

Multiple Sclerosis Society of Portland, Oregon, Inc.

MULTA SPES

MUCH HOPE

Improving the Quality of Life for Those with MS since 1949

Volume XV Issue IV

Summer 2014

Heat and MS by Rebecca Spain, MD, MSPH

The what, why, how, and tips to beat the summer heat



Summer to most in the Pacific Northwest is a welcome end to the rainy winter months. But to many people with Multiple Sclerosis (MS), summer brings with it a feared companion - hot weather. To many (but not all) people with MS, hot weather causes a worsening of fatigue, lethargy, and even a return of prior MS symptoms not seen for many years such as blurry vision or a foot drop. Why does the heat make me so tired? Is the heat making my MS worse? Should I avoid the heat? These

are questions I discuss often at MS clinic visits during the summer. I will answer these questions and give you some tips to beat the summer heat.

operates best when neither too hot, nor too cold, but at the “just right” temperature. Demyelination from MS makes nerve cells even more sensitive to the effects of temperature, causing the electrical nerve impulse to be blocked at the site of an MS lesion. When enough impulses are unable to make it from the brain to the destination - a muscle for an eye movement or lifting the toe - double vision or a foot drop occurs.

Continued on Page 5

In 1889, Wilhelm Uhthoff, a German ophthalmologist, described a temporary worsening of vision in a patient with prior optic neuritis (inflammation of the optic nerve usually due to MS) after exercising. The term “Uhthoff’s Phenomenon” is applied to reappearance of any MS symptom due to an increase in body temperature. The raised body temperature can be from hot weather, exercise, fever, sauna or hot tub. Interestingly, researchers have shown that the body temperature in people with relapsing MS is actually higher (although still in the normal range), than people without MS even without exercising or other such explanation. Why does the raised body temperature make old MS problems reappear? The nervous system is like Goldilocks - it

New Column

The MSSP has started a new section entitled “In My Words,” This is an opportunity for clients and caregivers to share their stories about living with MS. Mike Stofiel has written a heartwarming and inspirational story about relearning the guitar (see page 3). So if you’d like to submit a future article send a printed or typed letter via email to candycchayes@msoregon.org or mail to: 2901 SE 122 Ave., Portland, Oregon 97236. Please keep your article to no more than three paragraphs and a picture would be terrific. MSSP has the right to refuse any submission. Please see page 2 for submission deadlines.

Inside This Issue

Heat and MS	1
New Column	1
Director’s Notes	2
In My Words	3
Project Helping Hands	4
Summer Comfort	4
Heat and MS <i>continued</i>	5
Marijuana Symposium	5
Ways to Support MSSP	6
Mark These Dates	7
Parks and Recreation	7

Multa Spes is the quarterly newsletter of the MSSP, distributed to MSers, consumers, families, professionals and friends.

Comments and articles are welcome. Publication depends on space available and is subject to editing. Submission deadlines are: 7/15/2014 and 10/15/2014.

Please send submissions to Candyce Hayes, Executive Director, at: candcycehayes@msoregon.org or mail: MSSP, 2901 SE 122nd Avenue, Portland, OR 97236.

If you are not currently receiving Multa Spes, we would be happy to add you to our mailing list. Direct all subscription requests or address changes to candcycehayes@msoregon.org or call 503.297.9544.

Advertising in Multa Spes does not represent an endorsement of any product, service or individual by MSSP, its staff or Board of Directors.

Each advertiser is solely responsible for the accuracy of their advertisement and for any claims, loss, damages, and liability that may result.



Director's Notes by Candyce Hayes



As you will see on page 5 MSSP held a Medical Marijuana Symposium on April 6, 2014. You may ask yourself why is the MSSP getting involved in medical marijuana education in the first place? It's a good question.

I've learned a lot about medical marijuana in the past few months. I'm going to give you a very rudimentary explanation and encourage you to visit our website at www.msoregon.org for more details or give us a call at 503.297.9544 so we can refer you to industry representatives.

As we learn more about the science behind cannabis we can start learning about how the specific components THC, CBD, CBN and Terpenoids work to help mitigate specific symptoms that affect sufferers of chronic disease and disorders.

The MSSP's position is to educate the public about the medical benefits of marijuana and then to let individuals choose what treatment(s) they prefer. marijuana is simply one alternative - another tool to fight the symptoms of MS - by no means does the MSSP endorse this or any other treatment for MS. We advocate education.

On another subject, we're delighted to announce MSSP was awarded a \$5,000 grant from Nike (via the Oregon Community Fund) to expand our air conditioner (Summer Comfort) program statewide. Thank you Nike!

If you'd like to keep current about MSSP events and activities in between our quarterly newsletters text mspdx to 50555 or sign up for our e-blasts by calling the office.

