

MULTIPLE SCLEROSIS SOCIETY OF PORTLAND, OREGON

# MULTA SPES

*MUCH HOPE*

IMPROVING THE QUALITY OF LIFE FOR THOSE WITH MS SINCE 1949

## Director's Notes *by Candyce Hayes*

First of all I have missed each and every single one of you. I hope to see you very soon at one or more of several upcoming MSSP events/activities. Please do me a quick favor. Grab your calendar and a pen. Then turn to page 2 and note upcoming events.

As usual it's been hectic at MSSP. Last Fall a group of terrific volunteers transformed the outside of the MSSP house from indigestion pink to gracious green! Please join me in thanking Paul Turner, Brent Johnson, Doug Bush, Clark Mehan, Mike Hasson, Jonathon Stout, John Skildum and Curt Harsted from 3M. We also want to acknowledge Home Depot in Tigard for discounting the project's supplies.

A few days ago we got word Teva Neurosciences approved our grant proposal. Teva's gift makes it possible for us to meet and now accept Portland Rotary Club's \$2,000 challenge grant. With this gift we can give "thumbs up" to the contractor to install a ramp to the MSSP house and finish the remodeling needed to complete our vision of a working demonstration model house that offers a warm and caring environment where MSers, their children/preteens, other family

members and friends will gain knowledge, share experiences, receive comfort and attend skill building classes.

Through my minds' eye I see a house bustling with energy and love. Outside an electronic sign advertises our upcoming events/classes and/or workshops. Inside the main house volunteers and staff answer telephones and greet guests. The kitchen is warm from an afternoon of baking. The timer buzzes to announce a batch of fresh baked chocolate chip cookies are done. Downstairs, in the family room, a group of family members and friends eagerly watch as the instructor demonstrates how to transfer a person from a wheelchair to a bed. They learn about tools like gait belts, hoier lifts and sliding boards. Meanwhile outside gardening volunteers prune bushes and cut roses that will later be lovingly made into beautiful floral arrangements and delivered along with freshly baked cookies to MSers during a short friendly visit.

Oh yes my friends, we stand at the threshold of many exciting opportunities, memories and adventures. The "official" MSSP

House grand opening will occur later this summer so look for your invitation soon.

One last note, thank you from the bottom of my heart for your understanding, patience, prayers and well wishes during my extended illness. I am feeling much better. And like you I am learning to manage chronic illness -- some days are better than others - so I do what I can, set it aside and pick it up again later.

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Multa Spes is the quarterly newsletter of MSSP, distributed to Msers, consumers, families, professionals, and friends.

Comments and articles are welcome - publication depends on space available and is subject to editing. Submission deadlines are 8/1/2006 and 10/1/2006.

Please send submissions to  
Candyce Hayes,  
Executive Director, at:  
[candycehayes@msoregon.org](mailto:candycehayes@msoregon.org)  
or Mail: MSSP,  
P.O. Box 16553  
Portland, OR 97292-0553.

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](mailto:candycehayes@msoregon.org) or call 503-297-9544.

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## Mark These Dates

We have lots of fun and exciting programs and events coming your way in 2006. All MSSP programs are free. Save the following dates:

<u>Event/Activity</u>	<u>Date</u>	<u>RSVP Deadline</u>
Bingo Party	April 29	April 24
MS & Sexuality Workshop	May 6	May 3
Medicare Drug Plan Enrollment	May 15	See page 3
Annual Picnic	June 17	June 14
Summer Comfort	May 30	*Registration Form Req.
Project Connect	June 30	*Registration Form Req.
Summer Comfort	Sept. 1	*Registration Form Req.
September Social	Sept. 9	Sept. 6
Christmas Party	December 9	December 6
Project Connect	December 31	*Registration Form Req.

Call 503-297-9544 or obtain forms online at [events@msoregon.org](mailto:events@msoregon.org)

### MS & Sexuality Workshop - May 6, 2006

at the Lloyd Center Doubletree Inn

MSSP and Teva Neurosciences are proud to sponsor another excellent free workshop on May 6, 2006 from 9-12:00 noon at the Lloyd Center Doubletree Inn. A continental breakfast will also be served from 8:30-9:00 am and on-site parking is included.

Three topics will be covered during this workshop by these local experts: "MS & Sexuality" - Jillian Romm, RN, LCSW Associate Professor, OHSU, "Connecting to Community Resources" - Tom Coogan, Vice President, Care Medical and words of inspiration by Life Coach Maria Lesetz. Registration is required by no later than May 3, 2006. Call 503-297-9544 or on-line at [events@msoregon.org](mailto:events@msoregon.org) to register.

