MULTIPLE SCLEROSIS SOCIETY OF PORTLAND, OREGON INC.

# MULTA SPES

MUCH HOPE

IMPROVING THE QUALITY OF LIFE FOR THOSE WITH MS SINCE 1949

*Spring/Summer 2013 Issue*

## Director's Notes: by Candyce Hayes

In this issue you will find inspirational stories and applications for upcoming programs and services.

Everything has calmed down and returned to a normal pace at the MSSP. I wish I could say the same about my home life. Recently my Yorkie, Tessa, got a hold of a chocolate protein bar. Boy was that scary. I'm usually careful about leaving things out, but I was on the way to get my taxes done and I was feeling anxious. I finished my appointment, stepped into the car and Tessa looked up at me with a frightened expression. Her mouth was dripping with chocolate and the darn bar was stuck between her teeth! I tried, unsuccessfully, to pry the bar loose. Now she was very unhappy and I was ***really*** stressed out. So we rushed off to the vet. Two hours and $112 later everything worked out fine. (Oh, the tax appointment went well too. Whew!)

Meanwhile, a friend bought me the sweetest little unsexed Fischer lovebird. I named "it" Charlie (unsexed means we didn't pay extra to learn Charlie's sex). Charlie is now settled in. Strange thing it took a week before it stopped hanging from the top of the cage like a bat! But with time and lots of care beautiful little Charlie swings on its toy and sings sweetly. It's lovely.

As you can tell I'm a big fan of pets. Whether it's a service/comfort animal, reptile or bird, having something to care for helps reduce stress/depression/blood pressure and improves quality of life. Guide/assistance dogs are especially important for people living with MS (see article on page 3).

I'm delighted to announce the MSSP program services committee has been hard at work reviewing existing services. They've decided to grow the massage program called "Project Helping Hands." Because summer is right around the corner we're also enclosing an application for the air conditioner program called "Summer Comfort." We're now accepting applications for both programs. If you have any questions, please call Kaisa (Kye-sah) at 503.297.9544 or email programs@msoregon.org

Have a Happy Summer

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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: 7/15/2013.

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

We often receive requests for caregiver referrals. While it's our policy not to refer individuals, we can offer a criminal background search once you've identified a candidate for a cost of $10 per screening.

Some places people find caregivers include family members, neighbors, and church. We discourage Craig's List.

## Caregiver Classes

MSSP continues to offer (on a request basis) basic caregiver classes at our office. Taught by a Registered Nurse, participants learn basic hygiene skills, how to safely transfer a loved one, and protect themselves from caregiver burnout.

## Yoga

Have you tried yoga? It's a great way to stretch, relax, and meet new people. Here's a little about the two MS-specific programs available in the Portland Metro area. Check your local community center or gym for yoga classes as well (they will not be MS specific but many offer beginning yoga).

The Lotus Seed offers Gentle Yoga for MS at 7 NE Tillamook St. Portland, OR 97212. There are two instructors, Amy Duncan and Cindy Irvine. They have both worked for over 10 years as yoga instructors and focus on alignment, breathing, stretching, and injury prevention. For more information contact: Susan at 503.230.2074 or Debra at 503.234.8425.

The other local MS-specific yoga class is offered through Julie Lawrence Yoga Center at Sunset Yoga Center located at 12923 NW Cornell Rd, Portland, OR 97229. The class is an offsite program of the Julie Lawrence Yoga Center, which handles registration. Their website is www.jlyc.com or give them a call at 503.227.5524 for more information.

## Collies for Mobility and Support

by Leslie Crane Rugg

If people with MS share one goal, it's to remain independent for as long as possible. That one life quality sustains hope and determination above all else. A major aspect of independence is mobility, often a tricky and difficult maneuver to achieve. Certainly, mechanical aids are available; from shoe orthotics to leg braces, from canes and walkers to wheelchairs and motorized scooters. They all offer useful support at some point and in many circumstances.

But life quality means more than the use of props. It means interaction, relationships, communication, and contact. So imagine the possibility of maximizing both mobility and support through service dogs trained specifically to respond to people with MS. Imagine Lassie at your side, not only alert and intuitive but prepared to handle issues of balance, fatigue, proprioception, and spasticity. Imagine a collie who not only helps you manage stairs, elevators, sidewalks and curbs, but who also is a stabilizing presence at home. Imagine your best friend at your side wherever you want to go.

Leslie Rappaport of Kings Valley Collies (Kings Valley, OR) has been quietly breeding, raising, and training rough (long coat) and smooth (short coat) collies for mobility and support for 20 years. While selecting and preparing her collies for people with a variety of physical challenges, she specializes in training and matching her collies with MS clients. Leslie is convinced that establishing a partnership with a mobility collie increases quality of life. She states, "the advantages a mobility collie provides include safe activity without the risk of drug side effects, ever-present companionship which relieves depression, and an increase in safety, security, and independence."

Walking with a mobility collie opens up a world of opportunities. Leslie's clients report an increase in their overall strength, cardiovascular health, and range of motion. They also note a decrease in reliance on visual cues for balance, at the same time feeling more stable and secure while exercising or walking, and more capable of proper alignment. For those people with MS who experience spasticity, mobility collies provide consistency of movement.

