

MULTA SPES

MUCH HOPE

IMPROVING THE QUALITY OF LIFE FOR THOSE WITH MS SINCE 1949

June 2010 Issue

Director's Notes: by Candyce Hayes



What does two trips to the beach, wearing purple during a summer picnic, music and learning something new to make life easier have in common? Answer: They're all fun things to do at an MSSP event (and a few of my favorite things) so look out Oprah.

Over the next few weeks your MSSP family/staff are going to play at Oaks Park and learn to play Slingball (it's like Bocci ball) at the 4th annual Marilyn J. Neu "MJN Help Defeat MS" Slingball Tournament in Lincoln City. Please visit www.slingball.com for more info. We will also send air conditioners to help folks manage the hot weather. Helping clients and playing away the summer - ain't life just grand? What else could we do? Well, how about taking time to care for and acknowledge those precious MS caregivers?

As you may know, caregivers are on the frontline in the fight against MS. They are often hoisted into

full and part-time jobs without training. They are overlooked and overworked yet quietly and diligently go about making it possible for clients to remain independent. So their time has arrived. MSSP announces its first "Caregiver Recognition Contest." The winner will receive a 2-night stay in Lincoln City, \$150 food/gasoline allowance, an hour massage thanks to our wonderful volunteer LMT Pam Pennington and care giving services from our respite sponsor Micki Carrier at Caregiver Connection. We would also like to thank CareMedical for their generous support in recognizing the caregiver. Please turn to page 5 to learn more about our sponsors.

Here are the rules and instructions for the contest: Client/caregiver must reside in Oregon or SW Washington and be 18 years or older by July 31, 2010. Only one completed application per client will be considered. Submit a 100-300 word essay describing how your MS caregiver has gone the extra mile to enrich your life. **ALL caregivers qualify, paid or uncompensated, family members or otherwise.** Applications are

enclosed and available on our website or by calling the MSSP office. ALL applications must include: (1) a current picture of yourself and your caregiver, (2) verification of the client's MS diagnosis, and (3) a copy of the client's utility bill.

About our contest sponsors: Caregiver Connection has been Portland's #1 registry for over

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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: 7/15/2010.

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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Bed Bath & Shower Aides

Are you bedbound and wish you could get a shower? Well thanks to the product below it's now possible.



The "Inflatable EZ Bathe" system accommodates people up to 6'2" and when inflated rests on the bed. The patient needs to be transported off the bed while the tub is put in place. An intake and drainage valve allows water to come from up to 25 feet away and drain into a tub, toilet, or waste-can nearby. The heavy duty vinyl allows a bruise-free shower with water. It's a great way to get clean without leaving your bed. Soaking is made easy with this product! You can adjust where the water goes by putting pillows or blankets underneath the bathe so certain areas can soak and the head stays above the water.



For those who would prefer just a shower here are two products that may help. The first is an "Inflatable EZ Shower Basin". This basin inflates and allows the caregiver to easily wash the hair. The basin does not come with an air pump so you'll have to pump it up manually.



Another accessory for the bathing system is a water holder. This holder has a hose attached to it for easy water control and contains up to 2.5 gallons of water. It conveniently hangs from an I.V. pole or bedpost.

These products are available from many medical supply companies such as CareMedical, The Wright Stuff, Inc. and Access at Home, Inc. The cost for the bath tub starts at about \$300 while the additional basin and water holder run about \$25-\$40 each.

(Pictures taken from:
The Wright Stuff, Inc.

<http://www.thewright-stuff.com/>

Click "Caregiver Products" / "Getting Ready" links for products shown above)



Message from Board President by Dave Peery

MSSP turned 61 this year and Candyce Hayes, your Executive Director, has been at the helm for eighteen of those years although she doesn't look a day over 35. Like most organizations we have had our ups and downs over the years, mostly centering around the same thing that affects you and me (money). It's a human condition and never changes, no matter how much you have...and we are NOT going to talk about it.

Today I want to talk about what really makes our organization go; the people that have dedicated themselves to helping the MS community. Your Board of Directors is made up of nine women and men who give their time and effort toward sustaining what we have and improving the organization, wherever we can. And then there are the volunteers, those kind folks who come out and do what needs to be done. Without them we would never reach our goals and for that we are extremely thankful.

