bednar and John Masino

THE PHILANTHROPY CIRCLE

MSAA gratefully thanks the following foundations and corporations for generosity and commitment to helping people affected by MS.

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Thoughts about Giving



Bruce Makous

Inspired to Give

After only ten months on the job, I must say I am amazed by the generosity of our supporters. I'm sure it stems from the good things people feel they can accomplish with their gifts.

Alyssa Lewanowicz of Holland, Pennsylvania, for example, is an eleven-year-old girl whose great grandmother passed away due to complications from MS. With the help of her mother and grandmother, Alyssa held a bake sale for MSAA in memory of her great grandmother. This lovely event initiated by a young girl raised more than \$1,000 to support MSAA's programs. We were pleased to be able to honor Alyssa at an event on September 28th at our national headquarters.

Another donor, Dr. Aida Chohayeb from Rockville, Maryland, is a retired dentist who understands the challenges that people living with MS face and sympathizes deeply with them. In order to help, she provides significant annual contributions for MSAA programs.

Also, we recently received a six-figure legacy commitment from a Washington State woman who is living with MS. She wants to provide funds through her estate that will support our equipment program. As a person who needs assistance herself in coping with the day-to-day challenges of moving safely

around her home, she knows the value of the equipment we give to people with MS. Her significant gift will help us provide walkers, grab bars, wheelchairs, cooling vests, and other equipment to a greater number of people in need.

These are just a few examples of individuals inspired by the idea of accomplishing good things through giving. These and all of our donors have one thing in common -- they care deeply about people living with MS, and want to help them. They also talk proudly about how good it makes them feel to do their part for people with MS.

MSAA is fortunate to have many thousands of such supporters nationwide who have these same feelings.

President's Circle Reception at MSAA's National Headquarters

MSAA was pleased to hold a special reception for its supporters at its headquarters in Cherry Hill, New Jersey. Attendees received tours of the building and witnessed first-hand many of the activities involved in MSAA's programs and services.

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

Holding Your Own Fundraising Event for MS

Many of our supporters inquire about putting together their own fundraising events and contributing the net proceeds to MSAA. This can be a rewarding way to honor someone you know who is living with MS or a loved one who may have passed away, while also helping people with MS.

MSAA will be glad to support you in your efforts. To learn more, go to support.msassociation.org/volunteer on the website and click on the

“Fundraising Events” box. Follow the other links to learn more about various types of events and to send us your event ideas.

For more information, please contact Malcolm Friend at (800) 532-7667, extension 117, or email mfriend@msassociation.org.



MSAA client Barbara Berkowitz and her husband Bernie are recognized as key supporters at the President's Circle reception in September.

Alyssa Lewanowicz (photo below) is an eleven-year-old girl from Holland, Pennsylvania, whose great grandmother passed away due to complications from MS. “I asked my mom if we could help other people with MS because my nana died of it,” said Alyssa at the MSAA President's Circle reception on September 28th. With Alyssa is her grandmother, Linda Somers, who helped Alyssa with the bake sale, along with Alyssa's mother Lynne Goldberg (not shown). Presenting Alyssa with a 2007 MSAA President's Award are Dorothea Pfohl of the Healthcare Advisory Council and Chairman of the Board Ross Maclean. “Now I know what pride feels like,” added Alyssa after receiving the award.



Year-End Charitable Planning

As this tax year ends, you should consider these two particularly interesting methods of supporting MSAA:

A gift annuity is an excellent way for donors to create a legacy fund with MSAA, while also receiving additional income. “I had been supporting MSAA through annual contributions, and decided I wanted to establish a legacy gift, too,” said Herbert Weisz of Deerfield Beach, Florida. In April, Herb and his wife created a gift annuity with MSAA and will receive income from this gift throughout their lifetime.

Until December 31st, donors may contribute funds directly from an IRA to a charity without declaring the gift as income. If you do not need the entire amount of your required minimum IRA withdrawal, this is an excellent way to use some of it as a gift to MSAA.

