Multiple Sclerosis Society of Portland, Oregon, Inc.

MULTA SPES

MUCH HOPE

Improving the Quality of Life for Those with MS since 1949

Fall 2013 Issue

Living a Swank Lifestyle

by Paula-Noël Macfie, PhD

(originally published for the Swank Foundation and can also be found on their website: www.swankmsdiet.org)

In my life, especially before and during graduate school, there were many times I had personal experiences with humans who are extremely influential: philanthropists, philosophers, public speakers, elders and scientists. The most meaningful and most profound meeting of such a person in my life occurred when I met Dr. Roy L. Swank.

During the summer of 2001, I had just finished graduate school and found myself in the hospital getting an MRI, due to a collision. Three months later, I was diagnosed with multiple sclerosis. After several pin pricks and neurological testing, a neurologist pulled my parents and me into his office and told me he was going to talk to us about "therapies" for MS. I was not really clear on what MS was or what the therapies would be, yet I knew with my seven years of graduate school and my education from indigenous elders and healers, that I would be able to handle what was given to me. Shortly after my diagnosis, when I was sitting in the circle of newly diagnosed MS sufferers, it began to sink in what this disease looked like. Not one person had the same set of complaints and there were varying degrees of obvious disabilities with canes and wheelchairs, to people like myself who looked "normal." When it was time for questions, I asked the same questions to the group that I did my very first neurologist: what about lifestyle? diet? exercise? a cure? One person mentioned yoga and a man named Eric Small who had adapted yoga for MS and had written a good book about it. Another woman said something about a doctor named Dr. Swank and his diet was the only diet they knew of for treating the disease.

After the workshop, I began to realize that the information I was seeking would be found within the people who had MS. Medical doctors began to seem more and more ridiculous to me. People who have the disease have the capability to navigate how to heal it. A woman came up to me as we started to leave the workshop. She told me, "If you are going to approach MS with nutrition and lifestyle, you must meet Dr. Swank. Here is his

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Paula-Noël Macfie, PhD

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: 12/15/2013.

Please send submissions to
Candyce Hayes,
Executive Director, at:
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2901 SE 122nd Ave.
Portland, OR 97236.

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

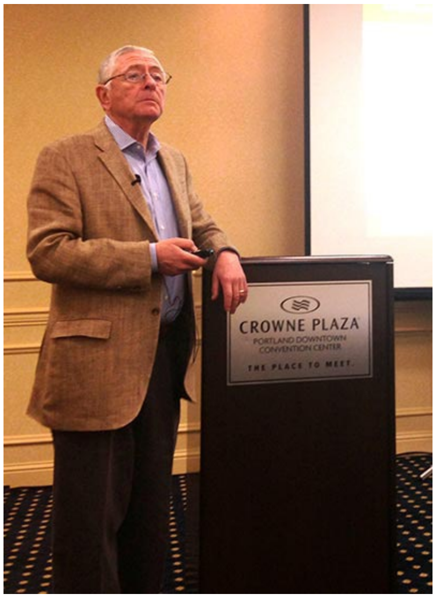
Director's Notes - by Candyce Hayes

A committee reviewed and recommended several changes to our newsletter. This issue is the first of many changes to come. I was encouraged to tell the "why vs what" we do. So look for more personal stories, more pictures and shorter articles. We encourage your feedback.

By the way, MSSP turns 65 in 2014! Got any ideas of ways we can celebrate this milestone?

Workshop Review

Participants enjoyed a morning of education during our August 17th workshop. The speakers were Dr. Stanley Cohan, MD, Jade Nelson and Dr. Thomas Sims, MD. The topics covered walking and MS, how to appeal health insurance declinations and medical marijuana. We also thank our principal program sponsors, TEVA Neuroscience and Allergen along with other contributing sponsors, Shamrock Medical, Acorda Therapetic and Genzyme.



Dr. Stanley Cohan, MD

Dr. Thomas Sims, MD

Jade Nelson

Living a Swank Lifestyle *continued from cover*

phone number.” A couple of people overheard our conversation and said that they followed Dr. Swank’s diet. Then the rest of the group joined in and we had a conversation about their experiences on his diet. I knew I needed to meet him.
I called his wife Leanna the next day and set up a time to meet Dr. Swank. I ended up spending the next two years of my life meeting with Dr. Swank. I met with him as a fellow researcher, a patient, and a wise elder on the subject of blood circulation, vascular conditions, neurology and multiple sclerosis. He understood multiple sclerosis - and other diseases such as heart disease, diabetes and stroke – as nutritional disease. To this day, 12 years later, I attribute my quality of life and my well-being to the research and selfless wisdom of Dr. Swank.

