

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*

As anyone living with MS has learned, **uncontrollable life events force us to make changes, delays and rearrange our personal and professional lives.** These are lessons I am reluctantly learning.

After receiving the “go ahead” from our Board of Directors in early February I excitedly began laying the groundwork for our newest fundraising program; **accepting donations of used clothing, household items and furniture.** The income potential for this project is astronomical but what I (and board members) like the most is: 1) it makes us less dependent on other fundraising programs, and 2) it **gives everyone an opportunity to give.** With the rising costs of gasoline, utilities, medicine and food – people are finding it increasingly difficult to make cash donations but literally EVERYONE can donate something from their closet/basement/and/or garage!

So there I was, working like a train—“full steam ahead” when I began experiencing stomach pains. I ignored the warning

signals by telling myself, “it’s probably just indigestion”. Long story short - the doctor scheduled me to undergo a simple day surgery on March 25, 2005. One ambulance ride, a second emergency surgery, three days in ICU followed by another 10 days of hospitalization later have left my body weak from it’s battle with peritonitis. However, I would be a miss to not add that my heart is filled with gratitude for surviving the ordeal and for the love and support of family and friends.

Lord willing I will make a full recovery but in the meantime I have asked (and with board approval) my eldest brother, Jeff Hayes, to step in temporarily and help with the clothing donation program. **Effective June 1<sup>st</sup> you can drop off your tax-deductible donations to the MS Donation Center** located at 2901 SE 122<sup>nd</sup> between 7:00 am and 7:00 pm. The Center will be open Monday – Saturday. **If you have items too large to take to the center, call 503 595-3889 to arrange a pick up.** Sorry, we cannot accept propane containers, baby furniture or mattresses. **You can also bring**

**your donations to the May 21, 2005 workshop (see page 2 for details)!**

So the March newsletter this year has been replaced by a “Spring” issue. Board members and other precious MSSP volunteers, family members and friends are helping out to ensure new and existing MSSP programs move forward and I am learning patience and how to pace myself during a recovery period. Yes, life can and does change in an instant!

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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 8/1/2005 and 10/1/2005.

Please send submissions to  
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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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## Mark Your Calenders

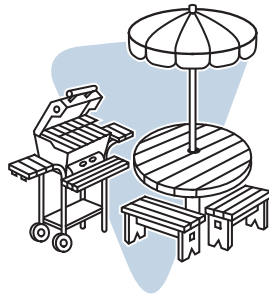
We have lots of fun and exciting programs and events coming your way in 2005. All MSSP programs are free. Save the following dates:

### Patient Education Workshop - May 21, 2005 at the Airport Shilo Inn

Speakers: Dr. Paul Ash, Laura Cooper & Maria Lesetz  
Breakfast: Continental (8:00-9:00 am)  
Program Time: 9:00 am - 12:00 pm  
RSVP: 1 866-227-9788 by no later than May 20, 2005  
Sponsored by: Teva Neurosciences  
More: Details to follow via separate mailing  
Don't Forget: You can bring clothing donations to event (see page 1 for details)

### Annual Picnic - June 18, 2005 @ Oaks Park

Cost: Free (includes fairway games/rides)  
Time: 11:00 am - 3:00 pm  
Open to: All MSers, family members and friends  
Lunch: Included (traditional picnic fixings)  
RSVP: No later than June 10, 2005 to 503 297-9544  
With number and ages in your party  
Sponsored by: MS Lifelines  
Note: Event is limited to 150 guests, **RSVP early!**

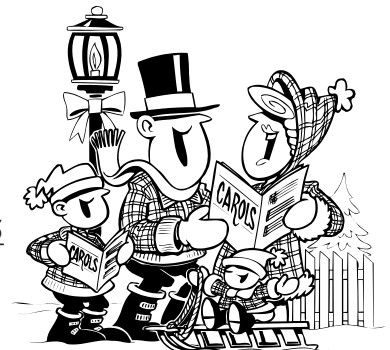


### Fall Event - September 10, 2005

TBA

### Christmas Party - December 10, 2005

TBA



## *A Light at the End of the Tunnel*

Help and Healing for People with MS Suffering from Depression

By Laurie Long, MS Association of King County

In 1999, Montel Williams, popular talk show host and celebrity, stepped out in front of a moving car in an attempt to end his own life. He had been diagnosed with MS just months earlier. In January of 2004 he went live in front of millions of viewers on his own talk show and discussed the attempt. Why did he finally talk about it?

