MULTIPLE SCLEROSIS SOCIETY OF PORTLAND, OREGON INC.

MULTA SPES

MUCH HOPE

IMPROVING THE QUALITY OF LIFE FOR THOSE WITH MS SINCE 1949

Fall 2009 Issue

Director's Notes: by Candyce Hayes

From time to time people ask me how I got into non-profit work. Here's my story:

I'd been working out of state for a private vocational rehabilitation company when my mother died unexpectedly. There was no will and the estate was a mess. After a year I decided to return to Portland. While I could have returned to the rehabilitation company at a lower position, I was young and decided to seek greener pastures. During the transition I went to work for a temporary agency called Pro-Tem, and was assigned to the Fred Meyer Charitable Trust. When I first received the information about where to report I proclaimed, "I'm not wearing one of those tacky blue smocks!" I didn't have a clue my world was about to change.

I attended board meetings and watched as millions of dollars flew out the door. Eager non-profit organizations routinely marched through the door praying their proposals would be funded. I was too young to appreciate the magnitude of the Trust's work. It was simply meetings. There were letters, albeit grant letters, bringing manna from heaven to starving groups. But to me, none of it was real. Three years later, one of the Trustees, Oran B. Robertson, chairman of the board for Fred Meyer, Inc., was instrumental in my landing a job in the President's office of Fred Meyer. I was responsible for the corporate side of giving, and that's when my eyes began to open toward the future.

A caseworker called one morning, asking Fred Meyer to help a family torn between buying food and medicine or diapers for their adult disabled child. Our standard answer was a $25 gift certificate, but this was inadequate. Someone needed to step in and rally support for the family. So I called the company buyer and pleaded the case for diapers. The buyer then called the supplier. Then one supplier challenged another supplier! By day's end the family's living room was filled with diapers!

Inspired by that response, I suggested Fred Meyer offer their employees an opportunity to volunteer with the organizations we supported. With the help of Mr. Robertson and other key players, the Fred Meyer Volunteer Council was born. The program continues today.

From these experiences, I learned that when money, volunteers and careful planning are combined, lives become enriched. These are the hallmarks that drive the work done at the MSSP. While we are tiny, we make a huge difference in the lives we touch. I invite you to read Joan's story on page 5 for an example. To learn more about other MSSP programs and services, please visit our website at www.msoregon.org or call us at 503 297-9544.

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 2009 submission deadline is: 10/1/2009.

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.

Could you be a Class Act?

By Victoria Gardner

Recently I was asked to listen in on a presentation by Jonathan Westin, Assistant Director Legislative Affairs of the Jewish American League. Mr. Westin was asked to describe the latest proposal considered to help tackle the long term care crisis that will affect all of us: whether you will need care or not. The Class Act 'Community Living Assistance Services and Support' Act of 2009 takes on the issues of how Americans are going to pay for long term care for our disabled and aging population. Medicaid is broke, Medicare does NOT pay for long term care and newest estimates anticipate that Medicare will be bankrupt in 7 years. The cost of long term care will affect all of us. It is a national issue and we need to talk to our families about the aging process and how long term care fits into the planning for our future. It is becoming clear that YOU MUST PLAN YOUR OWN CARE or take the risk of having someone plan your care for you.

Care in many cases is already dictated by cost. The numbers we are facing about our aging population are scary and the mass of Americans with no long term care protection is overwhelming. Currently there are 78 million baby boomers which will be turning 65 soon. Statistics show they have not planned for their long term care needs and worse, they have no savings. As boomers age, Alzheimer's is expected to occur in epidemic proportions. For boomers with a family history of medical problems or disabilities, they need to be insured before a medical crisis develops. Already in various types of insurance, carriers are asking applicants about their family history and denials can be based on that history. (For the spouses of those too ill to qualify, it is wise to seek coverage, as all resources could be used for the one who cannot get coverage.)

