Multiple Sclerosis Society of Portland, Oregon Inc.

MULTA SPES

Much Hope

Improving the Quality of Life for Those with MS since 1949

Fall 2012 Issue

Director's Notes: by Candyce Hayes

I've missed you. We didn't issue a Spring newsletter due to my battle with cancer. I'm doing much better now. I share my diagnosis with you because I want to tell you about a great non-profit program I used during my recovery. It's called CaringBridge.

Through this program I was able to update my family and friends about various stages of recovery and they got to write me notes in my guest book. I tell you the guestbook feature was like getting greeting cards, advice, words of encouragement and levity during dark times.

Another (important) feature CaringBridge offers is a task list called Build Your Planner. This is where the patient/family members can list what needs to be done and others sign up to complete the task. For example, if a patient needs help with transportation or grocery shopping the task is listed and a trusted person commits to carrying out the assignment. It's important to note that only "invited persons" can visit your site.

I updated my journal on a regular basis. I even wrote a list of things people could do for me: Granted this list was designed for cancer recovery but you can modify it to your needs. Here's my example:

- Just call to chat
- Send your contact information to friends, colleagues encouraging frequent phone calls, greeting cards, emails, flowers & updates
- Have someone cook you a healthy meal
- Go to a matinee and/or lunch or ask if you can drop by with a funny movie and popcorn
- Pick up your "to do" list and complete errands like groceries, post office, housecleaning and banking
- Just call to chat
- Get added to a prayer list
- Share your hobby with a friend
- Just call to chat
- Massage your muscles
- Send "e-hugs"

To visit their site go to **CaringBridge.org**

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: 10/15/2012.

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.

FYI

Acupuncture

Have you been curious about acupuncture but wasn't sure it was right for you? We've got great news.

Between now and 12/31/12 we're offering a free introductory session. Additional sessions are available on a sliding base fee. To reserve your spot call 503-297-9544 or email candycehayes@msoregon.org.

An MS diagnosis isn't required. Anyone 18 years and older is welcome to try the program. Please help us spread the word.

Transportation

For free transportation to medical appointments in Multnomah and Clackamas counties try Ride Connection at 503-226-0700.

Cardio Classes

Low Impact Wheelchair Cardio Classes are available at many locations. Contact Portland Parks & Recreation to learn more at www.PortlandParks.org or 503-823-PLAY (7529).

Thanking Our Volunteers

MSSP relies on volunteers to help us to operate. Here's a partial list of our wonderful helpers.

Mike Stofiel is an artist. He also serves as a board member, webmaster and graphic designer.

Mark Woodlief is a seasoned writer-editor. He is responsible for "polishing" up our newsletter.

Minuteman NW gives us reduced prices on our printing.

Shannon Tebbetts' fingers fly as she does data entry.

Mark Henley from Shamrock Medical drops by monthly to update our medical equipment closet.

LouAnn Lindberg, a board member, faithfully volunteers every Tuesday.

Splinters from the Board

Hello, my name is Art Richards and I am honored to serve as the new President of the MSSP. I have been involved with this great organization since 1996 when I became their insurance agent and became friends with Candyce. I have always been impressed with her love and compassion for those impacted by MS and her dedication to fulfilling the mission of MSSP. We have a great Board of Directors who are also actively involved in building our organization.

Several years ago I was asked to head up the fundraising committee. I didn't have a lot of experience at fundraising, so I went with something that I really love: Blues music. Over 25 years ago, as an early member of the Cascade Blues Association, I was tangentially involved with the planning of the first 'Waterfront Blues Festival'. Over the years we have seen this great benefit concert grow to become the second largest festival of its kind, just behind the Chicago Blues Festival.