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

— Bruce Makous
Vice President of Development

MSAA Needs Volunteers!

VOLUNTEERING ASSIGNMENTS INCLUDE:

- **Fundraising:** Events such as bake sales, trivia nights, and charity dinner parties have all benefited MSAA. Will you organize something similar to benefit MSAA?
- **Resource Detectives:** Research and report on local resources that help individuals with MS.
- **Ambassador Support:** Facilitate speaking engagements to community groups and hospitals for our Ambassadors.

For more information about volunteering with MSAA, please contact MSAA's Director of National Volunteer Services Malcolm Friend:

Phone: (800) 532-7667, extension 8

Email: volunteering@msassociation.org

Web: support.msassociation.org/volunteer

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

RESOURCE DETECTIVES™ NEEDED

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

For more information, please contact Bonnie Yares at **(800) 532-7667, extension 132** or visit **support.msassociation.org/detectives2007**

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



Foot Lift Assist

For assistance walking due to the effects of MS, or physical injury. Lightweight and easy to wear, this dynamic aid will assist the wearer's walking. If you can stand and start to walk, the "Lift" will help you lift your leg (or legs) and use less effort to walk. For free information, please write:

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Symptom Awareness

Difficulties with Swallowing

Swallowing problems can be a common symptom of MS. Also known as “dysphagia,” swallowing dysfunction can greatly affect one’s quality of life. Anyone experiencing swallowing issues should contact his or her physician. Patients with swallowing problems are usually referred to a speech-language pathologist (SLP) for a swallowing evaluation.

Prior to developing swallowing problems, most people don’t realize the complexity involved with this function. Eating and swallowing are normally automatic and can be easily accomplished by the smallest of children. Yet it is an extremely involved process, requiring muscle tone, coordination, and signals from the nerves to instruct the parts of the mouth with how to handle different types of food.

The swallowing process begins with recognizing the food, detecting its texture and taste. When the food enters the mouth, oromotor control is needed to close the lips, holding in the food while breathing through the nose. Facial tone helps keep the food in place. Coordinated jaw and tongue motion is used to chew the food and reduce it to a consistency that will be comfortable and safe to swallow. Most foods are formed into a cohesive ball before it is moved quickly into the stomach. Along the way it must pass through the pharynx (back of the mouth) and the esophagus (tube that transports the food).

Meals are an important gathering time for the family. When a family member has

problems swallowing, meals can become very stressful for everyone involved. Choking can frequently occur, and this is both frightening and dangerous. Choking occurs when food gets into the airways and lungs, and the first priority is to clear the airways so the person may breathe. This also carries the risk of pneumonia and infection, as food particles can remain.

In addition to choking, symptoms of dysphasia can include coughing, congestion, throat clearing, and gurgling sounds, particularly during or after a meal. Someone with swallowing issues may have trouble getting foods to move down the throat, and he or she may have a weaker voice when dealing with these problems. Anxiety and fear can often result. Over time, if the individual is not able to take in adequate calories and nutrition, he or she may experience weight loss and related health problems.

Swallowing requires four stages, each using different sets of muscles. These stages are: oral preparatory (chewing, changing the consistency, forming a ball of food); oral stage (tongue pushing the food to the back of the mouth); pharyngeal stage (initiates the swallowing action as food or liquid is moved to the beginning of the throat); and esophageal stage (food travels down the esophagus to the stomach). For some individuals, the food may not move along the route smoothly. It may stick in the throat or travel too slowly. Others may have trouble preparing the food for swallowing,

or the swallowing reflex may not respond well.

Fortunately, help is available. By seeing an SLP, one's swallowing may be evaluated and specific trouble spots identified. An SLP will examine a patient's swallowing process using a videofluoroscopy. Using a dye, this procedure is similar to a moving X-ray, and different types of food are videotaped as it is chewed and swallowed. Once the specific problem areas have been identified, a plan may be designed to enable the patient to safely get the nutrition that he or she needs.