People with MS often have difficulty in sensing the relationship between movement and location since MS can interfere with brain signals sent to arms and legs. Mobility collies help alleviate proprioception and bring a renewed level of awareness to their human partners. Leslie trains her mobility collies to maintain a consistent working position next to their partners. Continually adjusting to their partners' movements whether forward or backward, left or right, mobility collies maintain a constant and steady reference point. While moving subtly, the collies maintain a working position with their partners, helping them also to maintain balance while walking or standing.

It can be exhausting for people with MS to execute a relatively simple set of routine motions, much less navigate going to the market or a doctor's appointment or just a stroll in a

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park. With a mobility collie, the fear and the fatigue are minimized. Leslie's collies have mastered the support, stability, momentum, and control techniques necessary for walking, stopping, or standing still alongside their human partners. Specifically, mobility collies support and stabilize their partners when descending stairs, while providing forward momentum when going up stairs or curbs. Mobility collies help their partners sustain forward momentum while walking and then control that momentum to make successful turns. Mobility collies lend crucial physical support when their partners stop or stand still.

As unbelievable as it seems, the skill set of Kings Valley Collies for Mobility and Support restores freedom and confidence to their MS partners. But believe it! Leslie's clients come back to Kings Valley time and time again for their next mobility collie. And the families and friends of people with MS are equally positively affected. To see examples of the great work done by Leslie, her collies, and her clients, visit her website- www.kingsvalleycollies.com - and her Facebook page www.facebook.com/kvcmsgal?ref=ts&fref=ts. Be sure to watch the video clips of the teams at work and read the service dog stories written by the MS partners themselves. For information about the cost of a mobility collie and organizations that help with costs, check out www.gofundme.org and www.modestneeds.org and www.oregon.gov/DHS/vr/Pages/index.aspx for Oregon's Office of Vocational Rehabilitation Services.

## My Story

by Robin Blue

This story gives true meaning to the saying "It takes a village…" As the mother of a daughter with MS, this is not really my story, but our story. It is the journey of a collective family that cares and loves deeply and, as Nikki would say about me, is E-M-O-T-I-O-N-A-L when it comes to dealing with the seriousness of her disease. My name is Robin Blue, and I am the mother of Nikki, a 29-year-old single mother who has been living with MS for the past five- and-a-half years. I was living in California and she was in Oregon when I got the phone call: "Mom, are you sitting down? Nikki has had 17 seizures in the past three hours. She is in the emergency room." Her older brother Danny phoned me. Nikki was too scared to tell me herself. This was just the beginning of our story.

She was pregnant. All her symptoms pointed to MS. Her MRI showed lesions on her brain. Her CT scans confirmed this as well. Her neurologist said because she was pregnant she could not have a spinal tap that would confirm a diagnosis. The good news was that her unborn child was a shield from the symptoms of MS. She would have to wait until after the birth of her baby to receive treatment and official diagnosis of her disease. She was able to take medication to control the seizures. This is when we learned about MS.

I had never really thought about MS before this. I had known a few people who had the disease, but did not know a lot about it. I knew that it was serious and life threatening, but did not know specifics. I am the type of person who needs to know everything. I crave knowledge. I am also hypersensitive. Nikki and I are very much alike in that way. We are both very emotional. She does not feel the need to know every detail. I do,

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# My Story

by Robin Blue

when it comes to information. This is where we help each other, and sometimes frustrate each other as well. She is extremely independent, and I respect that. As a mother, I know there are occasions that I need to be there for her when she is going through tough times. I know at times she says I hover and I agree, I probably do. However, when her symptoms have included irritation, agitation, fatigue, forgetfulness, extreme exhaustion, and most recently extreme stress it is beneficial to have someone who truly has your best interest at heart nearby to provide love and support, even if it is a little irritating sometimes. She has a five-year old daughter and can't do everything by herself all the time and I realize how hard it is for her to ask for help and that it is frightening sometimes to be in her shoes.

When she first started treatment for MS, she began using an injectable medication. This began right after the birth of her daughter LeeAna. The treatment worked well for five years. Nikki had very few exacerbations since her diagnosis. Actually, so few that I did not even know what the word exacerbation meant until a few months ago, when Nikki's health took a turn. She began having left-side seizures, over 357 in three weeks. After numerous tests and no answers, I finally was able to talk to her neurologist on the phone. We kept a running log of Nikki's "moments," as we called them. They interrupted everything about her life. She had to quit working for nearly a month, she could not take care of her daughter or even do something as simple as get up and wash the dishes without having a "moment" (exacerbation). These "moments" caused her entire body from the neck to toe on her left side to seize for anywhere from 30 seconds to 1.5 minutes. They came like labor pains for a woman about to give birth, every few minutes. This went on for weeks.

Her doctor finally discovered the culprit. A lesion on her internal capsule nearly destroyed Nikki's spirit. She is a preschool teacher. She had to leave her job and tell her employer that she was having seizures. Nikki was afraid she might drop a child. While this was the responsible thing to do, it was devastating for Nikki. She is back at work now, but only part time. She has to keep her stress level low, and as she says to me, she puts her stress "in a box." Stress is a huge trigger for her. It brings on exacerbations.