With this in mind, our committee decided to have our own concert and with the help of Robbie Laws, one of the best and kindest bluesmen around, his sweet wife and Greg Johnson of the Cascade Blues Association we launched the first annual Blues4MS concert in 2011. Our concerts always include a guitar raffle (see me pictured to the right presenting the guitar to last year's winner). The raffle raises about 30% of the concert's proceeds. We followed up earlier this year with Blues4MS II and have Blues4MSIII scheduled at the Aladdin Theatre on March 3, 2013. I'm excited to announce this year, we are raffling a fabulous and expensive ($4,599 MSRP) Martin 000-28 EC (Eric Clapton) acoustic guitar, hand-signed by Eric himself. Raffle tickets will be sold at $10 each or 3/$25. The winning tickets will be selected following The Knuckleheads, set on March 3rd and the lucky ticket holder need not be present to win. You can order raffle tickets on-line by visiting www.blues4ms.org or call the MSSP office at 503-297-9544.

We have a number of existing fundraising projects, like the flu shot program and Slingball. This year's Pacific City Slingball tournament raised $11,250 and the Portland Tourney will be held October 13 (see pg 11 for details). We are looking for additional fundraising projects to further the good works of the MSSP. Let me know if you have a great idea for the next fundraising project and want to help make it a reality. We are always open to new ideas and wonderful people who want to help. Remember, we pray for the cure, but we work in the "here and now" using our efforts and funds to help lighten the burden of those affected by MS. Here's to a bright future.

Art Richards

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TriMet LIFT Changes

There are two changes to the LIFT service area. These service changes will impact current and future trips for active LIFT customers. It is important that you have this information when making travel plans. You should receive notice from TriMet directly.

On September 2, 2012, TriMet adjusted the LIFT paratransit service boundaries to provide service within ¾ of a mile of bus/MAX service in accordance with the Americans with Disabilities Act (ADA).

There will be six LIFT service boundaries to correspond with the fixed route service on weekdays, Saturday, Sunday, and all respective evenings. Some LIFT trips previously provided to and from the outlying areas of the TriMet service district will no longer be available in the evenings after 7:30 pm and on the weekends.

An interactive map is available at **http://maps.trimet.org/ada.html**. The following are frequently asked questions and answers:

1. **What changes are being made to the LIFT service area?**
   This change will align the LIFT service area with fixed route service in operation provided by day of the week and hour of the day. There will be six LIFT paratransit service boundaries: weekdays, weekday evenings, Saturdays, Saturday evenings, Sundays and Sunday evenings.

   The vast majority of trips that will be impacted are trips taken in the evening after 7:30 pm and on the weekends, primarily in the outlying areas of the TriMet service district.

2. **When will the changes go into effect?**
   The changes will take effect on September 2, 2012.

3. **How will LIFT customers be notified of the change?**
   TriMet will notify all active LIFT customers by mail. Active LIFT customers who have taken a significant number of trips that will no longer be provided will be sent a letter with the details.

4. **How will I know if my trips are within the service area?**
   LIFT customer service and reservations staff will be able to tell customers if a trip is within their service area.

5. **What if I travel to my destination by LIFT before 7:30 pm but then a return trip isn't available after 7:30 pm?**
   You would have to make other arrangements for the return trip. If a LIFT trip is available within the day service boundary but the location is not served within the evening service boundary, the return trip must be scheduled to be completed by

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TriMet LIFT Changes

7:30 pm. Reservations for such trips will not be accepted when the estimated completion is later than 7:30 pm.

6. **What if I am a LIFT eligible customer and I live or move outside the new service area?**
   If you are currently eligible and live or move outside the new service area, you will still be eligible but you will have to find alternative transportation to a point within the LIFT service area in order to use the LIFT. Ride Connection may be able to provide this type of service and you may contact them at 503-226-0700.

7. **What if I live within the LIFT service area but need service for destinations outside the LIFT service area?**
   TriMet only provides service within the LIFT service area. You will have to make other arrangements for any trips to/from locations outside the LIFT service area.

8. **What if only one segment of the trip is in the LIFT service area?**
   You will have to make other arrangements for the segment of the trip that is not within the service area.

9. **Are there any other options for trips outside the area?**
   Depending on your location, there may be other services for certain times of days. We suggest that you contact Ride Connection at 503-226-0700 for assistance.

Additional Questions or Comments?
Contact LIFT Customer Service at 503-962-8000, option 2

Multnomah Project Independence

Multnomah Project Independence is a Multnomah County-funded program that provides assistance to residents aged 18-59 with disabilities who need support services so they can live independently in the community. Enrollment is contingent upon the availability of funds.