I am honored to be a part of the Swank Foundation as an Advisory Board Member, and a writer for the Swank Foundation website. It is my continued self-discipline and respect for the legacy of Dr. Swank’s research and his memory that inspires me to write about ‘Living a Swank Lifestyle”. For twelve years, I have managed multiple sclerosis primarily with Dr. Swank’s MS Diet Book. It is my intention that by writing about my life, incorporating Dr. Swank’s lifestyle recommendations, sharing recipes, and contributing to nutritional healing, I will inspire others to find a balance in their lives with diet, rest and exercise. This is also for those who have friends or family with multiple sclerosis. It is my hope that they will be inspired to encourage a lifestyle of well-being for those touched or devastated by the disease. This disease includes everyone. The cause and the cure for multiple sclerosis lie in the hands of each person who has it and the support of each sufferer. It’s a choice to treat MS solely with lifestyle changes and/or prescription drugs. I hope that by sharing my choice for a Swank lifestyle that others may be inspired to live a life of well-being.

My passions are dark leafy greens, backyard habitat, gardening and nutritional healing for multiple sclerosis

I am a single mother of two young children, ages two and six. I am a homeowner, a householder, a gardener and a cook. I have a daily life that is challenging, lesson-learning and a blessing all in one. I live with relapsing-remitting multiple sclerosis and other health challenges. I am thankful beyond words for the human beings in my life, like Dr. Swank, who have listened to me in such a deep way that it catalyzed finding a profound acceptance of living with multiple sclerosis. Dr. Swank’s research, writing and support of his patients is a gift to a disease that affects millions of people daily. It is my hope that by sharing my version of a Swank lifestyle, I will be encouraged to stay focused on a path that brings me balance.

“Living a Swank Lifestyle” is my way of opening my life, from the day-to-day routine of parenting and self-care to the philosophically profound. To write about Dr. Swank and a lifestyle he insisted upon is a purpose in my life that is meant to inspire others with multiple sclerosis. Changes to create a lifelong lifestyle can heal the body. There are many times I feel isolated in my daily life, yet writing my experiences of a Swank lifestyle heals my mind because I know that there are others reading this and saying, “Yes, I choose to incorporate a lifestyle of proper nutrition, rest and exercise”.
I am a proud mama of two daughters and a philosopher who loves research. I spent several years with indigenous elders and healers developing a psychological process for western mind decolonization called “Remembering Our Ancestors”.

My passions are dark leafy greens, backyard habitat, gardening and nutritional healing for multiple sclerosis. I “live the research” of Dr. Swank and fully support everyone doing it. I can be reached at: haleakuahonu@gmail.com

Heat Relief

According to Dr. Dennis Bourdette, at OHSU, “People with MS cannot tolerate heat. Unfortunately, medical insurance does not cover the cost of providing air conditioning units for people with MS, despite the well-recognized deleterious effects of heat on MS. Many people with MS are disabled and must live on a very limited income, often making it impossible for them to afford purchasing an air conditioning unit. By providing air conditioning units to people with MS who could not otherwise afford them, the MS Society of Portland’s Summer Comfort Program is a unique service.”

Here are words of appreciation from a few of this year’s Summer Comfort recipients:
“We received your letter on June 28 the same day the air conditioner arrived! What a wonderful surprise because it was really heating up. Norman and I thank you very much. He would have written the note if he could. PS our dogs say thank you too.” James W.

“Thank you for the air conditioner – it has changed the way I schedule my life. Before having the air conditioner I had to limit my work and social activities because the heat wore me out. I can now do my housework pretty much without limits.” Heidi S.

“I’m so thankful for your generous donation. I’m a single mother of two beautiful daughters just getting by. I was diagnosed in 2009 and have been struggling ever since. I live in a condo that heats up in the summer time…” Shivon C.

Applications are now being accepted for the June 30, 2014 deadline. For more information call 503.297.9544 or visit our website at www.msoregon.org

Lucky Winner

Paula Von Kuster was the lucky door prize winner at our August workshop. She won a light weight transfer chair. Through tears of joy Paula said, “I’m so excited. Now my family can take me to the Zoo and Multnomah Falls.” We give a special thank you to Mark Henley at Shamrock Medical for donating the chair, for running our medical equipment closet and for helping our clients. He always does a great job. To contact Mark call 503.233.5055 or visit their website at www.shamrockmedical.com

Got Rhythm?

Robbie Laws, renowned blues guitarist, has offered to give free “rhythm” classes at his studio or at the MSSP annex to our clients. Robbie will even provide the instruments! For details email candycehayes@msoregon.org or call 503.297.9544.

Medical Marijuana - Does it really help? By Chris Campagna & Thomas Sims, M.D.

Spasticity with its associated pain (especially pain in the lower back and extremities) is a well recognized, frequent and disabling condition for patients with multiple sclerosis. Medical marijuana has long been suggested as a relief for those symptoms, but the evidence it really helped was only anecdotal. Now there is a medical study that backs up that assumption and suggests that careful use of medical marijuana for the relief of spasticity associated with multiple sclerosis truly helps.

In a medical study lead by Dr. Jody Corey–Bloom of the University of California, San Diego in May 2012, researchers learned that marijuana had a very positive effect on reducing spasticity and pain in patients who suffered from multiple sclerosis.

