Multiple Sclerosis Society of Portland, Oregon, Inc.

MULTA SPES

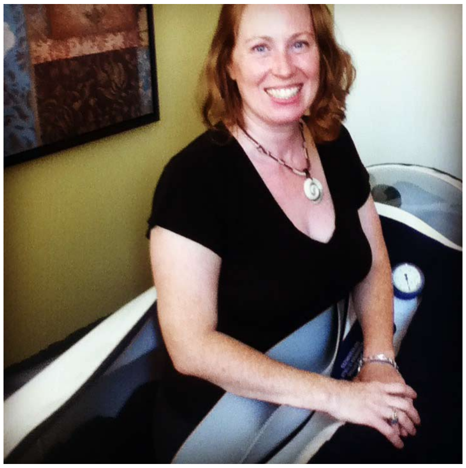
MUCH HOPE

Improving the Quality of Life for Those with MS since 1949

Volume XVI Issue IV Fall 2015

A Choice for Optimal Wellness

by Paula Noel Macfie, Ph.D.



Optimal Wellness. These are two words that resonated with soothing calm the second my eardrums heard them. I was visiting Dr. Satya Ambrose at her Sunnyside Collaborative Care clinic this past June with my father for a conversation about hyperbaric oxygen therapy. My dad looked at her, scared for his daughter and said, "I just want her well!" Dr. Ambrose looked squarely at my dad and with a sweet yet firm smile said, "I don't just want her well, I want OPTIMAL WELLNESS for her." These words just resonated deeply for me. Yes!

After fifteen years of having an Multiple Sclerosis (MS) diagnosis, I hit my personal "rock bottom," when the worst migraine I've ever had struck me this past Mother's Day. I have been suffering from them most of my life and was diagnosed with Trigeminal Neuralgia prior to my MS diagnosis. When I was five years old, I was struck in the head accidentally with a baseball bat in my frontal lobe slightly to the left of my "third eye." For years, I've unknowingly suffered from a traumatic head injury with symptoms mimicking MS.

My parents stopped by my house on Mother's Day and my dad said he had never "been so scared in his life" when he saw me in bed with my migraine suffering from sounds, lights, pain and fatigue. At the lowest he had ever seen me he decided he would do whatever it takes to help me to get well. I called Dr. Ambrose and within two weeks walked into her office and clearly remember her looking me up and down listening to my complaints and challenges and saying simply... "Oh, you are easy!" She said that I am like a research puzzle and we will investigate things on different levels with lab tests and I would collaborate with her to find a solution, but that "I really needed the hyperbaric oxygen chamber." I honestly didn't care what we did at this point I just needed some kind of relief.

Dr. Ambrose put me on an anti-inflammatory diet with my children. This is a dietary protocol with no sugar, wheat, dairy, corn, soy, potato or tomato. She gave us stool tests to take home (my eldest daughter has tummy troubles) and sent me on my way to research Hyperbaric Oxygen Therapy (HBOT) and to discuss it with my family. I wanted to know more of what oxygen therapy is about! It is costly and out-of-pocket, plus a time commitment with two children to care for.

My father and I had several conversations about the therapy, learning about its benefits and asking questions about its possibilities.

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Inside This Issue

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. The next submission deadline is 10/15/2015.

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

If you are not currently receiving Multa Spes, we would be happy to add you to our mailing list. Let us know if you want it by snail or email. Direct all subscription requests or address changes to candycehayes@msoregon.org or call 503.297.9544.

Director's Notes by Candyce Hayes

As the giving season approaches I encourage each of you to give to the MSSP. Our client-focused programs and services make a real difference in the lives of Oregonians and SW Washingtonians. So far this year over 100 new, portable air conditioners were given to clients. This is an all-time record! Our Board of Directors said, "No one will be turned away!" So everyone who submitted a completed application in our service area received relief from record-breaking heat. While many agencies would worry about the budget the MSSP remains focused on serving the community.