They offer an MPI Case Manager to meet with individuals to complete a comprehensive assessment of their needs. Available community resources are reviewed. The Case Manager and participant will develop a plan that will assist the participant to remain in his or her home through either one-time assistance or ongoing case management and services.

Posssible services include: Case Management, Personal Care Assistance, Housekeeping, Home Delivered Meals, Transportation and Shopping.

Unfortunately the program is not available in Washington or Clackamas Counties. Persons living in those counties should contact their local Area Agency on Aging. Washington county is 503-640-3489 and Clackamas County is 503-655-8640.

Meet Julie: *Advertisement*

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.

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

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

Coloplast

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.

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Meet Julie: *contined from* **Page 6** ***Advertisement***

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 caths 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.

Acupuncture at the MSSP

It has been my pleasure to work with the MSSP for a little over a year now, offering acupuncture treatments Monday mornings. The regular community that joins us is wonderful and have received many health benefits, including increased energy, reduced effects of stress, less depression and less pain. The space is active, yet tranquil, and often I am the only awake person in a room full of snoring, healing people!

According to the Chinese calendar, autumn began August 7th. While it still may be warm and sunny for a while, for many this means the beginning of an onslaught of colds, flus, decreased energy and depression. I encourage you to try something new this year for your health, whether it be a new food or recipe, a new type of movement, or acupuncture.

One of my favorite foods for fall is pear crumble. Pears nourish your lungs, a key component of your immune system and the organ correlated with fall. The warm spices increase your blood circulation and decrease inflammation, and prepare your body for the cold of winter. Here is a recipe!

Slice a few slight hard pears, mix with cinnamon, clove, grated or powdered dried ginger, and honey. Put this in the bottom of a pyrex pan. Top with a mixture of oats, honey, butter, coconut, and walnuts and put in the oven at 350 for 40 minutes or until browned slightly on top. Eat it warm or let it cool.

Whatever you do this season, may you enjoy it in good health.

Alison Loercher, L.ac, MaOm

* * *

My Story

My name is Stacey Bankhead and I have been living with MS for six years. To make a long story short, we had fertility problems for about 6 years. It seemed that nothing went our way, adding stress to our relationship. It was after my last miscarriage that a perinatal doctor from OHSU sent me for a full work-up. They found out I had a clotting disorder that could potentially be treated with baby aspirin and had nothing to do with my MS. Armand Robert Bankhead IV (Bobby) was born September 12, 2010, and our lives changed forever for the better.

My baby boy is the best thing that has ever happened to me. Don't get me wrong, it is difficult. Being a mom with MS means you do things a bit differently than other moms. For instance, while other mothers carry their children in their arms, I use a stroller pretty much all the time. This is not only for his safety but mine as well. I cannot risk a fall while carrying him. If I get hurt in a fall, who will take care of us?

Luckily for us I have a husband that is up to the task. By the end of the day I am usually pretty wiped out. But then the cavalry arrives home from work. There are days that I have trouble finding the energy to set the table etc. and that is where help comes in handy.

Having a baby is definitely life changing. I pretty much bring him everywhere I go. But I find that Bobby (now 19 months) finds little ways to help me out that often bring a tear to my eye. Just recently we were getting ready for a walk and I was putting my AFO on for my foot drop. My wonderful son brought me my sneakers (without me asking) which were on a shoe rack in the kitchen.