“Because we [MS sufferers] need to stop lying about ourselves”, Montel explained. “We need to stop lying about the pain we’re in.”

According to various studies, up to 50% of patients with MS will suffer a major depression during the course of their illness. This is three times the prevalence reported for the general population and higher than other neurological disorders. In addition, suicide was found to be 7.5 times higher among patients with MS compared to the general population. Yet despite these high prevalence rates, depression remains under-recognized and under-treated in MS. This is distressing, not only because depression can often be successfully treated with antidepressant drugs and psychotherapy, but also because depression may worsen MS symptoms. Dr. David C. Mohr, Director of Medical Psychology at the Mt. Zion MS Center of US San Francisco, explains, “There’s some early evidence that depression can increase the immune deregulation associated with MS. So getting treatment for depression may be even more important for people with MS than it is for the general population.”

So why hasn’t more been done to recognize and treat this issue? In some cases the signs of depression may not be recognized as separate

from the general symptoms of MS. The symptoms of MS fatigue, especially, can mirror those of depression: extreme tiredness, loss of appetite, loss of interest or pleasure in everyday activities, sleep disturbances, problems with thinking or concentration and a slowing of reactions. But in addition to these symptoms, depression may also cause a deep sadness that continues

more than two weeks, feelings of worthlessness or guilt, and persistent thoughts of death or suicide. Often the depressed or suicidal person will not come out and tell you how they are feeling. Depression, often viewed as a “mental health disease” rather than a physically-based disease, may not be reported by the sufferer or by close friends or family because of the perceived stigma attached.

*(continued on page 4)*

### *Don't Assume*

Don't assume that because I look well that I feel well. Looks can be very deceiving. Many days I look great but feel terrible.

Don't say “I know how you feel.” No one knows how anyone else feels. We all have varying thresholds of pain, and pain cannot be measured.

Don't tell me about your Aunt Gertrude and her MS and how she managed in spite of it. I am doing the best I can.

Don't tell me “It could be worse.” I don't need to be reminded.

Don't decide what I am capable of doing. Allow me to make those decisions. There may be times I'm wrong, but I'll know soon enough.

Don't be upset that you cannot ease my problems. It won't do any good for both of us to be miserable.

Don't ask me how I feel unless you really want to know. You may hear a lot more than you are prepared to listen to.

Don't assume that because I did a certain activity yesterday that I can do it today.

Don't tell me about the latest fad cure. If there is a legitimate treatment, my doctor will let me know.

Do realize I am angry with the disease, not with you.

Do let me know you are available to help me when I ask.

Do offer me lots of encouragement.

Do understand why I cancel plans at the last minute. I never know from one day to the next how I will feel.

Do continue to invite me to activities. Just because I am not able to bike ride along with you and the gang does not mean I can't meet you for the picnic at the end of the trail. Please let me decide. Thanks.

*Author Unknown*

(continued from page 3)

## How to Recognize Depression

There are a number of symptoms that someone suffering from clinical depression will exhibit. According to Dr. Jon Richard, psychologist, in a recent interview, “Typically, serious depression is not just a single symptom or feeling, like a bad mood, but is a syndrome, a group of symptoms or feelings that may include loss of appetite, sleep disturbance, most typically bad insomnia, intense anxiety ...and also may include intense feelings of worthlessness or guilt or shame. An especially important feature of

clinical depression is a pervasive feeling of hopelessness that occurs for many people; the sense that not only do things feel terrible and not only does the outlook seem to be terrible from within the depression, but there is a distinct feeling that this will never change.

Dr. Richard also emphasized that any time these feelings continued for two weeks or more, it is an indication that professional help is needed. Wishes for death or thoughts of suicide, even if other symptoms are absent, are red flags for immediate professional support.

If these periods of depression are mixed with periods of overexcitement, impulsiveness, irritability and agitation, then the person may be suffering from bipolar disorder. Bipolar disorder is 13 times more common in people with MS than in the general public.

It is important to recognize the difference, because the drugs used to treat bipolar disorder are not the same as those used to treat depression.

## How to Help

If you think you have been experiencing some of the symptoms listed above for two or more weeks, especially those that are specific to depression alone, then you should consult with your doctor as soon as possible. There are a wide variety of antidepressants available to treat depression and, in conjunction with psychotherapy, the depression can be greatly reduced and even eliminated. If you have a friend or loved one who you think may be suffering from depression, talk to them about it openly. Dr. Sarah Minden of Harvard Medical School and Brigham and Women’s Hospital in Boston states, “People are ashamed of being diagnosed with depression. By and large, it’s treatable, and since it can be debilitating and disabling, it is a shame when someone doesn’t get treatment for depression – either because they won’t ask for help or because they’ve gone to the wrong type of provider. Dr. Minden believes people with MS and their families should be educated and encouraged to recognize depression and seek referral.

