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July 2020 Newsletter

Offering support, care, and hope...right here at home!

All Support Group Meetings and Newsletter folding are Cancelled for the Summer!

We are continuing to work behind the scenes to make sure the telephone calls, emails, and office needs are being handled. It is important to us that we provide up-to-date information on our website and Facebook page for you. Please stay home, stay safe, and stay well!

*The Mission of the Tri-State Multiple Sclerosis Association
is to enhance the quality of life for individuals living with multiple sclerosis and their
families in Southern Indiana, Southern Illinois, and Western Kentucky.*

***Please send your email address to officemanager@tristatems.org to receive newsletters and the latest program updates.**

Tips for Dealing with Summer Heat

Susan Reynolds, RN, MSCN

July is here! It is time for the worst of the summer heat to start rolling in. I am never ready for it. I choose to do most everything indoors in the air conditioning in the summer time. I find I can tolerate heat a little better if I stay out of the direct sunlight. If I go outside, I stay in the shade or do outdoor activities when the sun goes down.

Hot weather or becoming overheated can temporarily worsen MS symptoms. The temporary worsening is due to an increase in body temperature and will usually disappear when the body temp returns to normal. Getting the body temperature back to normal can be as easy as taking a cool shower, a cool bath, or jumping in the pool.

Heat intolerance to people with MS is felt as increased symptoms, such as: decreased cognitive function, numbness in the extremities, fatigue, blurred vision (known as Uthoff's sign), tremor, or weakness.

What causes heat intolerance? People with MS have plaques or places where demyelination has taken place. Demyelination slows down the transmission of the nerve impulses. An increase in body temp of $\frac{1}{4}$ to $\frac{1}{2}$ of a degree can worsen MS symptoms because heat further impairs the ability of the demyelinated nerve to conduct electrical impulses.

Heat produces only a temporary worsening of MS symptoms. It does not cause actual tissue damage. As stated before, the symptoms can be rapidly reversed when the body is cooled. This list is intended to help people with MS deal with heat in the summer. The list is in no way comprehensive, but it does contain things that have worked for me and things I want to try.

- 1. Air conditioning:** If an air conditioner is needed for your home because of MS-related heat intolerance, the cost of this equipment may be tax-deductible, if your doctor has written a prescription for it. Air conditioning is the number one way to stay cool on a hot summer day.
- 2. Cooling products:** There are a large variety of personal cooling products available, including different types of vests, neck bands and bandanas. The Multiple Sclerosis Association of America has a Cooling Distribution Program to get those products to people with MS that need them but cannot afford them. I have a vest that was made by my mother-in-law! Patterns and instructions are available online.
- 3. Avoid direct sunlight:** Wear loose clothing in the summer, and stay out of the sun. Choose a shady spot if you must be outdoors. Take along your own battery-operated misting fan.
- 4. Don't blow-dry your hair:** Take time to let your hair dry naturally. If you must blow dry your hair, use the coolest setting possible.
- 5. Order a sandwich:** Instead of soup or anything hot, eat only cool foods. Try not to eat too much cool food that is high in sugar content, such as popsicles and ice cream. This can contribute to fatigue by causing a sudden drop in blood sugar.
- 6. Drink cold beverages:** Drinking cold beverages can really help lower your body temperature. Keep a couple of plastic bottles filled with water in your freezer to take along in the car and drink as they melt.
- 7. Pre-cool:** Cool down with a cold shower before activities. Getting chilly before heading outside seems to buy a lot of time before you feel the heat. You will have to experiment with how cool of a shower you can endure and how much it helps you, but you might be surprised at the increase in your tolerance for the heat.
- 8. Go for a swim:** Pools with water that is 85 degrees or cooler are ideal places for exercising or just relaxing outside.
- 9. Use a microwave:** Don't use the oven in the summer. If you use an oven, don't open the door to check on the food. The blast of hot air is enough to trigger symptoms.
- 10. Take an aspirin:** Some Neurologists suggest taking one regular strength aspirin before going out in the heat, to keep your core body temperature down.
- 11. Get "The Handicapped Tag":** If you are ambulatory, it may not have occurred to you to get a disabled parking placard to avoid crossing blazing hot parking lots in the summer. Some of you might be resistant to getting one. A "Tag" can be a lifesaver during the hot summer months. Get one, just in case you need it. Save your energy for what you want to do than burning up all your energy getting from the car to your destination.
- 12. Hydrate!** Drink plenty of cold water! This may be the most important way to stay cool.

For information and to apply for FREE a cooling vest go to:

msaa.com MSAA has free cooling vests for anyone with MS who completes an application and who fits the income requirements. Or call: 800-532-7667.

Consortium of Multiple Sclerosis Center's Annual Meeting 2020

Susan Reynolds RN, MSCN

Some of you will be surprised to learn that I was able to attend the CMSC 2020 Annual meeting that took place at the end of May. The meeting was held entirely online. I was able to attend all of the seminars from the comfort of my home. The leadership at the CMSC did a great job putting together the annual meeting in spite of the cancellation of the live meeting that was supposed to take place in Orlando. The presentations covered many areas of research in multiple sclerosis. Topics included: progressive MS, vaccines, depression, rehabilitation strategies, diagnosing MS, nutrition, psychiatric treatment, cannabis, a stem cell update, emerging therapies, genetics, and cognition. Presentations also included women with MS, aging, and women's reproductive lifespan from adolescence to childbearing and menopause.