Management plans can include changing the texture of the food, sometimes adding a thickening agent, and other times moistening food for smoother movement. Warming or cooling the food may help with the swallowing reflex. Other strategies can include alternating between liquid and solid food to keep things moving; reducing the size of each bite; and having smaller meals more frequently through the day, if needed. An SLP can give instruction for changing the position of the head and chin, and can also assign exercises to make swallowing easier.

Meals should be a time of both social enjoyment and nutrition, while safety needs to be the top concern. Family members should be familiar the Heimlich Maneuver; for instructions, readers may visit www.heimlichinstitute.org. For a list of references or to speak with a Helpline consultant, please call MSA at (800) 532-7667. Anyone experiencing swallowing issues should contact his or her physician. ♦

— Susan Wells Courtney

continued from page 29

consider. Unfortunately, not every patient is able to take advantage of these treatments, perhaps due to type of MS, lack of response to treatments, or financial challenges. The search is intensifying to find treatments and help for all MS patients.

A Total of 17,000 MS Patients on Tysabri®

Tysabri has now been started in 17,000 MS patients (10,500 in the United States). No new cases of progressive multifocal leukoencephalopathy (PML) have been reported since the original report of three patients who developed PML, two of whom died. ♦

DUE TO THE CHRONIC, OFTEN DISABLING NATURE OF MS, APPROXIMATELY 20%-25% OF INDIVIDUALS WITH MS NEED LONG-TERM CARE AT SOME POINT DURING THE COURSE OF THEIR ILLNESS.*

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Health and Wellness

Tips for Preparing Food

When You or Someone You Know Has Chewing or Swallowing Problems

Written by Shelley Peterman Schwarz

You're Not Alone

In my late 20s, five years before I was diagnosed with MS, I had the mumps and was sicker than I had ever been before. The worst part was that I was unable to swallow anything, including water. This was scary, painful, and I've never forgotten the sensation of being unable to swallow.

Today, more than 40 million people in the United States have chewing, swallowing, or dry mouth disorders; some of them also have MS. Although I've never had severe swallowing problems again, I have had times when I've needed to choose foods that were "softer and easier to swallow." In addition, I've been dealing with severe dry mouth for more than 20 years as a result of the medication I take for depression.

Today, however, you can find ways to make chewing and swallowing easier. An important strategy is to adapt how we prepare our foods, and to do so in a way that they're not tasteless, shapeless, or similar to pureed baby food.

Please note that many of the items listed include ingredients such as milk, cream, yogurt, and cheese. Some individuals with MS limit their intake of dairy products, and those who do may need to adapt certain recipes to fit their individual dietary requirements.

Tasty and Nutritious Food Preparation

Except for a few rare exceptions, most people are able to enjoy and swallow foods with some texture. Be creative when thinking about food. With a little ingenuity, almost any regular meal can be transformed into a tasty and easy-to-swallow dish. To follow are some helpful ideas to enhance flavor and improve the nutritional value of the foods you eat.

Serve soft foods: Try mashed potatoes (sweet potatoes for more nutrients), yogurt, cream cheese, scrambled or poached eggs, creamy cereals, apple or berry sauces, gelatins, puddings, custards, milk shakes, ice cream, sherbet, sorbet, or gelato.

Cook and blend: Cook cereals such as Cream of Wheat®, Farina®, and oatmeal. To change the flavor, add spices such as cinnamon, or small pieces of apple or dried fruit when cooking. To enjoy sauced fruit, such as applesauce, mix with apricot puree, berries, or cinnamon for variety. Put harder-to-eat cooked meat and vegetables in a blender with broth or gravy; then stir them into soups and sauces. Foods with a skin left on – like peas, oranges, apples, and grapes – may be more difficult to swallow.

Cut or grind food: Use ground meats, finely diced vegetables, and fruits to add color, flavor, and nutrients to your diet.