So how does CLASS ACT 2009 work? The CLASS ACT of 2009 is a proposal endorsed by many government entities and AARP which would provide a payroll deduction program for long term care. Individuals would opt in or out through their employers human resource department. If you opt into the plan, you would pay into the program for 5 years after which time you would be eligible to receive either a $50 or $100 a day benefit for long term care. You would choose your daily benefit when you enroll in the plan, with the maximum monthly benefit currently proposed at $3,000. The latest age an individual would be allowed to enroll in the program would be age 60 so that at 65 years of age, a person would be able

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Could you be a Class Act? By Victoria Gardner

to receive plan benefits in the 61st month after beginning participation. Payments into the plan would be based on age with younger individuals paying far less every month than older individuals. There would be no medical underwriting and the plan would include inflation protection and spousal coverage. Plan benefits would be triggered two ways. For the $50 a day benefit, a person should be unable to perform two Activities of Daily Living (ADL'S). For $100 a day benefit, a person should be unable to perform three ADL's. If you feel that the daily benefit amount offered by CLASS ACT of 2009 is not adequate, a person would have the option of buying a private long term care policy to 'wrap around' the benefit. Insurance Agents would not be involved in the payroll CLASS ACT program.

As of last week, CLASS ACT of 2009 is now just a proposal. There is no proof that the plan would work however, the message is very clear we must address the critical need for long term care now. The bottom line – be a "Class Act" yourself in 2009. Plan your own long term care. If you have any questions I can be reached at the InsuranceStoreOnline.com

Bingo Party Future Uncertain

The last two bingo parties have not been well attended. This leaves us wondering: A) Should we stop doing Bingo parties? B) Does the Bingo party simply need an overhaul? and/or C) What else would our guests like to do in the Spring? So we need to hear from you. If you want to save Bingo -- 35 people need to write, email or call the MSSP office by December 31, 2009. Otherwise, we will replace Bingo with another activity.

Mini Quiz

When asked what do you think is most at risk when you bring a stranger or "unknown caregive" into your home? A gal replied, "my husband!" Here are some other things to ponder:

Identity theft, peace of mind, and personal belongings.

Q: What are the top three things most at risk from being stolen by "unknown caregivers"? (see page 7 for answers)

The best way to protect yourself from "unknown caregivers" is to increase your circle of support. MSSP is here to help you do just that! You identify people YOU trust: family members, neighbors, friends, church members, etc and they attend MSSP's free caregiver training classes (see page 7 for schedule or call 503 297-9544 for details).

S-t-r-e-t-c-h-i-n-g Your Dollar!

Food prices rise so fast these days it's impossible to keep pace. It's not our policy to endorse or encourage customers to shop one store over another. However, we're making an exception. Each holiday season Food 4 Less offers a great budget stretching holiday meal deal. They haven't announced this year's "package" but typically for about $25 you can pick up traditional fixin's for a family of four!

Caregiving Conflicts & Challenges

Women with physical disabilities are more likely than other women to be victims of domestic violence. According to the Colorado Department of Health upwards of 85% of women with disabilities are victims of domestic violence. Other studies show that men with disabilities also experience a higher rate of abuse than their non-disabled constituents.

In families or in caregiver relationships, maltreatment can be so subtle that many of us do not see it. This can come in the form of ridicule, pity, or of being treated as an eternal child. The family member or caregiver may also isolate, threaten to withhold treatments or medications, make belittling statements, mock, or attempt to manipulate.

Of course abuse can be even more blatant. For example, those who are vulnerable due to MS may experience being screamed at, physically threatened, or physically assaulted.

Those who experience this treatment are often left feeling lonely or fearful that they will lose their home and the love of their family members if they speak out. They may feel there is no hope. At the same time, family members or care providers may be feeling the very same way, even when they are in their worst moments, treating their loved ones in a non-supportive or abusive fashion.

There are stressors that tell us when a family may be headed towards an abusive situation. Being alert to these can turn the course of events around. According to another study: "No matter how well a family adjusts to caring for a person challenged with a disability, over time everyone feels stress. Family members can be drained by the continual demands of caring for a loved one with special needs. When a caregiver feels overwhelmed, physical, mental, emotional, or even sexual abuse can occur."

Some of these stress factors include:

- Increased external pressures - for example; finances or needs of other family members.
- Increased risk for isolation for all family members.
- Constant responsibility. Physical and emotional demands on the caregivers can be exhausting.
- Feelings of disappointment and frustration. The person with the disability may fall short of the hopes and expectations of loved ones. Additionally, the person with the disability may experience a sense of unremitting guilt.

Vulnerable individuals in these situations need to remember that there is hope and there are always options. The same is true for the caregivers and the non-disabled family members. Some self-care options for those with disabilities may include:

- Building a network of friends and resources, joining a support group, enrolling in college classes and looking into jobs or volunteering. The more involved you are the less isolated and more empowered you will become.

