

MULTA SPES

MUCH HOPE

IMPROVING THE QUALITY OF LIFE FOR THOSE WITH MS SINCE 1949

Spring 2012 Issue

Director's Notes: by Candyce Hayes

I'm excited to announce a major milestone: March 8th 2012 is my 20th anniversary with the MSSP - my how time flies.

Over the years it's been my pleasure to meet and serve thousands of people. It's hard to choose my favorite MSSP program because I bounce between fundraising and client services. It's this mixture of activities that keep the job rewarding. If pressed I'd have to say it's a tie between the air conditioner (Summer Comfort) program and our socials. It touches my heart to give a new air conditioner to someone suffering from the heat and I love to watch the smiling faces of guests as they arrive at the Christmas party or the Oaks Park picnic. Candidly our socials feel more like family reunions.

Now I don't want to give the impression that I do all this alone. Contraire I've been blessed with wonderful assistants over the years, Cleo, Clara, Harold, Sarah and now Kaisa. Let's not forget the terrific volunteers and our board of

directors who give so generously of their time and talents. They make it fun to come to work each day.



As for keeping the doors open – we've done everything from annual flu clinics, a Bug Run, phoneathons, a Mothers' Day Tea and Fashion Show, Roses For MS, raffles and Blues 4 MS. Please plan to come out to the 2nd Annual Blues for MS Concert. This is a free benefit concert on March 4th at the Roseland Theatre. The fun begins at 3:00 pm and wraps up around 9:00 pm. Robbie Laws (the musician from the Christmas party), Duffy Bishop and Randy Oxford are among the featured entertainment. We're also raffling off two fantastic guitars; a signed Buddy Guy Fender Stratocaster and a Martin 000-15M! Tickets cost \$5 each. I hope to see you there. In the meantime, thank you for everything, I look forward to serving you in the future.



Sandwich Generation:

Raising kids is hard enough but for many they face additional challenges. Those who are raising kids and caring for someone else, such as an aging parent, all while trying to be a productive employee and engaged spouse are called "sandwich caregivers" or the "sandwich generation".

According to the Pew Research Center, 16% of American households have at least 2 adult generations living under the same roof.

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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: 4/15/2012.

Please send submissions to Candyce Hayes, Executive Director, at: candycehayes@msoregon.org or mail: MSSP, 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.

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FYI

YOGA

Yoga for MS with Cindy Irvine

Tuesdays 12-1:30 pm

Upcoming sessions are 10-12 weeks long:

April 3-June 5th

\$140 10 Classes

June 12-August 14

\$140 10 Classes

September 25-December 11

\$168 12 Classes

Location:

Julie Lawrence Yoga Center;
1020 SW Taylor Street; Suite 780,
Portland, OR

Registration:

Send \$25 nonrefundable, nontransferable deposit or payment in full with your name, address, phone number and email to JLYC. For additional information please call 503-227-5524 or visit www.jlyc.com.

Words of Wisdom

WORRYING does not take away tomorrow's TROUBLES, it takes away today's PEACE. (Author Unknown)

Medical Equipment

We are now able to accept medical equipment in good working condition thanks to Shamrock Medical.

Personal Chef

Have you ever thought about getting a personal chef? Once thought to be a luxury item, personal chefs can be a valuable service. They bring prepared meals to your door at a surprisingly low cost!

“Wow, this is great! Not only am I eating new foods I'm also feeling better. It's like going from regular to premium gasoline. I look forward to those weekly visits from my Chef and dining on her treats”, says JJ*.

There are many chef services around town. You can find them by searching online or the phone book. Here are two chefs that MS clients use:

Muffin Batiste
Le Sous Chef
Custom Catering & Personal Chef
360-253-6248
www.lesouschef.com

David Plutte
Personal Chef
503-250-3891
dplutte@msn.com

* *name changed*



Sandwich Generation: *Continued from Page 1*

While some enjoy this chaotic and challenging environment others see it as a huge difficulty. This is especially true as adult children try to raise their own kids, care for aging parents with a progressive disability-like MS, and be successful in the workforce. Some in this position have not figured out how to reach out to formal and informal resources that can help. They are stuck trying to “do-it-all” or don’t want to bother anyone else with asking for help.

However, there are resources available including:

- Professional counseling to help with the changing relationships
- Ask neighbors or close friends to help with food preparation and cooking
- Hire an in-home chef to prepare one or more meals a week
- Join a support group
- Talk to your employer to see if accommodations are available
- If possible hire a part-time caretaker so the adult child can have a break

The goal is to figure out a plan to diminish the feeling of being overwhelmed, constantly anxious/stressed, underappreciated, lonely, and pulled in too many directions. And the general feeling of lacking or not being able to succeed in all the various responsibilities the adult has with their spouse, children, and parents. The list above is just a start and remember there is help.