General Tips to Aid Swallowing

- **Give yourself plenty of time** to eat a meal. Don't rush or push yourself to eat as fast as other people.
- If you **eat something very cold or sour**, like lemon or lime sorbet, before you begin to eat, this may help improve saliva production for people with dry mouth; it may also reduce any swelling and stimulate the muscles necessary for swallowing. Another strategy is to suck on a few crushed ice cubes about 20 minutes before mealtime.
- **Drink frequently** while eating.
- If possible, **sit in an upright position** with both feet on the floor while eating. This allows natural body functions and gravity to help you swallow. Staying upright for 30 minutes following a meal helps you to digest your food. Avoid reclining or lying down when eating.
- **Limit any noise** or distractions when you eat.
- **Lowering your chin** so it is pointed down as you chew and prepare to swallow, helps to keep food from getting into your throat before you are ready.
- When the time comes to swallow, **lifting your chin** and moving your head forward may be helpful. Gently touching or massaging the throat if necessary may also aid swallowing.
- **Take smaller, bite-sized portions**, chew deliberately and completely, before swallowing and taking another bite. If helpful, you can use a teaspoon to remind yourself to eat smaller quantities.
- **Avoid foods that could pose a choking hazard**, such as peanuts, seeds, popcorn, cookies, uncooked carrots and apples, etc.

Turn any variety of fruits into refreshing shakes and smoothies; just blend with ice, juice, milk, or ice cream. Add soy or whey protein and ground flaxseed for more nutritional value.

Enjoy soups of blended meats and vegetables. Squash soup is wonderful. Even broccoli, cauliflower, and corn can be finely chopped or blended into soups or gravies.

Another idea is to make easy-to-eat casseroles with rice, risotto, or cut spaghetti. Be creative with sauces; the same rice and meat dish can become Mexican with tomatoes, beans, and chili; Asian with pineapple and green peppers; or Italian with tomato sauce or a creamy risotto style sauce with finely chopped vegetables like asparagus.

Maximize nutrients and fiber with whole foods: Use juices with pulp when possible. Spice up a basic cake or muffin recipe with shredded carrots, crushed pineapple, or small pieces of dried fruit. Berries or dried fruit, simmered in fruit juice, becomes syrup when poured over pancakes. These may also be used as a flavor enhancer for cereal, fish, or vegetables.

Increase protein by adding eggs, cheese, or milk to recipes: Chop cooked eggs finely and add to sauces and casseroles. Prepare egg-rich beverages such as eggnog, or desserts like angel food cake, which can be broken into small pieces and served with a cream or fruit sauce – it will almost melt in your mouth!

You may also add grated cheese to casseroles, vegetables, and sauces. Cooking hot cereal in milk or soy milk instead of water will increase protein as well. To vary the flavor, you can try chocolate milk in hot cereal.

Blend yogurt or cottage cheese with a few herbs to make a great dip or a sauce for cooked foods. If you are allergic to milk products, try adding non-dairy (soy or rice) protein powder, available from health food stores, to gravies, sauces, hot cereals, soups, smoothies, and more.

Use sauces and liquids to aid swallowing: Adding condiments such as ketchup, mustard, marinades, oil, and vinegar, not only increases the flavor, but also adds “slipperiness” to foods. Mix meat, vegetables, and rice or bite-sized pasta, with gravy or sauce to allow foods to slide down more easily as well.

You may also put liquids into dry or sticky foods. For example, many of us already use milk in cereal, but you may also try something like yogurt with fruit compote on pancakes. By adding liquids, the consistency becomes looser and this may help with swallowing.

Review of the *I-Can't-Chew Cookbook*

A unique resource for flavorful soft-diet recipes is the *I-Can't-Chew Cookbook*, by J. Randy Wilson (Hunter House Publishing). This is not just a liquid or blender recipe book; it contains more than 200 mouth-watering, soft foods. It includes casseroles, quiches, soups, and ethnic recipes. Readers will also find main dishes using crab,

salmon, chicken, and other meats, plus fresh vegetables that are chopped, not pureed.

Don't forget the dessert! This cookbook features 32 cakes, pies, puddings, mousses, custards, and iced desserts to delight your palate. This is real food for real people – even when entertaining. Many vegetarian recipes, or recipes that may be easily adapted for a vegetarian, have been included as well.