If you are feeling suicidal, tell someone and follow this up by contacting a therapist or the Crisis Clinic (503-988-4888). It is important to talk to someone as soon as possible. The Crisis Clinic is open 24 hours a day. They are experts at assisting individuals who are having a rough time emotionally, or who are feeling suicidal. They provide counseling, support and referrals. If the caller is unable to agree that they can keep themselves safe, they will provide immediate intervention. Remember that there are always options, and relief can be obtained even though depressive thoughts may try to convince you otherwise.

For the person who has been told by a friend or loved one that they are feeling suicidal, let them talk about it. Try not to edit their words. Accept that it will make you uncomfortable. Listen and encourage or assist them with calling the Crisis Clinic, or calling a therapist that day.

(continued on page 5)



## 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 [candycehayes@msoregon.org](mailto:candycehayes@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!**

## Things You Can Do

In addition to antidepressants and therapy, you can help yourself in overcoming depression by increasing positive, pleasant things and decreasing negative things in all areas of your life. For instance:

- Do as many little pleasant things as you can each day. Read a fun book, hold hands, look at the clouds, and relax. Avoid frustrations and hassles whenever possible.
- Stop or limit negative thoughts whenever possible. Think about good things; count your blessings instead of dwelling on your problems.
- Be comfortable, learn to relax, try meditation or yoga. Don't stay tense all the time.
- Have good times with your friends and family; don't close yourself off. Make social dates, talk to people.
- During pleasant activities or good times, don't allow negative thoughts, physical tension or minor hassles reduce your enjoyment.
- Don't set difficult goals or assume large responsibilities. Set priorities, make a schedule and pace yourself. Break things down into manageable pieces.
- Avoid alcohol and recreational drugs.
- Don't blame yourself. Emotional changes and depression are common, treatable, and often part of the disease process. Treat it like any other symptom by understanding it and getting help for it.

Montel Williams views his MS and the depression that it engendered as a chance to speak up. "It gave me the opportunity to get the message out there – it's not a shame to be ill. It's not a disgrace." He continues, "I used to want people only to see me at my best – now I don't."

"Had I not come out," Williams explains, "I probably wouldn't have realized how blessed I am."

(Note: Quotes from Montel taken from the Montel Williams Show, January 13, 2004.)

## Resources for Depression:

### Local -

Crisis Clinic Line: 503-988-4888

Community Resource Referral Line: 211

### National-

National Foundation for Depressive Illness: 1-800-239-1265 <http://www.depression.org/>

Depressive & Bipolar Support Association: 1-800-826-3632

<http://www.dbsalliance.org/>

National Mental Health Association: 1-800-969-6642 <http://www.nmha.org/>

National Hopeline Network: 1-800-784-2433 <http://www.hopeline.com/>

NAMI (National Assoc. for Mentally Ill) 503-228-5692



## For your Information

### Air Conditioner Deadline

Each year MSSP's "Summer Comfort" program gives portable window air conditioners (as funds are available) to MSers to help offset seasonal heat (one per household). The deadline to apply is June 30, 2005. Interested individuals must furnish evidence of their diagnosis along with a completed Summer Comfort application. The fastest way to register for the program is to visit MSSP's website at [msoregon.org](http://msoregon.org) – click on Summer Comfort, print application and follow directions. Don't forget to mail your completed application to: POB 16553, Portland, OR 97292-0553.

“EASY” WAYS TO HELP

*Make a cash donation to MSSP*

*Bring your reusable clothing/household donations to MSSP Donation Center*

*Organize a clothing drive to benefit MSSP*

*Spread the word about MSSP, it's programs and needs*

*Encourage your friends, neighbors & coworkers to support MSSP*

*Don't forget -MSSP will provide free pick up of remaining items from garage/moving/estate/sales or if your items are too large to bring to donation center – call 503 595-3889*