Ultimately, the decision was hers, but I am happy to say that she includes me in her visits to her neurologist. I am able to help her understand and talk out things with her care team. It helps to have two of us present so we can both ask questions as well. She has different treatment options available to her.

As a family, we took turns staying with her, to help Nikki get through this time. Even if it was just to hang out and watch a movie with LeeAna or fold a load of laundry. Helping advocate for her was

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## My Story

by Robin Blue

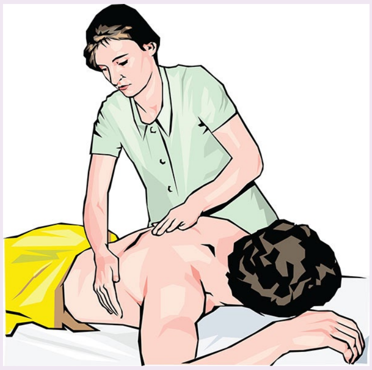
an important part of this time also because her symptoms include mood swings and frustration at times. It is not easy if these “moments” occur in public places sometimes. They can however be humorous, too. Sometimes, we have to laugh to keep from crying. Nikki, her older brother Danny, and I were all having coffee in Starbucks one day. Danny did not know just how many “moments” Nikki had been having. So, Nikki and I explained to Danny just how serious Nikki’s problem had become. We told him that Jordan and I were taking shifts at her house just hanging out with Nikki and LeeAna. Personally, I just wanted to be there for Nikki in case something more serious happened. We did not know much about exacerbations, they were both frightening and exhausting to Nikki, and none of us really knew what they were all about. During this conversation, Nikki began to have a seizure. She became embarrassed because we were in a public place, and I made light of the situation and made a joke, making her laugh. I then choked on my food. The Starbucks clerk asked that no one die on her shift, and Nikki started to cry and laugh at the same time, accidently spitting out all her coffee at Danny, who had on a brand new Oregon Ducks T-shirt and cap. She was still stuck in her seizure. We couldn’t stop laughing, though. He tried to be mad, but couldn’t and just laughed as well. These are the “moments” that get us through the rough times together as families.

Nikki is a very amazing young woman who works very hard to maintain a stable home for her daughter. She goes to work each day, riding the bus and not getting home until sometimes late in the evening. She maybe gets to spend two hours with her daughter before bedtime during the week, yet she makes that time a peaceful, happy, and playful time for her. The weekends are spent with her daughter and us. She goes to the basketball games of her nephew Niklaus, watches her niece Kailee practice cheerleading, and she will come spend the night with me if she is in the mood for a movie. If she wants to shop or play cards, she will spend time with her brothers Danny and Jordan and sister-in-law Jesse. The point is that each week, this is her circle, it is all of us that make life less difficult and quite beautiful sometimes.

Nikki was moved by the Blues4MS benefit concert. We met some really nice people. We stayed the entire time. LeeAna is typically a really shy little girl, too. She wouldn’t dance until she found another 5-year old who danced with her. Then there was a family who had children and they danced with LeeAna, too. Everyone was so welcoming and had so much fun. This father who was dancing with his daughters was so cute, he let LeeAna dance with them too. He had all of them in his arms and one on his back. His wife was dancing, as well. It was beautiful how everyone just came together and enjoyed the music and each other.

## Massage Program Reopens!

Project Helping Hands is accepting new clients between June 1 - September 30, 2013. Call the MSSP office for program details.



# MARK THESE DATES

| Event/Activity | Date | RSVP |
|---|---|---|
| Acpuncture @ the MSSP Annex. Call 503.297.9544 for more information | Mondays 10:00-1:00 pm | Ongoing |
| Annual Picnic “See Below“ | 6/22/13 | 6/12/13 |
| Slingball @ Pacific City. See www.slingball.com for more information | 6/29/13 | |
| Advancements In MS Treatment 2013 & Navigating The Health Insurance System Workshop | **NEW DATE**<br>8/17/13 9am to Noon | 8/9/13 |
| Summer Comfort Application Deadline<br>Project Helping Hands Application Deadline | 6/30/13<br>9/30/13 | |

# KEEPING OUR DOORS OPEN

MSSP enjoyed another successful Blues4MS concert on March 3, 2013. Everyone had a great time and we raised over $11k. A special thanks goes to the fundraising committee, Greg Johnson, our sponsors and attendees. We’re already planning our next Blues4MS which will be held on March 2, 2014 at the Aladdin Theatre – further details to follow.

# ANNUAL PICNIC

| | |
|---|---|
| **Date:** | June 22, 2013 |
| **Location:** | Oaks Park<br>7805 SE Oaks Park Way<br>Portland, OR 97202 |
| **Time:** | 11:30 - 2:30 pm |
| **Cost:** | FREE Donations Appreciated |
| **Limit each party:** | 4 (additional guests at $6.00 each) |
| **RSVP Deadline:** | June 12, 2013 |
| **Call or Email:** | 503.297.9544<br>events@msoregon.org |

**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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