The medical study involved a placebo-controlled crossover study using 30 adult patients (mean age 51 years) who suffered spasticity that was unresponsive to existing medical treatment. In the study patients were randomly assigned to use either cannabis once daily for three days or placebo cigarettes (in this study the cannabis was smoked) and then they switched for another three days. Patients did not know whether they were smoking tobacco cigarettes or cigarettes laced with the same base material found in marijuana (delta-9-tetrahydrocannabinol). After smoking either cannabis or placebo patients were asked to rate the amount of muscle spasm and pain they experienced during the study, and their complaints of spasticity were scored on the modified Ashworth Scale – a well-recognized measurement tool used to evaluate spasticity in a host of medical conditions.

The study revealed that patients who used the marijuana for three days experienced an almost 1/3 decrease in their modified Ashworth's scale score over patients who smoked tobacco cigarettes did not. This led the researchers to conclude that cannabis did exert a positive therapeutic effect on the relief of spasticity in those MS patients who had not received relief from other treatments.

The authors of the study were quick to point out they did not necessarily recommend the use of medical marijuana for MS. Using cannabis also had cognitive effects such as sedation and reduced ability to concentrate. They also expressed concern that smoking marijuana had its own potential respiratory side effects.

The study is very interesting in that it does support the anecdotal evidence that medical marijuana can help with spasticity associated with multiple sclerosis. More study is necessary and advised to learn more about this important finding as we continue our search for treatments of this disabling condition.

On August 14, 2014, Gov. Kitzhaber signed HB 3460 that spells out how dispensaries will operate. Meanwhile, Dr. Sanjay Gupta reversed his position on medical marijuana in a CNN special "Weed." He said we have been "systematically misled" on marijuana and DEA lists marijuana as a schedule 1 substance with "high potential for abuse." We'll keep you updated about developments. In the meantime, to learn more about medical marijuana or to apply for your Oregon medical marijuana card, please visit www.oregonmedicalmarijuanacards.com.

* * *

Massage Program Extended

The application deadline for Project Helping Hands has been extended to December 31, 2013. For more information call the MSSP office at 503.297.9544 or visit our website at www.msoregon.org for program details.

WAYS TO SUPPORT MSSP

Attend an Event
Donate Real Estate
Tributes & Memorials
Workplace Giving
General Donations
Designated Gift
Planned Giving
Donate Stocks
Vehicle Donations
Volunteer

The Multiple Sclerosis Society of Portland is partnering with Dash 2 Dare for their upcoming Urban Adventure Race on Sunday, October 13. Join them for a competition that is part trivia challenge, part photo scavenger hunt and a whole lot of fun. A portion of the proceeds from the race will be donated to MSSP.

Dash 2 Dare races focus on fun and savvy instead of pure strength. At the start of the race, participating teams are provided with a dozen clues. The solutions to these clues point to different destinations around Portland. The teams make their way either by foot or public transportation to each location. When they arrive at each spot, participants take a picture of the entire team completing a challenge.

All participants receive a Dash 2 Dare multi-tool and a chance to win raffle prizes at the post race party. Awards will also given to the fastest time, best team costume and best picture from the event.

Go to www.dash2dare.com for more details or to register your team. Join them for a great day and to help get the word out about the Multiple Sclerosis Society of Portland.

To learn more about the MSSP's programs email candycehayes@msoregon.org or call 503.297.9544

Royal Volunteers

Beauty Princesses Camille and Juliette Liggins volunteered their time to spruce up the MSSP yard. On an 80 degree day they pulled weeds, pruned roses and even packed supplies for the flu clinic program. These young ladies prove it's never too early to volunteer.

MARK THESE DATES

Event/Activity	Date	RSVP
Acupuncture MSSP Annex Portland, OR	Open Mondays 10am-2pm	503.297.9544 On-going
Portland Slingball Tournament Foothill Park (SW Park Way & Hillsdale, Portland, 97225)	10/5/2013 11:30am-3:30pm	None required
Flu Clinics Greater Portland Area	9/15 - 11/1/2013	503.297.9544
Christmas Party 232 SE 80th St. Portland, OR	12/14/2013 11:30am-2:30pm Note new time	Required 503.297.9544 Seating limited
Blues4MS Aladdin Theater 3017 SE Milwaukie Portland, OR	3/2/14 3:00-9:00pm	None required FREE concert See **blues4ms.org** for more info

PLEASE JOIN US AT OUR CHRISTMAS PARTY

Date:	**December 14th, 2013**
Location:	**Montavilla United Methodist Church** **232 SE 80th St.** **Portland, OR 97215**
Time:	**11:30am-2:30pm (Note new time)**
Cost:	***FREE "Donations Appreciated"***
Limit each party:	**4 per family**
RSVP Deadline:	**December 8th, 2013**
Call or Email:	**503.297.9544** **events@msoregon.org** **or register online at** **www.msoregon.org/calendar.htm l**

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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Time Dated Material

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