The book also contains a section on good nutrition, written by a dietician. Each recipe has a complete nutritional analysis, so you can monitor fat content, sodium, fiber, protein, and calories. Two sample recipes from the book appear on the following page.

The *I-Can't-Chew Cookbook* may be borrowed through MSAAs Lending Library (MSAA book # 222). Please see page 48 for ordering information. The book may also be purchased; please see the following details.

This article includes excerpts and information from the *I-Can't-Chew Cookbook: Delicious Soft-Diet Recipes for People with Chewing, Swallowing and Dry-Mouth Disorders*, copyright 2003 by J. Randy Wilson. To order online, readers may visit www.hunterhouse.com, or contact Hunter House at (800) 266-5592.

Readers may also be interested in the following titles:

1. *MS and Your Feelings* by Allison Shadday
2. *Living Beyond MS: A Women's Guide* by Judith Lynn Nichols
3. *Women Living with Multiple Sclerosis* by Judith Lynn Nichols
4. *The Anti-Inflammation Diet and Recipe Book* by Jessica K. Black, ND

TURKEY AND BROCCOLI TETRAZZINI

*¾ cup reduced-fat mayonnaise
⅓ cup all-purpose flour
2 tablespoons minced onion
1 teaspoon garlic salt
2 ¼ cups fat-free milk
1 cup (4 ounces) shredded reduced-fat
Swiss cheese
8 ounces thin spaghetti, cooked, drained,
and finely chopped
2 cups finely chopped, cooked turkey breast
1 package (10 ounces) frozen broccoli,
thawed, drained, and finely chopped
¼ cup chopped pimiento
1 can (10 ¾ ounces) reduced-sodium,
reduced-fat cream of mushroom soup
(condensed)*

Blend mayonnaise, flour, minced onion, and garlic salt in a large saucepan. Add milk and cook over medium heat until thick, stirring constantly. Add cheese, stirring over low heat until melted. Stir in remaining ingredients and spoon into a lightly greased, 9 x 13-inch baking dish. Bake uncovered, at 350 degrees until hot and bubbly (about 30 minutes). Makes six servings.

Per Serving: 446.7 calories; 29.5 g protein; 48.2 g carbohydrate; 2.8 g fiber; 14.4 g total fat (3.4 g saturated fat and 57.5 mg cholesterol); 723.9 mg sodium

BAKED CHILIES RELLENOS

*1 pound twice-ground lean beef
½ cup finely chopped onion
1 teaspoon salt (used as two, half-teaspoons)
½ teaspoon black pepper (used as two,
quarter-teaspoons)
2 cans (4 ounces each) hot or mild green
chilies, finely chopped (each can used
separately)
1 ½ cups (6 ounces) shredded, reduced-fat
cheddar cheese
4 eggs, beaten
1 ½ cups fat-free milk
¼ cup all-purpose flour
4 dashes hot pepper sauce*

Cook ground beef and onion in a large skillet until beef is browned, crumbling beef finely with a fork; drain, and stir in half of the salt and pepper. Spoon one can of green chilies into a 10 x 6-inch baking dish; sprinkle with cheese and top with meat mixture. Spoon second can of green chilies over the meat mixture.

Beat eggs, milk, flour, hot pepper sauce, and remaining salt and pepper in bowl until smooth. Pour over mixture in baking dish. Bake, uncovered, at 350 degrees, until topping is set and sharp knife inserted comes out clean, about 45 minutes. Let stand five minutes. Cut into squares and serve. Makes six servings.