I could sit here and write all day about Candyce and the extraordinary effort she contributes toward MSSP on a daily basis and I could tell you about Kaisa, who is proving invaluable in helping the organization grow. But I won't. I am simply going to give you three examples of what happens around the MS house every day and the caring solutions that this fantastic staff comes up with to help people in need.

- A state caseworker, Donna, called with an urgent request. Donna described a client in NE Portland that desperately needed to escape an abusive spouse. The client had family out of state where she could relocate. The caseworker found monies to purchase the bus ticket but discovered funds could not be used to transport the client to the bus station. The bus was leaving in two days. Donna asked if MSSP could help get the client to Greyhound. Within minutes we responded with a YES! The caseworker was amazed and delighted. Early that Saturday morning MSSP staff called Radio Cab to verify the client was scheduled for pick up. While we (caseworker & MSSP staff) may never meet, we created a bridge to take the client to her new, safe life.
- Another client called to say her job required a lot of walking and she felt without a scooter she would lose her job. Within 24 hours her husband picked up a free scooter from the MSSP medical equipment loan closet enabling the client to keep her job and her mobility.
- A hospital social worker contacted MSSP to say a client/patient needed prism glasses and lacked financial resources or insurance. We researched the glasses and purchased them online from a medical equipment vendor. Within weeks the client's new glasses were delivered to his doorstep.

In the midst of their daily work, Candyce and Kaisa have always found the time to help.

MS Brain Games

Partnering with Microsoft and Bayer, the National MS Society created online games to help with brain power. As we learned at the March 27th workshop, we are losing brain power every day. To help MSers with cognitive learning, www.MyMSMyWay.com created free online games just for MSers to help increase brain power as we learn new things. The research team, including MS healthcare professionals, created games that provide fun and interactive challenges.

To ensure that the games are accessible to the MS community, technical modifications were developed. This includes minimal mouse and keyboard movement. Many of the games only use two keyboard keys for all actions. The appearance also helps as the font is large and the colors are bright.

According to the National MS Society, approximately 50% of the people with MS have cognitive difficulties. Sites, such as www.MyMSMyWay.com, www.fitbrains.com, and www.lumosity.com, offer free games that are easy to play while increasing memory, focus, and problem-solving. This information is based on findings from on-going studies.

You and Your Bladder!

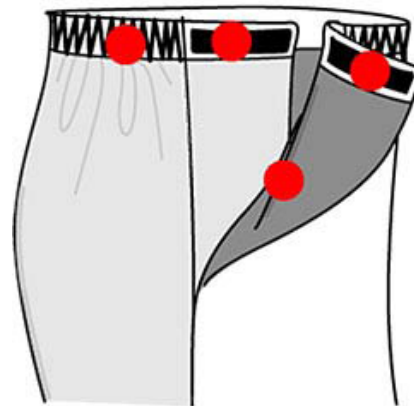


Bladder health is critical to your overall wellbeing. Plan to attend our free June 26th workshop (see insert for details) where Dr. Nina Davis, a urologist, will share important information about incontinence.

In the meantime if you are limiting fluids because of urgency and mobility issues, check out the solutions below! Silverts offers a variety of slacks and pants with Velcro® side openings. From the pictures below you can see the Velcro® side opening allows for easy unfastening. The pant front has a faux fly to look like traditional pants. These pants are comfortable as they have an elastic waistband and are made from a washable fabric. They come in a range of sizes and a variety of colors. These are a great way to ease bathroom worries and they look like regular pants! The dots indicate elastic waist, Velcro® closure, and the side opening. The cost ranges from \$30-\$45 per pair of pants.

www.silverts.com or call 1-800-387-7088 for free catalog.

Other products can be found on the internet. Try these websites/search engines: Google incontinence clothing or go to networkofcare.org/Oregon/adaptativeclothing.



Milestones

Alan Roth



A long-time board member, client, friend and MSSP family member slipped away on 02/28/10. Alan was an amazing human being, always positive, warm and caring. As I sat with his family at Hospice House, I overheard many beautiful stories from his life. Such as, how he taught himself the alphabet in reverse so he wouldn't disturb his wife's morning routine, or how he loved to send daily emails to his grandchildren. His children grew weary of hearing him repeat, on a daily basis, how much he cherished and adored his wife, Linda.