We want to thank Randy, Tracy, Carter and Wendy Neu for creating and organizing annual Slingball Tournaments. As a tribute to their late mother, Marilyn Jean Neu, her family continues a legacy of care and help for those affected by MS. The next tournament will be held on October 17, 2015 at Foothill Park (see page 6 for details).

The "Summer Comfort" air conditioning program is just one of the many programs and services the MSSP provides. Please join the Neus by making a tax-deductible donation today. No gift is too small and it goes directly to improve the quality of life for those affected by MS.

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CHEROKEE PARABLE

An old Cherokee parable recounts the story of a grandfather speaking to his grandson about a battle that is waged inside of all people. The old man said that the battle is between two wolves.

He told the boy, "One wolf is evil. It is anger, envy, jealousy, regret, greed, arrogance, self-pity, guilt, resentment, inferiority, lies, false pride, superiority and ego." The boy's eyes grew wide as he listened.

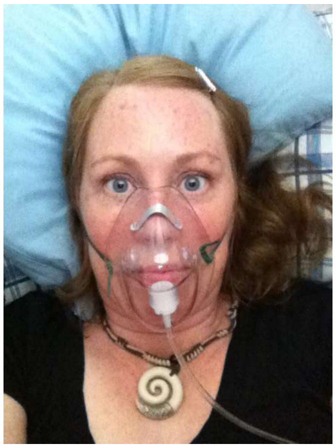
"The other wolf is good. It is joy, peace, love, hope, serenity, humility, kindness, benevolence, empathy, generosity, trust, compassion and faith."

The young child pondered what his grandfather had said and asked, "Which wolf wins the battle?"

The old Cherokee replied, "The one you feed."

A Choice for Optimal Wellness

by Paula Noel Macfie, Ph.D.



Ultimately, I was desperate and was willing to do anything non-invasive to help me out of the debilitating pain in my body, especially my face and head. I could not sustain where I was at and if I didn't do something I knew I would start to deteriorate, especially with cognition and emotional self-regulation, because I severely struggled. In my lowest low and weakest hour, my greatest supporters stood behind me and we moved forward with the HBOT therapy which required 40 days in a row, five days a week for 90 minutes a day.

After my stool test revealing a clean system, sticking to the anti-inflammatory diet for a month and losing 12 pounds, I set all 40 appointments spanning from mid-June to mid-August. My children spent their entire summer in childcare at the community center (not their ideal whatsoever) while I took a journey into the deepest depths of healing my body on a cellular level, all with the assistance of oxygen under pressure. "When oxygen is under pressure, it acts like a drug and has drug-like effects on the DNA and other components of each cell, bringing about permanent changes in the cell and surrounding tissue… In chronic wounds HBOT is a DNA signaling drug, which provides stimulation of the DNA in each cell, thereby allowing the growth of new tissue. It also seems to recruit stem cells to wounded areas. So, using HBOT acts as a stimulus to tissue regeneration, and this is what makes it such a versatile treatment." (The Oxygen Revolution, by Paul G. Harch, M.D. and Viginia McCullough).

For people with MS, having such a variance of symptoms individually, the effects of HBOT can vary, yet as mentioned by Dr. Philip James (excerpted from The Oxygen Revolution) that "in acute neurological insults, we have shown that hyperbaric oxygen therapy protects and repairs the blood-brain barrier." This therapy "restores function and/or ameliorates acute episodes of MS." I personally find this one of the most encouraging statements I have read about the possibility of healing this disease. The reality of my own body being able to repair itself with oxygen under pressure is sci-fi beyond my wildest dreams!

Dr. Roy L. Swank, a mentor and respected elder of mine, treated MS as a vascular condition and often treated patients with blood transfusions and nutrition. Currently with HBOT, by adding oxygen to plasma under pressure, it appears my body has an opportunity to stimulate stem cells and repair the damaged tissue along with creating new neural pathways around and through the areas of injury. The repair is happening while I feed my body with nutritious foods that heal. I've found that there is a connection between the vascular system, proper nutrition and healing MS with oxygen!