Per Serving: 338.3 calories; 29.1 g protein; 10.4 g carbohydrate; 1.7 g fiber; 19.8 g total fat (8.7 saturated fat and 203.8 mg cholesterol); 850.5 mg sodium

General Tips for Dry Mouth

Dry mouth (also known as “xerostomia”), is a condition that is caused by a lack of saliva, brought on by medical conditions and/or medications. Dry mouth can make chewing, eating, swallowing, and even talking difficult. It also increases the risk for tooth decay because saliva flushes the mouth of germs and food particles. Consult your physician and dentist if you have persistent dry mouth. Here are some general tips to help if you have dry mouth:

- **Brush your teeth** four times a day with fluoride toothpaste. Since you may not have enough saliva to flush out food particles that produce bacteria, the fluoride can assist in keeping the bacteria in check.
- **Floss daily.**
- **Rinse your mouth** several times a day.
- **Avoid mouthwashes with alcohol.**
- **Ask your pharmacist** about over-the-counter products for dry mouth.
- **Make your own solution** using ½ teaspoon salt and ½ teaspoon baking soda in 1 cup of warm water.
- **Drink sips of water** throughout the day.
- **Chew sugarless gum** or suck on sugarless candies to help increase saliva flow.
- **Use a cool mist humidifier**, especially at night.
- **Keep a glass of water** on the nightstand in case you wake up during the night with a dry mouth.

To view a full list of Hunter House publications, a full catalog may be downloaded from their website at www.hunterhouse.com.

PLEASE NOTE: Anyone experiencing chewing difficulties, swallowing problems, or dry mouth, should consult a medical professional before making any changes to his or her diet or routine. The information in this column is meant to assist those who would benefit from a softer or less-dry diet. This may not be helpful for all individuals with MS or for all those with swallowing problems.

Readers should consult their physician about appropriate food consistencies for their individual needs and follow any direc-

tions closely. Readers are also advised to check with their doctor about specific dietary recommendations and/or restrictions regarding the types of food they include in their recipes.

If an individual has swallowing problems, this carries a higher risk of choking. Family members and care partners should become familiar with the Heimlich Maneuver. Detailed instruction may be found on the Heimlich Institute’s website at www.heimlichinstitute.org.

For more information on swallowing dysfunction, please see the “Symptom Awareness” column in this issue, beginning on page 38. ♦

Stories to Inspire

A Time for Everything — Including Rest

Written by Barbara P. Marchant

Do you know that January is often a difficult month for people with MS? This is a time when disease flare-ups occur more frequently. Do you know why? A combination of factors is probably involved, but one of them could surely be the stress we go through during the holiday season.

We are all “super busy” around the holidays. We find ourselves visiting relatives and attending parties, not to mention the gift wrapping and cards to do. There are a million things that HAVE to be done and we just overdo. I would guess that we are all guilty of doing too much. It just goes with the season, right?

But those of us who have MS know there is usually a price to pay for overdoing things, and sometimes that price is rather high. Being stubborn like I am, I had to learn this the hard way.

I started overdoing things long before the holidays, and continued on until my MS stopped me in my tracks. My husband told me I worked very hard for this setback; I “earned it” so to speak, so I truly wasn’t surprised. But

it came at a most inopportune time.

Let me explain. I was not only busy with the usual holiday activities, but I was also busy pursuing my dream of writing a book. This has always been a lifetime desire

for me. In all honesty, I never thought I could really write a book, but then a good friend of mine gave me the push I needed. She told me to stop saying “I don’t know how,” and just do it! So I took her advice and began writing. As the pages began adding up, so did my self confidence.

Getting back to overdoing things during the holidays, I was right in the process of working with a publisher to finish my book, when my MS raised its ugly head. Yes, this was an inop-

portune time!

I was forced to go on intravenous steroids. On top of that, I woke up one morning almost completely blind. One eye could only see shadows and the other eye was extremely blurry. My hands shook and my fingers could not stay on the keyboard. Even my legs would not cooperate, so I was back in the wheelchair. (Thank God for adaptive equipment!)

While this was the setback I “earned,” I didn’t let it stop me. I called my publisher on the phone and explained that I could no



Getting into the Holiday Spirit! Friends Lita Higginbotham, Bonnie Brothers, and the author, Barbara Marchant, celebrate the holiday season.

longer read email, so after that I got the instructions verbally over the phone. I used a magnifying glass to make corrections, re-submitted the necessary files, and the book came out just fine.