His children also grew tired of hearing him repeat, again on a daily basis, "Have I told you today how much I love your Mom?" Alan's playful nature occasionally surfaced as he would change the familiar phrase from "Have I told you today how much I love your Mom?" to "Have I told you today how much I love you?"

Alan was an unselfish man with a zest for life that few grasp. He once told me, "In my heart I'm wearing a black leather coat and riding a motorcycle. In reality I'm in a scooter with a poodle in my basket!" It was an honor and a privilege to have known him.

MaryLou Braddy



Our friend passed away at a care home on the morning of 3/3/10 following a brief battle with liver cancer. MaryLou had the voice of a songbird and the elegance of a time gone by. She lived with MS for over 40 years, never allowing it to rob her of that beautiful smile and caring heart. MaryLou loved to share a memory, joke or story from Readers Digest. She was a long time member of her church. MaryLou had two sons and 7 grandchildren. Her favorite saying was, "I think that's great" and if you spent a moment with her you'd agree she was very special lady indeed.

Director's Notes: by Candyce Hayes *Continued From Page 1*

10 years. They refer independent caregivers that can be hired directly for a reasonable referral fee. Caregivers earn 85-90% of the total fee and thus, they are able to attract Portland's finest caregivers. They can provide companionship to end-of-life care; are screened, bonded and insured for liability, and take ongoing education at their own expense. Call them today for a free consultation at 503.246.4672 or visit www.CaregiverConnectionPDX.com



Care Medical & Rehabilitation equipment is dedicated to being the NW's "Partner in Care", providing quality home medical and respiratory equipment and supplies, caring and personalized service, superior products and after-sale support maintaining their primary commitment to improve the equality of life for their customers. Call them today at (503) 288-8174 or visit www.CareMedical.com.

Keeping Our Doors Open:

Music For MS Benefit Concert

Thank you to Jason Mockley, the Kennedy School McMenamins, and the rest of the amazing bands for a great concert!! On February 21, 2010 we danced, sang, laughed, and celebrated with seven different bands to benefit the MSSP. The music ranged from children's interactive music to the grand rock finale with Jesus Presley. The 100 plus attendees listened to Uncle B & Aunt E & J-Dog, Floating Pointe, Panhandle Pete and Cookie, Adam + Kris, David Bryan Wilson & the Wild Frontier, Pale Blue Sky, and Jesus Presley. We raffled off two great items including a strat-like guitar with all the signatures from the musicians and an ocean-front 2-night hotel package. Thank you to all who contributed to make the afternoon a great success! We were able to raise about \$2,000 for the MSSP! Please check out our website for pictures from the concert!



Guitar winner Kerry Romei and her sister Diana Barnard



We are delighted to announce that Jason Mockley has agreed to join our Fundraising Committee. In the future, we plan to organize more music benefits. Thank you to all the bands and members of bands who have expressed interest in future concerts.

Mark These Dates

Event Activity	Date	RSVP Required * Application Deadline **
Annual Summer Picnic	June 12	June 7 *
Caregiver class @10:00 a.m. @ MSSP House	June 19	June 14 *
Educational Program - See Insert “Living Your Best Life”	June 26	June 18 *
Marilyn J. Neu Slingball Benefit @ Pacific City, Oregon	June 26	View www.slingball.com for details.
Caregiver class @10:00 a.m. @ MSSP House	July 17	July 12 *
Caregiver Recognition Contest	June / July	July 31st **
Summer Comfort	“Spring” “Summer”	June 30th ** August 1st **
Caregiver class @10:00 a.m. @ MSSP House	August 21	August 16 *

Please Join Us At Our Summer Picnic

Date:	June 12
Location:	Oaks Park SE Spokane St Portland, OR 97202
Time:	11:30 - 3:30 pm
Cost:	Free Donations Appreciated
Limit each party:	5
RSVP Deadline:	June 7th
Call or Email:	503-297-9544 events@msoregon.org



**Wear Purple
Win a Prize**

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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