After 40 treatments, I no longer feel the debilitating effects of fatigue, I can physically write with my right hand again, my writer's block has unstuck (cognition), plus I have improvement in memory and emotional self-regulation (more patience). The reality for me is that through all of the treatments, I still suffer from Trigeminal Neuralgia and mild migraine pain daily. It appears that my baseball bat injury to my frontal lobe lingers although it has significantly improved.

What this transformative therapy and healing experience has meant for me is that I have made a breakthrough with my health. I have found my way through all that has set me back while being diagnosed with MS. No longer do I limit myself by "surviving the day" or getting through the day "managing my symptoms". My days are focused on the path of OPTIMAL WELLNESS. On a daily basis I ask myself what will bring me optimal wellness? What am I doing for myself today? Being encouraged and being "seen" in the light of optimal wellness by Dr. Ambrose, I strive each moment of the day to check in with my body, listen to where things are off and see where I can adjust to bring myself back to my optimal wellness.

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A Choice for Optimal Wellness

by Paula Noel Macfie, Ph.D.

What this means for me is: eating an anti-inflammatory diet for the rest of my life, reducing my stress levels (water music, yoga and meditation help me) and utilizing the alternative therapies and treatments currently available outside of the mainstream neurological setting. I have found great personal healing with Hyperbaric Oxygen peeling back the layers of MS in my body to reveal a traumatic brain injury. Had the oxygen therapy not relieved my fatigue, nerve pain, insomnia and mental deterioration, I can write with certainty that "optimal wellness" would not be on my mind.

Optimal wellness, for me, is doing what it takes to create an environment of well being that heals my heart, mind, body and soul. Optimal wellness is taking care of my self on every level. Having a social life with my friends, going to concerts for music therapy, reading thought-provoking books from the library, seminars focused on well-being and nutrition are all things that cultivate my optimal wellness. It is taking time for me to adjust my lifestyle around optimal wellness being my priority. My children have changed their diets and lifestyle as well. We have shut off media in our house, except for writing and emails. We have more crafts, playtime and cooking together. We cultivate daily activities, relationships, food and interests that bring us optimal wellness.

As I now explore the meaning of having a traumatic head injury, my personal prescription for optimal wellness will continue. I have changed to an anti-inflammatory diet (along with Dr. Swank's dietary protocols), have completed 40 treatments of hyperbaric oxygen therapy, take Luminous Botanicals Meadow Blend (cannabis oil) daily, and make stress reduction a priority while focusing most of my day on the two words: OPTIMAL WELLNESS.

With every choice I make I ask myself now: does this bring me optimal wellness? With all of my good thoughts and intentions, I hope that you too find what makes you "optimally well."

* * * * *

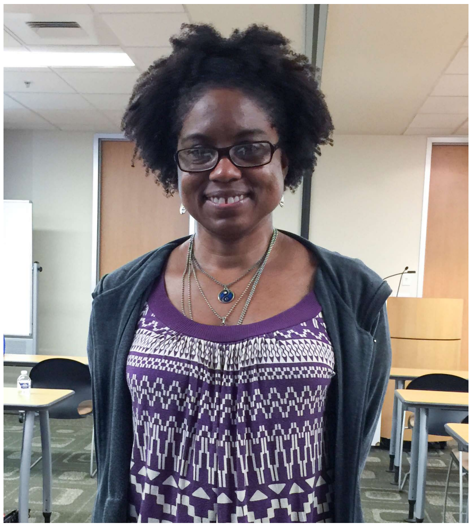
Coming in September

MS Wellness Education Classes

Please join MSSP and Paula-Noel Macfie, PhD, for a series that encourages personal wellness through social, emotional, physical, intellectual, environmental, spiritual and nutritional lifestyle support.

Please contact the office to register by either calling us at 503.297.9544 or emailing programs@msoregon.org. We look forward to seeing you there!