So the lesson is: if I can write a book and get it published with so many problems – from loss of sight and mobility, to suffering from “brain fog” and the jitters – then perhaps my story will help to inspire you to pursue your dreams as well. With MS, we may need to make adjustments... to what we want to do and how we plan to accomplish it, but the important thing is that we continue to work toward our goals. In the words of my friend... just do it!

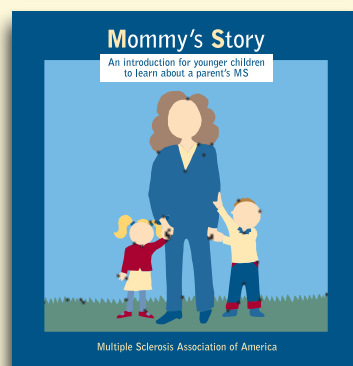
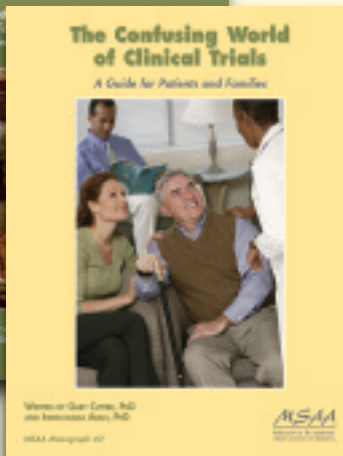
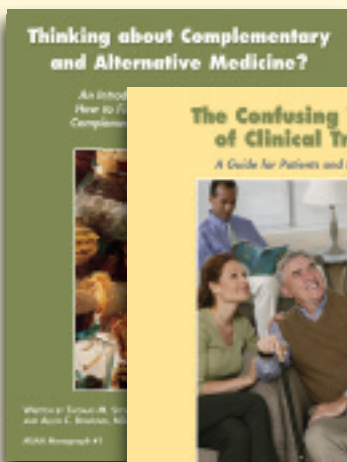
Can you guess what my New Year’s resolution is for the year? I’ve decided that

I WILL listen to my husband and set my goals at a more leisurely pace... I’ll refuse to do and be everything to all people at the same time... and I must learn to say “no,” dropping some of the activities I enjoy, making sure I get enough rest.

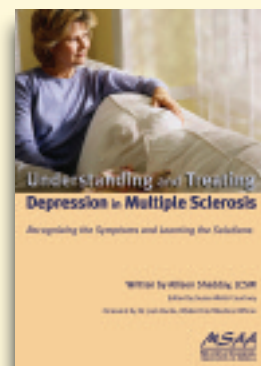
I wish all of you well in the New Year and I hope you continue to pursue your dreams and goals. Just be sure to plan your activities carefully and give yourself plenty of time for rest! ♦

Barbara’s book is called *Dance On* and can be ordered online at www.amazon.com and www.borders.com, ISBN: 1-4196-5168-4. It is also available from MSAA’s Lending Library (please see page 48 for ordering information).

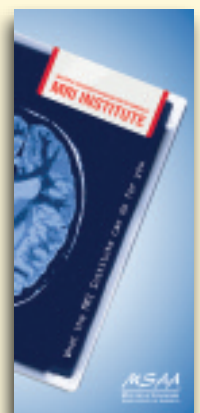
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Mommy's Story



Understanding and Treating Depression in Multiple Sclerosis



What the MRI Institute Can Do for You

Thinking about Complementary and Alternative Medicine?

The Confusing World of Clinical Trials

Request a copy of these or any other MSAA publications by contacting MSAA at **(800) 532-7667, extension 107**. You may also visit MSAA’s website at **www.msassociation.org**, select “Publications,” and complete the order form. In addition, MSAA publications can be viewed and downloaded from **www.msassociation.org**.