**Let go...**

to “let go” does not mean to stop caring, it means I can't do it for someone else

to “let go” is not to cut myself off, it's the realization I can't control another

to “let go” is not to enable, but to allow learning from natural consequences

to “let go” is to admit powerlessness, which means the outcome is not in my hands

to “let go” is not to try to change or blame another, it's to make the most of myself

to “let go” is not to care for, but to care about

to “let go” is not to fix, but to be supportive

to “let go” is not to judge, but to allow another to be a human being

to “let go” is not to be in the middle arranging all the outcomes but to allow others to affect their destinies

to “let go” is not to be protective, it's to permit another to face reality

to “let go” is not to deny, but to accept

to “let go” is not to nag, scold or argue, but instead to search out my own shortcomings and correct them

to “let go” is not to adjust everything to my desires but to take each day as it comes, and cherish myself in it

to “let go” is not to criticize and regulate anybody but to try to become what I dream I can be

to “let go” is not to regret the past, but to grow and live for the future

to “let go” is to fear less, and love more

Anonymous



## KEEPING OUR DOORS OPEN

### *Financial Update*

Well folks, we're chipping away at the \$80,000 operating deficit caused by last fall's fundraising shortfall. A bequest, the SOS emergency appeal and an abbreviated flu campaign together brought in nearly \$70,000 leaving us just \$10,000 remaining.

MSSP is very grateful to each and every donor for their kindness and generosity. Please rest assured MSSP DOES NOT sell or make its donor's and/or membership list available to the public. We purposely used initials to protect the following SOS appeal donors' privacy.

#### ***\$300-\$500***

Care Medical  
Rose City Banjoliers

Vancouver Neurologists  
Columbia Lions Auxilliary

K Moss

#### ***\$100-\$299***

Dr. S Cohan  
A Anderson  
G & V Everton

G Morgan  
L Meacham  
J Frank

P Lawler  
J Albertus  
Ainsworth Pharmacy & Drug

#### ***\$50-\$99***

D & E Byrd  
K & M Baclawski  
R Brock  
T Brinckman  
K Vollmer  
D McClard  
D Karns

J Shown  
W McPherson  
G Eisenzimmer  
M Thomas  
D Reich  
L Landis  
A & D Bishop

W Carleton  
C White  
M Woodlief  
G Wrisley  
R Douglas  
R Milton

#### ***\$49-below***

L Hanson  
S. M. Ruonala  
J Jones  
G Murphy  
F Veith  
B Jones  
N Moeller  
J Piper  
L Dick  
K Edwards  
A Constantine

D Beninger  
C Hart  
T Fridley  
N Apelian  
B & J Hoeft  
D Beninger  
D Brown  
M Stofiel  
V Gogoleski  
K. Cedarlin  
V Clow

W. Fransen  
M VanderKam  
K Kelso  
M Flynn  
L Estep  
G Boehm  
P Prindle  
S Ahl  
J Martell  
L Richards  
W Gawntt

### *MS House Update*

In a nutshell, we haven't made progress in this area although several grants are pending to cover the cost of remodeling MSSP house. We'll keep you updated.

## Revealing the Uncommon Symptoms of MS

By Laurie Long, MS Association of King County

You have a recurring headache or hearing loss. Your first thought is probably not that these are potential symptoms of MS. But they could be!

When people talk about the symptoms of MS, they naturally tend to focus on the most common symptoms. But other possible symptoms of MS, which are either uncommon or under-recognized, are not often discussed. Sometimes one of these can even be the presenting (first) symptom of MS. People with neurological symptoms and the doctors attempting to diagnose their case may be unaware that these indicators could be MS related. Also, MS patients might not recognize a medical problem that they are trying to deal with as an MS symptom. In some cases, of course, the symptom may *not* have any connection to the MS. That is why it is important to discuss these symptoms and their treatment with your doctor or neurologist. Once they are recognized, many of the symptoms of MS can be effectively treated. It is also important to remember that not everyone with MS gets these symptoms.

Before looking at the uncommon or under-recognized symptoms of MS, let's review the symptoms that receive most of the focus:

- Blurred or double vision (optic neuritis, diplopia)
- Coordination and balance difficulties
- Tremors
- Slowing or slurring of speech
- Muscle *spasticity*, or stiffness
- Numbness and/or tingling sensations
- Pain, burning, itching, electrical shock sensations (Thermittes), facial pain (trigeminal neuralgia)
- Weakness in the arms or legs
- Paralysis
- Swallowing problems (dysphagia)
- Bladder or bowel problems
- Diminished sexual sensation
- Overwhelming or unusual fatigue
- Heat sensitivity
- Anxiety
- Depression and/or mood swings
- Aphasia, Dysphasia (problems with speech comprehension and production)
- Confusion, difficulty focusing, organizing or planning
- Memory problems

Even some of these symptoms remain under-recognized and under-treated. Areas such as cognitive issues, emotional problems and sexual dysfunction are often too difficult or embarrassing for the person with MS to discuss with or acknowledge to a doctor.