In My Words - Carpe Diem! by Shari Staten



I belong to a support group on Facebook, Pacific NW MS Friends. We gladly welcome new members, so check us out the next time you're online! The other day someone in the group asked if anyone had done something positive in spite of their diagnosis of Multiple Sclerosis (MS). I thought back to a day when my view of the world was literally panoramic: the day I went skydiving.

Now 16 years diagnosed with MS, I recently thought back to a time I moved to Oregon from Michigan. One day I checked my email and there was a Living Social deal from Capital City Skydiving in Fowlerville. My then boyfriend, Steve, and I always talked about jumping.

I was an MS patient of 9 years at that time. Steve had already tested my endurance via tubing on boat outings as well as small treks through the state park and camp grounds of Tahquamenon Falls and the beautiful forest of Heartwick Pines, both landmarks in a state best known for the cars it produces. We talked about the risks of me jumping with MS. His words were supportive and reassuring. I sent him the link. He paid for the deal. The date was set. An appointment was made four weeks out.

The day finally arrived. We received a 90-minute orientation and directions on safe jumping once we got there. We each went up separate both with a tandem diver. Steve went first. The sky echoed a rip and I had to squint to see Steve floating down to earth with the tandem diver attached to the harness behind him sailing through the air and down to the ground. He landed, face flushed with adrenaline. Now it was my turn and my heart was pounding nervously.

I boarded the plane. Nervousness turned to panic as the plane climbed altitude, but I wasn't about to have the plane backtrack and return to its take-off point. Yielding to the jump of the diver behind me I closed my eyes and fell.

About ten seconds later I opened my eyes. The deployment of the parachute jerked about 25 seconds later and I was sailing through the vault of the Heavens. It was like I was in a commercial 747...without the 747. A familiar view, the terrain was blocked off in squares of earth brown, yellow and green. Above us was an arced cloth with multi-colored triangular sections of white, red, green, gold, blue and orange. My tandem, a customer service pro in this field, made the jump even more fun by initiating corkscrew spins about a half mile down and just below the clouds. I guess it would have been fun if the nerves I had prior to the jump and the thin air at this altitude didn't have my tummy wanting to toss my pancakes from breakfast. I didn't, though by this time I was belching my breakfast. It left a calling card of nausea by the time I safely landed from the jump. After a couple of Tums and a ginger soda the nausea was gone by the time I got home.

Though I don't necessarily endorse skydiving as a chosen recreation, I will say this, 'MS may prevent you from doing some of the things you love. You may not be able to do some of the things you used to do BUT if you let MS convince you that you can't, then you won't. Don't be that person. Carpe Diem! Seize the day. Say "YES" to the things you know you'd regret otherwise. Modify activities to suit your individual limitations when you can and don't forget to have fun!"

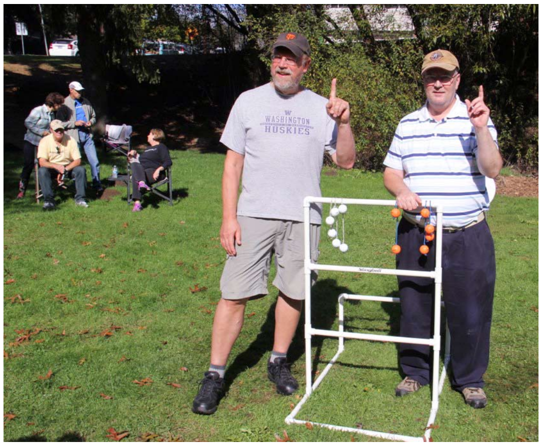
Lastly, if you're wondering if I would ever jump again? The answer to that is a resounding, "HELL YEAH!"

WAYS TO SUPPORT MSSP

In Honor of Marilyn Jean Neu

The Neu Brothers Invite You To The 5th Annual Portland "MJN Help Defeat MS" Slingball Doubles & Mini Marilyn Kids Tourneys!