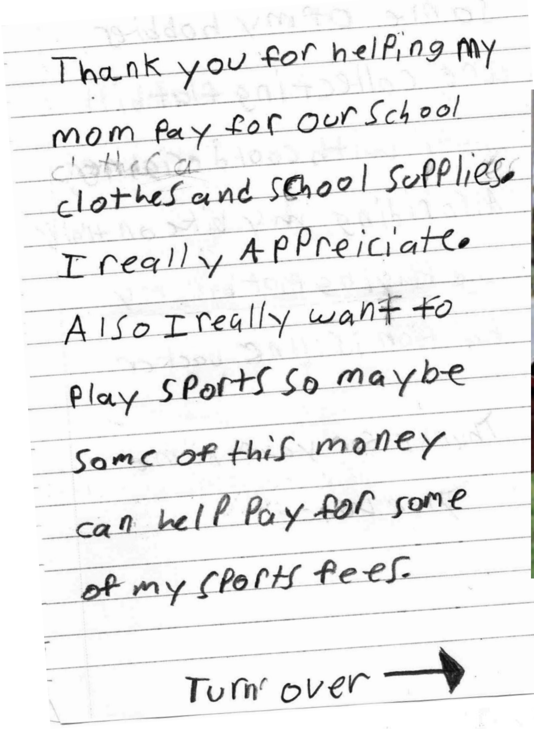
I think the most important thing that I always try to remember is that I do the best I can as Bobby's mom. Keeping him safe is always a priority, even though doing so requires me to do things in an altered way. Most other people understand my limitations and often offer to help. In particular, women in my moms group seem more than happy to help me out when I need it. Most of the time I gladly accept it. Not saying "no" to help or asking for it when you need it is a key strategy I utilize quite often.

I truly love being a mom. It is an experience that I have been blessed with. I would encourage any one with MS to strongly consider having a baby if they want to. I was lucky enough to not have an attack in the first few months after having him, but there are no guarantees.

Don't let your diagnosis of MS get in the way of the things you want in life. I see it as just one of those things that you have to deal with as best you can. No one can ask you for more than that.

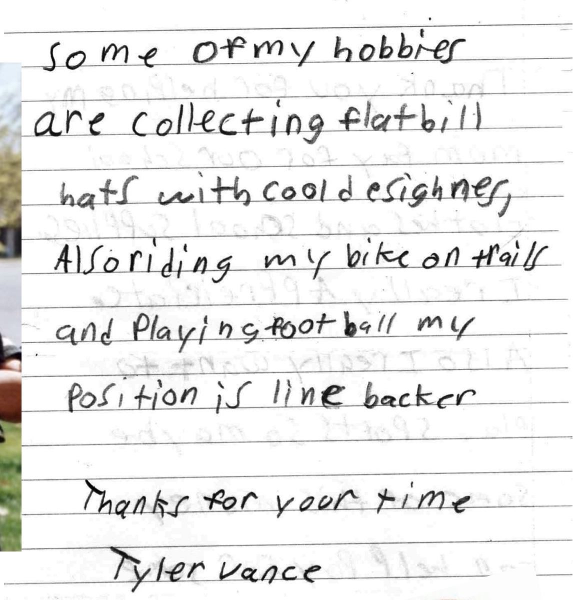
Sheila's Gift

MSSP received funds from Sheila Converse who had MS. She gave strict instructions for us give the money to children of MS clients in Southern Oregon. She wanted to enrich their lives. The following are letters from a family touched by Ms. Converse's generosity.



Thank you for helping my mom pay for our School clothes and school supplies. I really Appreiciate. Also I really want to play sports so maybe some of this money can help pay for some of my sports fees.