Other symptoms which are less common (or less recognized) are:

### Headaches

Although headaches were once thought to be an infrequent symptom of MS, more recent studies indicate anywhere from 31% to 57.7% of the test subjects with MS suffered from headaches – the most common being tension-type headaches and migraines. A study of MS pain (including headaches) found that—“in 68% [of the subjects] insufficient care by the physicians consulted was reported. This was even true for the most frequent pain, migraine, in which clear treatment recommendations exist. There is thus an urgent need for physicians to keep this problem in mind when treating MS patients.” Another study from the University of California Davis Headache Clinic found evidence that suggests” “dysfunction within the midbrain/periaqueductal gray matter caused by a demyelinating plaque ...increases the incidence of headache in patients with MS”.

### Hearing Loss

Hearing loss is considered an uncommon symptom of MS, although existing studies tracking its prevalence vary widely in reported occurrence. The etiology of Sudden Hearing Loss (SHL) recognizes MS, as well as migraines, as a potential neurological cause. More often, there is a loss in hearing sensitivity.

*(continued on page 9)*



MRI tests on brain stem lesions showed that whenever a lesion overlapped the Auditory Pathway, some Bin Aural (auditory) performance was abnormal. Other tests show that “up to 40% of MS patients who have normal audiograms experience difficulty hearing in everyday listening conditions” (i.e. background noise). This can be the difference between hearing sensitivity and processing of auditory information. Those with cognitive symptoms that include difficulty with information processing find that this can influence the ability to filter and process what is heard.

Hearing loss can also occur during an exacerbation, although deafness due to MS is extremely rare and most acute episodes of hearing loss through MS tend to improve.

### *Sleep Disorders*

Sleep disorders are fairly common in people with MS. One study on sleep disorders in people with multiple sclerosis found that 36% of the test subjects with MS suffered from some form of sleep disorder. The study also found that age, sex, and degree of disability did not bear any direct relation with sleep disorders. The only symptom of MS the study found that had a direct relationship to problems with sleep was depression. Other studies on fatigue and sleep disorders in people with MS found that there was a significant correlation between fatigue in MS patients and disrupted sleep or abnormal sleep cycles. It also found a relationship between excessive daytime sleepiness and fatigue in MS patients. Some postulate that stress, spasticity, inactivity and increased need to go to the bathroom also contribute to broken sleep patterns in people with MS.

### *Vertigo*

While dizziness is common in people with MS, vertigo (sensation of spinning) is less so. One study suggests that, “True vertigo is estimated to occur in about 20% of MS patients.” Lesions in certain areas of the central nervous system can provoke vertigo in patients with MS. This form of vertigo can be treated, but before that happens other possible forms of vertigo, such as benign paroxysmal positional vertigo (BPPV), should be checked for “in order to avoid unnecessary treatment with corticosteroids and vestibular suppressants.”

### *Seizures*

Although seizures can occur in MS, they are fairly rare. Some studies suggest that seizure incidence is the same as, or only slightly more than, the incidence for the general populace. More than one study shows, however, that seizures in patients with MS can be correlated to alterations in their MRI and EEGs. One study explains, “These images have shown that epileptic seizures can be caused by cortical and subcortical lesions and by their accompanying oedema.” Most seizures can be controlled by medication. According to one study on seizures in patients with MS, “Most of the patients with MS who experienced seizure activity had a benign and transient disorder that was responsive to antiepileptic drug treatment and required no therapy.”

### *Pseudobulbar Affect*

Pseudobulbar affect is pathologic laughing and crying, sometimes also called “emotional incontinence”. Some studies suggested that this syndrome may be caused by dysfunction of the prefrontal cortex. One doctor explains, “The frontal lobes are involved in judgment, social propriety and planning, among other things. When pathologic laughter is seen, other cognitive functions also tend to be lost.” This syndrome has been regulated with Elavil and similar drugs. Fluoxetine has also been used very successfully and a new drug, Neurodex, will hopefully be available in 2005.

### *Conclusion*

Because MS is so variable, it is often difficult to diagnose – especially when the presenting symptom is one not often associated MS. Yet most of these “unusual symptoms” have at least one documented case showing that symptom as the first MS symptom experienced. Both doctors and patients should be aware that these symptoms can be related to MS, and almost all can be controlled with the proper treatment. People experiencing these symptoms should discuss them with their doctors and work together to find the best solution for the unusual symptoms of MS.”

## 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:*

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