Grab your spouse, grab a friend, or even team up with your son or daughter for the 5th Annual PDX "MJN Help Defeat MS" Doubles Slingball Tourney! You will hold Doubles bragging rights, win Trail Blazers tickets along with other cool prizes! Who will take down last year's Champs, Ron Albertson & Stephen Page?



PDX Doubles Tourney Details:

Where: Foothill Park (SW Park Way & Hilldale, Portland, OR 97225)
When: Saturday, October 17th 2015
Hours: 10:30am-3:30pm (if necessary)
FYI: Please remember to bring food, chairs, tents, blankets, etc. There will be a few picnic tables available
Adult Entry: $25 per person - (Doubles, $50 per pair Double Elimination)
Kids Entry: $15 per child - (Singles tourney - Double Elimination)
Non-Players: You can still donate $25 to the cause or purchase Slingball sets, t-shirts or other merchandise! See www.slingball.com for more information
Prizes: Adult Doubles: 1st-4th Place - Trail Blazers tickets and other cool prizes! Kids Singles: 1st-4th Place - Prizes & Medals!

Multiple Sclerosis Society of Portland, Oregon (MSSP)
Tax ID # 93-0511355

Spread the word. Help Defeat MS. Have fun!
The Neu Brothers and the MSSP
Visit our website to register at www.slingball.com

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All proceeds help fund programs and services that directly help those living with MS, their family members and caregivers in Oregon and SW Washington.

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.

Make a Designated Gift

By supporting a MSSP client program 100% of your gift will be used exclusively for that purpose.

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.

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Your tax-deductible donations can be made here: www.msoregon.org/donate/form

MARK THESE DATES

Event/Activity	Date	RSVP
Acupuncture Different Locations Available	Weekly	503.297.9544 Ongoing
MS Wellness Education Classes MSSP Annex Once a month every third Monday starting in September	9/21/2015 3:00-5:00pm	RSVP required 503.297.9544
5th Annual Portland "MJN Help Defeat MS" Slingball Doubles & Mini Marilyn Kids Tourneys!	10/17/2015 10:30am-3:30pm	Register to donate, play or volunteer by going to www. slingball.com
Christmas Party - NEW LOCATION - see below Mt. Tabor Prebyterian Church TaborSpace 5441 SE Belmont St, Portland, OR 97215	12/12/2015 11:30am-2:30pm	RSVP required 503.297.9544 Parking lot on 54th Call for TriMet Lift parking details
Check out our website for updated programs at www.msoregon.org		

CHRISTMAS PARTY

We are excited to announce that the Christmas party will be held at TaborSpace which is located in the Mt. Tabor Presbyterian Church (see below for details). Entertainment includes Amber Cobb and Friends who will have a sing-a-long complete with wheelchair dancing and, of course, the Rose City Banjoliers. A traditional Christmas dinner will be served.

Date:	12/12/2015
Location:	TaborSpace 5441 SE Belmont St. Portland, OR 97215
Time:	11:30am-1:30pm (lunch served from 12:00-1:00pm)
Cost:	*FREE "Donations Appreciated"*
Limit each party:	4 per family
RSVP Deadline:	12/07/2015 RSVP required
Call or Email:	503.297.9544 events@msoregon.org

Multiple Sclerosis Society
of Portland, Oregon, Inc.
2901 SE 122nd Ave.
Portland, OR 97236

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Yes, I want to help improve the quality of life for persons with MS!

Here is my contribution to the Multiple Sclerosis Society of Portland, Oregon, Inc.

☐ $250 ☐ $100 ☐ $50 ☐ $20 ☐ other ____________

My Contribution is for:

☐ Client Emergency Fund
☐ Summer Comfort
☐ Caregiver Classes
☐ Social Programs
☐ Medical Equipment
☐ Greatest Need

My Name:
Address: ____________
City/State/Zip: ____________
Email: ____________
Phone: ____________
____

If you would like to send this gift in honor or remembrance of someone, please include a note with their name & address or if applicable, the name of whom we should send acknowledgement to with their address.

Please clip this form and mail with check payable to MSSP:

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