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Caregiving Conflicts & Challenges

- Seeking out individual or family counseling. This can be very helpful in assisting you and your family to identify what is occurring, and to make positive life choices.
- Getting out of unhealthy living situations if it becomes clear that the situation will not improve. Call a hotline or social agency, or tell someone you need help.
- Reading an assertiveness training book, or taking a class.
- Most importantly, remembering that you deserve to be treated with respect and dignity.

The following are self-care tips for the caregiver:

- Arrange for respite care either through a day program, agency, or friends.
- Set aside some time each day to take care of your own needs. You will become depleted otherwise, and feelings of resentment, frustration, guilt and anger may surface.
- Avoid isolation. Keep up old friendships, or cultivate new ones. Become involved again with at least one activity you used to enjoy.
- Give yourself permission to seek out individual or family counseling. Also give yourself the opportunity to explore all options for your relationship, including separation. Caregivers often feel such tremendous guilt concerning this that they cannot tolerate thinking about it.
- Call a 24-hour support-line when you are at the end of your rope. Giving yourself time to vent and be listened to can diminish the pressure and give you a renewed sense of energy and perspective.

If you are being abused – tell some, NOW. If no one believes you, keep telling your story until help comes: tell the doctor, nurse, family, clergy, anyone and everyone you trust – just keep telling. The Portland crisis line is 503 469-8620, in Vancouver, Washington call 1 800 827-8840.

Joan's Story

A 58-year old woman with MS called MSSP saying she was $2100 behind on her rent and was about to be evicted. She was waiting on her Social Security Disability application to be approved. We informed her that once approved it could take at least six months before any money would arrive from that source. Within a week, MSSP staff and volunteers helped pack her belongings, and MSSP provided $110 towards the cost of a rental truck, $150 in gas cards and $40 for motel expenses to enable her to move to Northern California and move-in with family members.

UPDATE: Joan called to say a month after arriving at her sister's house, Social Security approved her application!

KEEPING OUR DOORS OPEN:

Everything's Coming Up Roses

We want to thank all the Portland/Vancouver area Roses Restaurant and Bakery employees and customers that participated in the "2009 Roses for MS" campaign.

Known for their delicious and gigantic bakery treats, Roses employees and customers proved they have big hearts to match. During a six-week campaign, the restaurants raised $3,642.04!

To the right, seller Heather Moran receives award for raising $573.00 at the Sherwood Roses Restaurant.

* * *

Ladies Arm Wrestling (LAW)

Thirty six lovely ladies gathered together and competed at the third annual B-Side Tavern's - LAW on June 28, 2009. In a little over two hours they raised $450.50 to benefit the MSSP thanks to organizer Joel Denton.

NW Bug Run

Blow up a VW Bug engine while having a blast at the Woodburn drag strip. That's what the Rose City Volksters, guests and volunteers did on May 28, 2009. By the day's end, they also raised $776.60 to benefit the MSSP! Thank you RC Volksters!

Mark These Dates

Event/Activity	Date	RSVP Deadline
Caregiver class @10:00 a.m. MSSP House	September 19	September 14
Caregiver class @10:00 a.m. MSSP House	November 21	November 14
Flu clinics – October 1-November 15 See website for details		
2009 Christmas Party -- (**NEW LOCATION**) Montavilla United Methodist Church 232 SE 80th St. Portland, OR 97215	December 12	December 7

Please Join Us At Our Christmas Party

WHO:	MSer's, Family and Friends
WHAT:	MSSP Christmas Party
WHEN:	Saturday, December 12, 2009 from 11:30 am - 3:30 pm
WHERE: (**NEW LOCATION**)	Montavilla United Methodist Church 232 SE 80th St. Portland, OR 97215
WHY:	Because it's FUN, FREE and FABULOUS!!
RSVP:	By December 8, 2009. Call 503-297-9544 or email us at events@msoregon.org Remember, we need the number in your party!

Flu Shots Save Lives

Each season MSSP goes out into the community to provide on-site flu shot clinics at major office buildings and private employers. Funds raised during these clinics generate nearly 50% of our annual budget. If you are interested in getting a flu shot, visit our website after October 1, 2009 for a full list of days and times. If you are interested in hosting a flu shot clinic at your job site call Candyce at 503 297-9544.

Answer: (to mini quiz=Money, Jewelry & Your Medicine!)

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:

☐ Project Helping Hands
☐ 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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