### PLEASE JOIN US at Spring Bingo Party

The afternoon promises to be lots of fun, with delicious Chinese food and loads of great new bingo prizes!

WHO:	MSer's, Family and Friends
WHAT:	MSSP Bingo Party Blast!
WHEN:	Saturday, April 29, 2006 TIME: 11:00am - 3 :00pm
WHERE:	Rose City Park United Methodist Church 5830 NE Alameda Street Portland, OR 97213
WHY:	Because it's Fun, Free & Fabulous!!!
RSVP:	<a href="mailto:events@msoregon.org">April 24th</a> to 503-297-9544 (We need to know the number in your party)

## Extra Help with Drug Costs

Many low-income Oregonians may qualify for extra help with drug costs from the Department of Health and Human Services (DHS). Interested individuals should submit applications if they want to qualify for extra financial assistance to reduce or eliminate costs associated with the new federal prescription drug program that started earlier this year.

Oregonians enrolled in or covered by Medicare and Medicaid, SSI, or a Medicare Savings Program automatically qualify for extra help, which can be used to cover the new program's monthly premiums and deductibles. People found eligible could save as much as \$3,600 per year.

Those with incomes under \$14,355 a year and resources under \$10,000 are most likely to qualify for the extra help. Resources are defined as savings, investments and real property other than a home.

Those who are married and living with spouses may qualify as well if they have incomes under \$19,245 a year and resources under \$20,000. Resource limits are higher if money is to be used for burial expenses; \$1,500 per person is allowed.

The Social Security Administration has sent letters and applications to more than 260,000 Oregonians who may qualify for this extra help. "Those who do qualify may also be eligible for other forms of financial help, such as a Medicare Savings Program," said James Toews, DHS assistant director for Seniors and People with Disabilities.

The new Medicare drug coverage began January 1, 2006. People with Medicare will need to decide by May 15, 2006 whether to join a Medicare prescription drug plan. After this initial enrollment period ends, most people will pay a penalty (higher premiums) for their Medicare prescription drug coverage if they go more than 63 days without "creditable coverage" (Coverage that pays out, on average, as much or more than standard Medicare

prescription drug coverage) from another source (such as an employer or union drug plan). To learn more about the program, to receive an application for extra help, or to get assistance filling out the application, contact Social Security. The toll-free number is: 1-800-772-1213 or TTY 1-800-325-0778 between 7 a.m. and 7 p.m., Monday through Friday.

(continued on page 4)

### Stepping Stones to Change - Author Unknown

We all say we want to change our negative behavior but then we don't take the steps to make concrete changes. When we keep doing things the same way, we keep getting the same results. The following are some simple changes that can mean big results:

**Give compliments** - don't save your compliments for big things and favorite people. "Catch" people doing a good job and give them a compliment.

**Smile Often** - especially when you see someone struggling with a task. A smile is an expression of esteem.

**Catch Your Negative Thinking** - wear a rubber band around your wrist for one week. Whenever you find yourself thinking unkind or ungrateful thoughts, snap the rubber band.

**Replace Critical Statements** - show your support and acceptance of the people in your life as they are - not as you wish they could be.

(continued from page 3)

## Extra Help with Drug Costs

The Oregon Department of Human Services can provide information and assistance to anyone unable to contact Social Security. Call DHS at 1-877-585-0007 between 8 a.m. and 5:30 p.m. Monday-Friday.

Shared Solutions can also help you with the medicare process. In 2006 people with Medicare will be able to receive Copaxone and other prescription drug coverage through Medicare Part D. This change in Medicare will offer coverage for "at-home" administered medicines like Copaxone.

This is an option that was not previously available and made therapy attainable for some. This change may mean:

\* You may have coverage that will allow you to choose Copaxone for the first time.

OR

\* If you're already on Copaxone, your benefit may have changed.

Shared Solutions can help you understand the prescription drug plan options available to you under Medicare Part D. We'll

assist you in gathering the information you'll need to choose the plan that best fits your prescription drug needs. Shared Solutions assists those starting and those continuing Copaxone (glatiramer acetate injection) verify your coverage options.

Call and let our Benefits Investigation Team help you today at 1-800-887-8100. Shared Solutions does not recommend or endorse any particular Medicare Part D plan.



## MSSP Newsletter Now Available On-line!

If you receive our quarterly newsletter delivered to you by mail, please let us know if you'd prefer to receive the newsletter by e-mail notification. Each quarter, you would receive an e-mail containing the direct link to download our newsletter (currently posted as a Microsoft Word document).