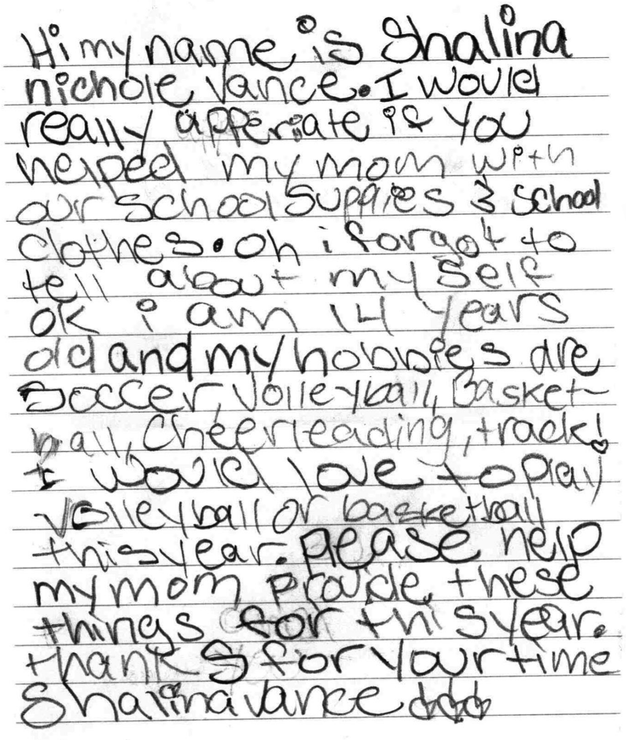
Turn over →



Some of my hobbies are collecting flatbill hats with cool designes, Also riding my bike on trails and playing football my position is line backer

Thanks for your time

Tyler Vance



Hi my name is Shalina nichole Vance. I would really apperiate if You helped my mom with our school supplies & school clothes. oh i forgot to tell about my self ok i am 14 years old and my hobbies are soccer, volleyball, basketball, cheerleading, track! I would love to play volleyball or basketball this year. Please help my mom provide these things for this year. thanks for your time

Shalina vance

KEEPING OUR DOORS OPEN:

Vancouver Brewfest

The MSSP was one of four non-profits invited to have a table at the first annual Vancouver Brewfest on 8/10 & 8/11. It was a great way to meet new people and tell them about MS and the MSSP. We were delighted to raise nearly $1,000 from Eric Clapton signed guitar raffle tickets (the drawing will be at the Blues4MS-III event- see page 3 for details)! Once the proceeds are tallied up, each non-profit will receive a donation. A special thank you goes out to Cody Gray and Andy Stromberg.

RAFFLE AND BENEFIT CONCERT

Martin 000-28 Eric Clapton

Signature Acoustic Guitar
Valued at $4,500
Tickets are 1/$10 or 3/$25

Drawing will be held at the
3rd Annual Blues for MS Benefit Concert
on 3/3/13 from 3:00pm - 9:00pm
Location: The Aladdin Theater,
Portland, OR

Band Lineup:

Robbie Laws Band
Dave's Killer Band *(Dave Dahl of Dave's Killer Bread)*
Kevin Selfe & The Tornados
Mary Flower
Terry Robb Band
The Knuckleheads

All proceeds benefit SW Washington and Oregon MS clients
Need not be present to win. Chance is based on total tickets sold.
More info at www.blues4ms.org or 503-297-9544

Slingball.com

“Helping Fight MS”

During the June 29-30 weekend, the Neu brothers (and family/friends) raised $11,250 during the Pacific Slingball tourney. Come join us for the second annual Portland tourney (see page 11 for details).

MARK THESE DATES

Event/Activity	Date	RSVP
Acupuncture MSSP Annex Portland, OR	Open Mondays 10-2 pm	503-297-9544
Portland Slingball Tournament Foothill Park (SW Park Way & Hilldale, Portland, OR, 97225) MAP	10/13/12 11-3 pm	None required See **www.msoregon.org/slingball.html** for more info
Flu Clinics Greater Portland Area	10/1/12-10/31/12	503-297-9544
Christmas Party 232 SE 80th St. Portland, OR	12/15/2012 11:30-3:30pm	Required 503-297-9544 Seating limited
Blues4MS Aladdin Theater 3017 SE Milwaukie Portland, OR	3/3/13 3:00-9:00pm	None required FREE concert See **blues4ms.org** for more info

* * *

PLEASE JOIN US AT OUR CHRISTMAS PARTY

Date:	**December 15th, 2012**	
Location:	**Montavilla United Methodist Church** **232 SE 80th St.** **Portland, OR 97215**	
Time:	**11:30 - 3:30 pm**	
Cost:	***FREE "Donations Appreciated"***	
Limit each party:	**4 per family**	
RSVP Deadline:	**December 8th, 2012**	
Call or Email:	**503-297-9544** **events@msoregon.org** **or register online at** **www.msoregon.org/calendar.html**	

Multiple Sclerosis Society
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Portland, OR 97236

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Time Dated Material

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:

2901 SE 122nd Ave. Portland, OR 97236