POLST: An Advanced Directive Update:

In addition to an Advanced Directive, the Physician Orders for Life-Sustaining Treatment, or POLST, clarifies a person’s wishes even further. This form is written by a physician and, since 2009, Oregon has kept track of POLST’s through an electronic registry.

The main difference between an Advanced Directive, AD, and the POLST is that a physician writes the POLST and the patient writes the AD. Also, since the POLST is electronic, doctors have access to it instantly wherever they are located.

The POLST outlines how a patient feels towards the use of CPR, feeding tubes, hospitalization, comfort measures, antibiotics, and other possible treatments. Explaining your wishes in more detail helps to avoid a medical misinterpretation of a DNR or an Advanced Directive.

According to Dr. Erik Fomme, “The POLST is only as good as the conversation you have about it. The questions come down to, where are we going to put our focus? On trying to extend life as much as possible, on maximizing quality of life, or somewhere in between?”

For more information about the POLST talk to your doctor and visit www.polst.org.

Meet Julie:

Julie was diagnosed with Multiple Sclerosis in 2007, at the age of 27. As a result, she began experiencing urinary symptoms and had to start using catheters. Julie shares how using Coloplast SpeediCath® Compact catheters has impacted her life.

What challenges did you face after you were diagnosed with MS?

It took six years to officially get diagnosed with MS, so when I was finally diagnosed it was a relief. While I know it sounds ridiculous to think getting diagnosed with a critical illness would be considered a blessing, at least I knew what I was up against. Immediately following diagnosis, I was informed I would need to start self-catheterizing. I was beyond devastated. The products that were offered to me were large, uneasy to handle and completely unbearable. After months of living in despondency, SpeediCath Compact was introduced to my life. My world had changed! I was given back my life, freedom and independence!

Why were you advised you needed to self-catheterize?

Although it isn't spoken about as much as other symptoms, bladder issues are actually pretty common with MS patients. I believe it is the embarrassment that people feel when talking about it that prevents them from speaking with their doctors and getting proper treatment. I've met too many women to count with MS-related bladder issues who thought that you have to be incontinent before needing to self-cath. It is important to know that this is not that case. In my case, frequency, retention, urgency and hesitancy have all been alleviated by self-cathing. Before SpeediCath, I truly dreaded having to cath and would try and cope with my symptoms without cathing. Because of this, I ended up with infections which made all of my other MS symptoms worse. Now, because SpeediCaths are so easy to use and pose no issues or discomfort, I can manage the symptoms the appropriate way and not run the risk of infection.

What are you able to do now that you use SpeediCath catheters?

Now my husband and I can finally live life. We go out to dinner, we can travel, we can go on road trips....we can live! I am no longer the recluse I once was (before SpeediCath). While I know MS will always have a major impact on my life, SpeediCaths have made one symptom completely controllable! No one would have a clue I have to use them if I didn't tell them. They are smaller than my lipstick and are easily concealed. The only reason I am so vocal about them is because I know how much they can improve quality of life. I remember how scary this all was in the beginning and I hope by hearing my story you will realize it really isn't as bad as you fear. Cathing is honestly the last thing I worry about now.



For Julie's complete story, please visit: www.tryspeedicath.us.coloplast.com or scan the QR code below.



Download a free QR codereader for your smart phone at www.i-nigma.com



Continued on Page 5

Meet Julie: *continued from Page 4***Why do you use SpeediCath catheters over the other options on the market?**

I only use SpeediCath! There is absolutely no comparison on the market....believe me I have tried them all. There are innumerable reasons why I believe they are the best product. With the other catheters I used to have frequent urinary tract infections. So far I haven't had an infection with these! The catheter's design limits contact with the actual catheter so you are less likely to introduce bacteria in to your body. They are sturdy, compact and very easy to use. Obviously I wish I didn't have to cath but if you do, these are the best and I believe the way to go. My life is better because of them and I will forever be grateful they were introduced to me.

Multiple Sclerosis and Balance Study:**VOLUNTEERS NEEDED:**

OHSU is currently recruiting people for research on dalfampridine (Ampyra©) and imbalance in people with Multiple Sclerosis. To participate you must:

- Be 20-59 years old
- Have multiple sclerosis
- Have poor balance
- Be able to walk at least 100m with or without a cane or other assistive device
- Have no other current medical conditions known to affect balance and gait, e.g. lower-extremity joint replacement, peripheral neuropathy, vestibular disorder, alcoholism, stroke, seizures, or be pregnant.
- Not have impaired renal function

Participation in the study requires that subjects undergo clinical and physiological assessments at OHSU on four separate occasions over the course of 12 weeks. This is a double-blind, placebocontrolled trial. Half of the subjects will receive dalfampridine and half will receive placebo.