To subscribe to this e-mail notification list, send an e-mail to Candyce at [candcyehayes@msoregon.org](mailto:candcyehayes@msoregon.org) containing your name and e-mail address, with "change format to e-mail" in the subject line or simply call us at 503-297-9544. Thank You!

# MSSP'S DOCTOR VISIT NOTES

Doctor's Name: \_\_\_\_\_ Doctor's Phone: \_\_\_\_\_

Patient's Name: \_\_\_\_\_ Appt. Date: \_\_\_\_\_ Time: \_\_\_\_\_

Reason for visit:: \_\_\_\_\_

\_\_\_\_\_

Symptoms: \_\_\_\_\_

\_\_\_\_\_

Questions for Doctor: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

<u>Current Medicine</u>	<u>Dosage/Frequency</u>	<u>Current Medicine</u>	<u>Dosage/Frequency</u>
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_____	_____	_____	_____
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_____	_____	_____	_____
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_____	_____	_____	_____
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Complete shaded area before visit

Weight: \_\_\_\_\_

Blood Pressure: \_\_\_\_\_ / \_\_\_\_\_

Height: \_\_\_\_\_

Temperaure: \_\_\_\_\_

Doctor's Diagnosis: \_\_\_\_\_

Doctor's Instructions: \_\_\_\_\_

\_\_\_\_\_

Medicine Prescribed Dosage/Frequency

\_\_\_\_\_

Treatments/Shots given: \_\_\_\_\_

Follow-up visit? Yes/No If so, when? \_\_\_\_\_

Additional Medical Services

Lab work: \_\_\_\_\_

Therapy: \_\_\_\_\_

Furthur tests: \_\_\_\_\_

Pther Services/Specialists: \_\_\_\_\_

Test Results

\_\_\_\_\_

\_\_\_\_\_

## Useful Tools, Tricks & Techniques

Little things can make a big difference when learning how to manage life with a chronic degenerative illness like MS. That's why MSSP is on a new mission: **To find, test and tell our community about helpful tools, tips and techniques that make life easier.**

For example: a wheelchair-confined woman, (let's call her Lana) recently called the MSSP office. Lana was delighted she could return to work part-time but now she faced a rather "sensitive" new challenge. Lana needed to learn how to independently adjust her clothing during restroom breaks! **Without learning this "real life skill" Lana faced, at minimum, public**

**embarrassment and, at maximum, a serious obstacle to continued employment.** So MSSP provided her several free tools; a grabber, a video, and the phone number of a female MSer who was willing to talk with her about how she has handled similar situations.

Currently three MSSP volunteers are **testing auto swivel seat cushions.** Our hope is this simple tool, available for pennies in most general and medical catalogs, proves helpful for getting in and out of a car or van.

In this issue you will find the **"first draft"** of a new tool - a preprinted doctor visit form (see page 5). This

form has two uses; the top portion should be completed prior to your visit and used as a checklist while talking with your health professional. Meanwhile the lower half of the form reflects the outcome of your visit. **Please help us by giving us your written feedback after you've tried the form.** Use the enclosed envelope to let us know how and why the form worked. **Please describe in detail any changes you suggest.** Look for results of the doctor visit forms and seat swivel cushion review in the Summer 2006 issue of Multa Spes.

### Gentle Yoga Class

Research has shown Yoga to be beneficial for those living with MS. For most of us with MS, the disease contracts our muscles. For all of us, yoga can stretch our muscles, calm our minds and improve our mood. Fortunately Portland has two fine programs;

For nearly a year **MSSP and the Christopher Reeve Foundation** have sponsored two-12 week Gentle Yoga classes. The Level 1 class, taught by yoga instructor Amy Duncan, meets from 11 a.m. to 12:30 p.m. and is for people with MS who are new to yoga and need more time and instruction. The Level 2 class, taught by yoga instructor Cindy Irvine meets from 8:15 a.m. to 9:45 a.m. and is for continuing students. Both classes are held at Wild Oats located at the corners of North-east 15th and Fremont Streets in Portland. The cost for the class is on a sliding scale from \$60 to \$120, with scholarships available. **You can download a registration form from the MSSP website: [www.msoregon.org](http://www.msoregon.org) or call Debra at 503-234-8425 or Susan at 503-230-2074 for more details.**

Meanwhile the **Julie Lawrence Yoga** classes continue at **OHSU**. For more information about their class times and costs **contact 503-227-5524.**

### Scooters, Chairs and More

The MSSP Medical Equipment Closet is overflowing again. If you need a walker, cane, wheelchair, scooter or even a lift chair or other specialty item call the MSSP office 503-297-9544 to make arrangements for free pickup or delivery. Please note for sanitary purposes we **no longer** offer commode or shower chairs.