Five Suggestions to Help Keep the Holidays Happy

With the holidays right around the corner, readers may benefit from the following helpful tips from Executive Career Coach Rosalind Joffe, MEd. The main idea is to plan ahead, set priorities, and pace yourself... and you may want to think about these strategies before the holiday season even starts.

Think about the Holiday Season in Advance

For some, the holiday season starts on October 31st with Halloween... and doesn't end until the last Valentine's Day card is handed out on February 14th. "That is a long period of time to be on the go, especially for someone who has MS," states Joffe. "The key is to identify which activities are important to you and focus on fully participating in those."

Think about What You Want

Living with MS or any type of chronic illness forces one to be more aware of what his or her limitations are. Sometimes goals and desires will need to be adapted, especially around the holiday season. Joffe explains, "Set goals and desires for yourself; do you want to attend a lot of parties, or spend quiet time at home with your family? By thinking of your goals and what you want to get out of the holidays, the season will be more enjoyable."

What are the External Factors You are Facing This Holiday Season?

Whether you are a parent, spouse, friend, or even a care partner, you will need to think about the expectations that loved ones are going to ask of you during the holiday season.

People need to realize what you can and can not do. "There is a lot of pressure around the holiday season to attend a friend or coworker's party," says Joffe. "It is up to you to prepare yourself for these expectations; to attend every event, or spend extra time with family." Joffe continues, "You have to be selective in what you do, you can't be all things to all people."

Be Kind to Yourself

Getting caught up in the spirit of the holiday season is very easy, which tempts people to do too much. Joffe emphasizes that one key factor is to watch for signs of exhaustion or stress. "Listen to your body, pay attention to how you are feeling," explains Joffe. "Plan and prioritize what you have to do, so you do not overextend yourself. The better you feel, the better you will be able to meet your expectations."

Take Time for Yourself

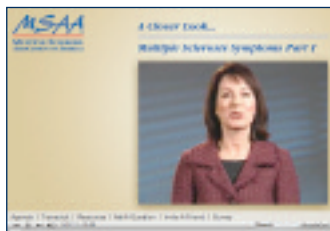
You need to have some time set aside each month to "recharge" during this hectic time. "Individuals with MS need to take time for themselves," states Joffe. "If possible, try to come up with one day each month to dedicate to you, even if it's only for part of the day. You need to be able to re-group."

Rosalind Joffe is an executive career coach and president of cicoach.com, a firm that gives people with chronic illness the tools they need to succeed.

— Amanda Bednar

Spread the Word

MSAA's new technology program, MSi (Multiple Sclerosis information) offers educational videos on topics such as ef-



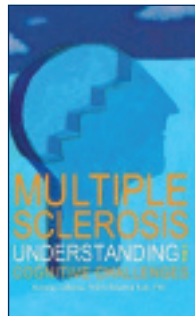
fective MS symptom management, medications and side effects, and the future of MS research, among other topics. These videos may be viewed on MSAA's new website www.msassociation.org. The latest video is highlighted on the home page of the website and other videos may be accessed by clicking on "A Closer Look... MS Education Videos" in the programs and services section of the website. These videos are also available on DVD and can be ordered through MSAA's Lending Library. Please see ordering information in the yellow box below.



100 Questions & Answers about Multiple Sclerosis

Written by
William A. Sheremata, MD
Published by Jones and Bartlett
Publishers, Inc.
MSAA Book #52

This resource, as the title suggests, is written in a question and answer format. The first topic highlighted is "the basics" of multiple sclerosis and defines the various terms associated with MS. The book continues with topics such as symptoms, causes, and treatments. Questions from MS patients were submitted and addressed throughout this book.



Multiple Sclerosis – Understanding the Cognitive Challenges

Written by Nicholas LaRocca, PhD,
and Rosalind Kalb, PhD
Published by Demos Medical
Publishing

MSAA Book #281

Individuals with MS who are experiencing cognitive challenges will find an extensive amount of helpful information in this book. The authors define cognition, outline research on this topic, and discuss the emotional and social impact of cognitive changes. In addition, the book offers treatment options and strategies to manage cognitive issues.

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