SMS subscription service. Up to 4msg/mo. Msg&Data Rates May Apply. **Text STOP to 50555 to STOP.** Full terms: mGive.com/E Privacy Policy: mGive.org/P

Let me leave you with some words to ponder: Three things in life that, once gone, never come back: Time, Words & Opportunity, Three things in life that can destroy a person: Anger, Pride & Unforgiveness, Three things you should never lose: Hope, Peace & Honesty, Three things in life that are most valuable: Love, Family & Friends & Kindness, Three things in life that are never certain: Fortune, Success & Dreams, Three things that make a person: Commitment, Sincerity & Hard work. Author unknown

In My Words — by Michael Stofiel

A few weeks back my friend, Art, gave me an electric guitar to mess around with - thank you Art! It has been several years since I tried to play. I played the guitar for about 33 years before getting hit with MS. I was eventually diagnosed with PPMS. Two-thirds of my body went numb back in '96, my hands and forearms along



with my legs got hit the worst. I still kept trying to play somewhat through the late '90s but I got so frustrated with not being able to play like I used to because of the severe numbness and tightness that I gave it up. There were more than a couple of times I wanted to smash my guitar against a wall!

That being said I've mostly had a "keep on keeping on, don't let things get you down" attitude throughout life and that brings me to now. I picked up the guitar that Art so graciously gave me and went to town on it playing some glass slide blues with it tuned in an open key. Even though I am unable to play regular chords or play lead guitar anymore, its ok. Being able to put that glass slide on my little finger and pound out some music and have it sound pretty good, well, I can't even describe how unbelievably awesome it felt to sit here and make music again. What a beautiful thing it is. The moral of the story is don't give up! If you can't play like you used to then figure out a different way or

pick up a different type of instrument and learn something new. If you had artistic skills figure out a different way to paint or sculpt or try a completely different medium like 2D or 3D art on your computer.

That brings me to MSSP's new, free, rhythm music classes taught by Robbie Laws that are held every other Saturday through July. There were three of us at the last class - Channah, Joi and myself - and what a blast we had. Robbie brought out some percussion instruments for Joi who played a bass drum with a foot pedal while playing on a djembe. Channah played a three-chord progression on her electric/acoustic guitar and I was able to play some slide riffs on my guitar. What a great jam session we had with Robbie playing along with his incredible skills.

If you have a love for music and are interested in some rhythm classes call the MSSP at 503.297.9544 to reserve a spot in the class. The classes are limited to fifteen people.



**Thank you
Robbie Laws
for your
time
and
talent!**



Project Helping Hands

Project Helping Hands is a MSSP program that provides discounted massage visits to offer comfort and stress reduction.

Through the program participants receive up to four discounted sessions at \$10 per sixty-minute appointment. Massages are performed by licensed massage therapists (LMT) at their office or at your home. Project Helping Hands is not meant to represent or replace physical therapy. Sessions are arranged by the participant and the LMT. We are glad to report the program no longer has a formal deadline. Instead we're initiating a "rolling deadline" which means you can apply at any time. **Former participants may reapply** if it's been more than 6 months since they received services. For more information visit our website at www.msoregon.org or call 503.297.9544.

Summer Comfort Changes

Due to staff illness this year we have adopted the following program schedule:

- 6/30/14 Application deadline (only completed applications will be reviewed)
- 7/08/14 Applications approved
- 7/15/14 Recipients notified by telephone or email
- 7/18/14 Declination letters sent to unapproved applicants
- 7/23/14 Air conditioners are ordered
- 7/30/14 Air conditioners are sent via delivery service to your door

No units can be picked up at the MSSP office.



We offer the most
comprehensive pesticides
screen in the State of Oregon!

QUALITY ASSURANCE TESTING FOR CANNABIS

Patient safety is our
number one priority.

Cannabis can relieve symptoms of MS, and even protect your nervous system. But is it safe?

When you see the Oregon Growers Analytical certification on your medicine, you can rest assured that it has passed the most stringent quality assurance testing in Oregon.

Ask for OG Analytical tested products at your local dispensary.

Trust your bud.™

CANNABINOIDS | MOLD | PESTICIDES

Visit our website for more information:
www.oganalytical.com

OG Analytical is a strong supporter of the MSSP and CAMS for MS.

Advertisement

Heat and MS by Rebecca Spain, MD, MSPH *continued from page 1*

Likewise, if impulses from the skin or eyes are blocked by an MS lesion in route to the brain, numbness or vision loss is experienced.

Often people experience severe fatigue or trouble thinking. This is likely due to a loss of communication between nerves from one part of the brain to another. When the body cools off, the impulses are able to again travel through the MS lesion and previous ability is restored.

It's important to realize that the reappearance of prior MS symptoms is due to old lesions combined with the effects of heat, and not due to new inflammation. Therefore a raising of your body temperature - whether it's from dancing, a hot shower, or suffering through a head cold - is not causing new damage to nerves even if the old MS symptoms appear. However it may not be a good idea to get in a hot tub if it makes you too weak to get out! So getting revved up and sweaty has to be balanced with how it affects a person's individual MS symptoms. And if you are one of the lucky few with MS who prefer the heat, then there is no reason to not get hot!

Fortunately for those who are heat sensitive there are ways to help. The first step is to tune in to your own body's responses to heat, what works and doesn't work for you. Next is to communicate your experience with heat to your family and care providers so they also know what to expect should you get a urinary tract infection or on your family hike on Mt. St. Helen's.