The good news is that there is going to be an explosion of new drugs to treat MS. Some of the more exciting categories of drugs will be from the neuroprotection and neuro repair categories. Benjamin Greenburg MD, MPH, Professor and the Cain Denius Scholar in Mobility Disorders, Department of Neurology and Neurotherapeutics, at UT Southwestern Medical Center in Dallas, listed twelve neuroprotective or neuro repair agents currently in phase I or II clinical trials. He talked about two new drugs to treat MS with novel mechanisms of action that have not been used before with disease modifying therapies. He also mentioned nutritional and vitamin based agents being studied. The High Dose Biotin Trial proved to be a disappointment with a negative result. He also spoke about an ongoing trial for Alpha Lipoic Acid (ALA) that may hold promise for reducing brain atrophy in MS.

Dr. Patricia Coyle spoke about diagnosing primary progressive MS. An authority on many aspects of MS, including progressive disease, Dr. Coyle is Vice Chair and Professor of Neurology at Stony Brook University and Director of the Stony Brook MS Comprehensive Care Center in New York. She stressed that primary progressive MS is difficult to diagnose. She recommends that people with primary progressive MS be treated with approved disease modifying therapy. She also counseled on the importance of wellness factors to promote brain health, cognitive reserve, central nervous system reserve and improve aging. She said it should be a major counseling priority for MS practitioners to counsel all PPMS patients with this information, along with newly diagnosed MS patients.

Many people are wondering about vaccines and MS, especially since we are experiencing a pandemic right now. Carolyn Buhse PhD, NP-C, MSCN, Clinical Professor at Stony Brook University School of Nursing gave a presentation on vaccines and MS. She said to follow the vaccine advice of the CDC and the American Academy of Neurology, which has guidelines for people with MS. The American Academy of Neurology advises that people with MS should not get live attenuated vaccines (nasal spray), mumps, measles, rubella (live attenuated), and yellow fever. These should be avoided, as it has been shown to increase relapse risk for people with MS. MS patients should be screened for Hepatitis B and screened and treated for any other infections prior to starting a DMT. MS patients should be vaccinated four to six weeks prior to starting most DMT's and refer to treatment specific recommendations in product labeling. MS patients should not be vaccinated during an acute relapse.

Susan Morrow MD, MS, Associate Professor of Neurology and Director of the Multiple Sclerosis Clinic at the University of Western Ontario in London, presented a discussion on cognition and MS. She said that this problem is under addressed and under recognized. The most common cognitive impairments for people with MS are in learning, memory, information processing speed, and selective attention. She said that at least one third of patients are showing cognitive impairment in at least one domain at the time of diagnosis. Five years after diagnosis, fifty percent of patients show cognitive impairment. She emphasized that MS clinicians should be using a twenty-minute screening tool in their offices for cognitive impairment. It is important to establish a baseline so that any cognitive decline will be caught in the screening. Cognitive rehabilitation has been shown to help in treating MS patients who have impairments. Mood disorders, such as depression and anxiety must be treated as they have a worsening effect on cognitive decline in people with MS.

If you have an area of interest from the list of topics that were discussed at the meeting, please let Debbie or myself know. I can share any information in the newsletter or personally with anyone who has a question. Please stay safe! Wear a mask in public buildings, and wash your hands often. It has now been proven that wearing a mask is one of the most important things we can do to stop the spread of coronavirus.

Upcoming Webinars

There are many online Webinars for MS patients through the month of July through Biogen. Go to msfocusradio.org to hear your choice of educational programs on demand. These programs are available whenever you have the time.

***The Importance of a Proven Treatment* Date: July 6, 2020 Time: 5:45 PM CST**

Join others in the MS community for a live, educational webinar about a proven treatment with more than 11 years of experience treating relapsing MS. You'll even get a chance to participate in a Q&A session. To register for this event, call 1-866-955-9999.

***Learn More About MS in African-Americans* Date: July 7, 2020 Time: 5:45 PM CST**

“Take Charge and Learn More About MS in African Americans” will take place virtually with Dr. Kalina Sanders. Please preregister for this important program by calling 1-866-955-9999.

***Understanding Your MS* Date: July 9, 2020 Time: 5:45 PM CST**

Living with multiple sclerosis can leave you with a lot of questions. Presented by MS expert Dr. Mary Alissa Willis. To register for this webinar, call 1-866-955-9999.

***Let's Talk Relapsing MS: What it means to eat well* Date July 14, Time:10:45AM CST**

Eating well is an important and valuable skill, with or without relapsing MS. While “healthy” means something different for everyone, we can all agree that it starts with a balanced diet and making the right choices for you. To register for this webinar, call 1-866-955-9999.

***Symptom Management: Sensory Components* July 14, 2020 Time: 7:00pm - 8:15 PM CST**

Speakers: Randall T Schapiro, MD, FAAN / Kathy SanMartino, PT, NCS, MSCS, CLT, ATP
Join us for a discussion on how MS can affect vision and sensation. Learn how these sensory changes impact mobility and balance. We'll also explore treatment / management strategies. To register for this webinar, call 1-866-955-9999 or cando-ms.org