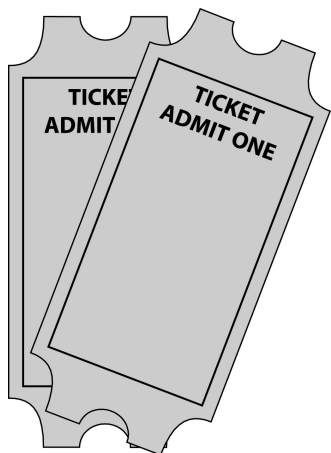
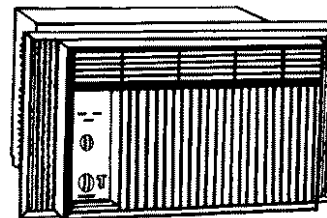


### *Air Conditioners*

MSSP's "Summer Comfort" program makes new, portable, window air conditioners available (one per household) to those in need each Spring and Summer. Registration forms and proof of MS are required.

This season's program deadlines are: May 30 and September 1, 2006.

Registration forms can be found on line at [msoregon.org](http://msoregon.org)



### *FREE Event Tickets*

From time to time MSSP gets free tickets to local events. The only catch is we never know what event or when we'll get tickets. If you want to be included in the "MSSP call list" for future activities and events, we ask you to [mail us a note with your name, number of people in your party \(limit 4 tickets per family\), the types of events you are interested in along with at least two telephone numbers and the best time to reach you.](#) You must submit your request in writing. We [cannot](#) accept telephone registration for free event tickets.

## *KEEPING OUR DOORS OPEN*

As you may recall last year we began a pilot fundraising program where we accepted and resold used clothing and household items. Unfortunately, despite our best efforts, we were not able to produce enough quantity to continue the program. As such we ended this program February 15, 2006. We're going back to the drawing board to find new ways to support MSSP programs.

In the meantime, if possible, [please make a contribution today using the enclosed envelope.](#) Our commitment is [serving the community](#) and this is possible because of the many [gifts from caring individuals like you.](#)

## *Rethinking Disability & Economics*

By Kent Wiles

Pathwise was formed because there is a complete absence in the nonprofit world of an organization whose mission is to help people with chronic illnesses and disabilities create viable plans that enable them to achieve true long-term financial independence.

Pathwise has two principal co-founders Laura D. Cooper, Esq. and Kent Wiles. Ms. Cooper is well known as the author of a recently published book "Insurance Solutions: Plan Well, Live Better - a workbook for people with a chronic disease or disability". Laura is considered a national expert on the subject of life planning and insurance law and is a member of the Oregon State Insurance Advisory Committee. In 2004, she received the Oregon State Bar Association's Pro Bono Services award. Kent hails from the National Multiple Sclerosis Society, Oregon Chapter, where he was their Programs & Services Manager for nine years. For more information, please contact Kent Wiles at 503-358-3381.



## *A Forum for Meeting MS Friends - Mike Stofe*

Greetings from your MSSP webmaster. A long time ago in a far off world, whoops wrong article. A long time ago I put a forum up on MSSP's website for people with MS and their families to meet others going through similar challenges. Although several people joined the forum, only a couple have posted there.

Then due to a major computer crash I was unable to recover the data. But good news - the new forum is up and running. I'm asking everyone who registered for the old forum to reregister. I hope the new forum gets more use because it is a very valuable tool. Also I'm [looking for a few volunteers](#) willing to contribute to the forum and keeping a conversation going on a regular basis. This would include [checking in on the forum](#), daily if possible, [contributing your own ideas](#) and [responding to others](#) who post on the forum. Interested folks please contact me at [webmaster@msoregon.org](mailto:webmaster@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      ☐ \$25      ☐ other \_\_\_\_\_

### My Contribution is for:

- |  |  |
|--|--|
| <input type="checkbox"/> Membership Dues (\$20.00) | <input type="checkbox"/> Social Programs   |
| <input type="checkbox"/> "Project Connect"         | <input type="checkbox"/> Medical Equipment |
| <input type="checkbox"/> "Project Helping Hands"   | <input type="checkbox"/> The Greatest Need |
| <input type="checkbox"/> "Summer Comfort"          |  |

### I am (please check one):

☐ MS Patient      ☐ Caregiver      ☐ Family/Friend      ☐ Friend of MSSP

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 acknowledgment to with their address.

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

**P. O. Box 16553 Portland, OR 97292-0553**

Time Dated Material

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