This is a research study and not treatment.
Subjects will be paid \$30 for each visit.

If you would like further information about this study or to refer a subject, please contact:

Dr. Michelle Cameron or Josh Adams at

(503) 220-8262 x52016

APPROVED: **Jun. 15, 2011**

Oregon Health Sciences University

3181 SW Sam Jackson Park Rd.

KEEPING OUR DOORS OPEN:

BLUES 4 MS
 a benefit concert
 the Multiple Sclerosis Society of Portland
 2012
 www.blues4MS.org
Sunday, March 4th 3pm - 9pm
Roseland Theater

Gunnar Roads Band
Chad Rupp & the Ruppshakers
AC Porter & The Live Wires
Boogie Bone
Robbie Laws Band
Duffy Bishop Band
Randy Oxford Band

MSSP American Benefits, Inc. The Oregonian CONCORDIA UNIVERSITY OF PORTLAND CONRAD Martin & Co. 1834 Fender KMHD

Free Admission- donations gratefully accepted.

Raffle: Signed Buddy Guy Fender Stratocaster or a USA Martin 000-15M Acoustic.

For more information on Guitar Raffle visit www.blues4ms.org.

Thank you to the following contributors:
(Partial List)

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 M. Sanders
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Mark These Dates

Event/Activity	Description	Date	RSVP
Acupuncture	Drop-ins Mon: 10am-12 noon Sat: 3-5 pm	On-going	Please call the office for additional information. There is a small fee per session.
Blues for MS II Roseland Theatre 8 NW 6th Ave Portland, OR 97209	Seven Blues Bands from 3-9 pm	3/4/2012	Free with donation accepted at the door. Raffles, Silent Auction. Visit www.blues4ms.org for more info
Spring Forward 2012-Managing MS Education Workshop	Dr. Michelle Cameron and Dr. Edward Kim Location TBA	5/5/2012	Call office to RSVP or email events@msoregon.org
Annual Oaks Park Picnic		6/23/2012	RSVP starts 4/1/12
Summer Comfort Applications	Portable Air Conditioner Program	Deadline is 6/1/2012	Call office for application or visit www.msoregon.org

Christmas Party Review:

We would like to thank the 80 plus guests and volunteers that came to the Christmas Party on December 10th. We had a great time listening to the Rose City Banjoliers and Robbie Laws & Skip. We also thank the Hands on Portland volunteers for all their help in making the event a success and the cooks (Noelle, Sheryl, Shirley, and Terry) for preparing our feast! We look forward to seeing many of you at our next event!



Coloplast[®] Care Program

Patient Enrollment Form

Coloplast Care is a program provided to you free of charge. We help make life easier for people, like yourself, who are living with intimate healthcare needs, and the Healthcare Professionals that support you by offering many different educational tools.

Benefits of the Coloplast Care Program:

- Access to education and tools recommended by your Healthcare Professional
- Monthly wellness education articles addressing lifestyle questions
- Dedicated Consumer Care Advisor to help answer questions you may have

Enroll Today!

First Name: _____ Last Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Email: _____ Phone: _____

Male Female Language: English Spanish Other _____

Intermittent Catheter French Size _____ Length _____ Male External Catheter Size _____

Peristeen[®] Anal Irrigation


Name of Clinic and Clinician who referred you: _____


Already referred to a supplier: No Yes, please specify _____

Insurance Provider: _____

Enroll in the program in one of the following ways:

 Fax - send Patient Enrollment Form to 1-800-501-8533

 Email - send request to samples@coloplast.com

 Call - contact Coloplast Consumer Care at 1-888-726-7872

*Patient/**Legal Guardian _____

*I agree to enroll in the Coloplast Care program, have read and acknowledged the privacy statement, and acknowledge that if required I have a prescription for requested samples.
** Legal Guardian must sign if patient is under the age of 18.

Privacy Statement

Coloplast cares about your privacy and complies with HIPAA requirements. Coloplast will not sell, rent, or give your personal information without your permission except where: (1) required by law; or (2) used by Coloplast, its agents, affiliates, contractors, or supply or service providers, to provide you with information by telephone, or other methods, about Coloplast products, services, and wellness education. Coloplast may change this privacy statement from time to time. If you do not wish to continue to receive communication from Coloplast, you may opt out by contacting Coloplast at 1-888-726-7872 or email samples@coloplast.com.

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 Medical Equipment
 Social Programs Greatest Need

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.

My Name: _____

Address: _____

City/State/Zip: _____

Email: _____

Phone: _____

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