Many simple measures can allow you to stay active in the heat:

- Choose to exercise or spend time outdoors earlier in the day when temperatures are lower.
- Try activities that naturally cool the body such as swimming in colder pools. Stay in the shade and wear protective clothes to avoid sunburn.
- Wear cooling vests that use frozen packs in a vest under or over your usual clothes to keep your core body temperature down.
- Try a cold towel around the neck or frozen water bottles under the arms. Take advantage of MSSP's window air conditioner program for those summer heat waves.
- Use aspirin or acetaminophen along with cooling devices and cool drinks if you have a fever.

By following these steps, you should be able to drop that body temperature the critical half degree or less that it takes to let your nerves impulses conduct past that lesion and let you, literally, get moving and on your way.

Marijuana Symposium by Candyce Hayes

On April 6, 2014 more than 100 guests filled the Roseland Theatre to listen to eight speakers ranging from lawyers, a physician, MS clients, dispensaries, growers and a cannabis processor. The event was a success.

However, in retrospect we should have changed the format; had fewer speakers and allowed more time for question and answers. The client survey feedback was very good. TV channels 6 and 2 came out and did interviews but only channel 6 ran the story. We thank the many sponsors and volunteers who helped to organize the symposium. Some of our sponsors and speakers were: OG Analytical, the Roseland Theatre, Amy Margolis, Geoff Sugarman and New Economy Consulting.

We're reviewing the program and the clients' interests to decide if future programs will be held. While there are no program materials to mail, you can get general information about cannabis by visiting our website at www.msoregon.org

WAYS TO SUPPORT MSSP



Quotes Earn \$20*

Collin Bonsey's mother has had Multiple Sclerosis all of his life. Understanding his Mom's challenges, Collin is participating in his company's fundraising program. **They will pay \$20 to MSSP for each insurance quote Collin provides between May 1, 2014-August 1, 2014.**

This is an easy way to support the MSSP so please consider giving Collin a call, and then share the opportunity with your family and friends. You can reach Collin at 503 885-8756 or email him at www.countryfinancial.com/collin.bonsey

*No purchase necessary. Limit one per household. COUNTRY Financial® is not affiliated with any third party provider.

0414-231

In Honor of Marilyn Jean Neu

The Neu Brothers Invite You To The 8th Annual Marilyn J. Neu "MJN Help Defeat MS" Slingball Tournament
Sponsored by [Cook Security Group](#)

The Neu Brothers invite you to help fight MS and have FUN! The goals are to raise money, increase awareness about MS and to have some fun at the Oregon Coast! Marilyn Neu was all about being good to people and paying it forward. She wouldn't have it any other way!

For more information and to register please visit

www.slingball.com/register/

For all you Blazers fans one of the many silent auction items is an autographed Trail Blazers game ball

Honorariums

There are many occasions when you want to say something special to a family member, friend or associate. Honorariums are a way to commemorate special occasions – birthdays, anniversaries, weddings, retirements, graduations or memorial gifts. Whatever the occasion, your thoughtfulness will be acknowledged immediately to the person you are honoring and to the family.

Donate a Vehicle

Ready to unload that old car, truck, RV or boat and receive a tax deductible donation? Let us help you! Call the MSSP today at 503.297.9544.

Workplace Giving and Matching Gift Programs

Many workplaces today offer the opportunity to make a donation. Contact Candyce Hayes at 503.297.9544 or candycehayes@msoregon.org for more details.



MARK THESE DATES

Event/Activity	Date	RSVP
Acupuncture MSSP Annex Portland, OR	Open Thursdays 10:00am- 1:00pm	503.297.9544 Ongoing
Rhythm Classes Sellwood Call office for details	Bi-Monthly Saturdays	RSVP required - Limit 15 503.297.9544
MSSP Annual Picnic Oaks Park 7805 SE Oaks Park Way Portland, OR 97202	6/21/2014	RSVP required by 6/15/14 503.297.9544
8th Annual MJN Slingball Tournament Pacific City, OR (Oregon Beach)	6/28-29/2014	Register to donate, play or volunteer by going to www.slingball.com
Check out our website for updated programs at www.msoregon.org		

Parks and Recreation Department

The Portland Parks and Recreation Department has a great program designed for people with MS and like diseases called AIR or Adaptive and Inclusive Recreation. This program offers community-based recreation and leisure services especially designed for youth through adults who have a disability or special need. Call the Portland Parks and Recreation Department at 503.823.4328 for more information.

ANNUAL PICNIC

Date:	6/21/2014 - MARK DATE!
Location:	Oaks Park 7805 SE Oaks Park Way Portland, OR 97202
Time:	11:30-2:30pm (lunch served from 12:00-1:30)
Cost:	FREE "Donations Appreciated"
Limit each party:	4 per family
RSVP Deadline:	6/15/2014
Call or Email:	503.297.9544 events@msoregon.org



NON-PROFIT ORG.
US POSTAGE
PAID
PORTLAND OR
PERMIT NO 829

Here is my contribution to the Multiple Sclerosis Society of Portland, Oregon, Inc. ☐ \$250 ☐ \$100 ☐ \$50 ☐ \$20 ☐ other _____