

Director's Notes by Candyce Hayes



I can hardly believe it's already 2013. It seems like yesterday there was all that hoopla about impending doom when the computers clicked over to 2000. Where does the time go?

I've been reflecting about what I want to accomplish this year. A couple of my goals are to increase program services and fundraising. No one likes to talk about money but let's face it – we need dollars to operate. Soon we'll be launching our annual phoneathon.

Some of my New Year's resolutions have gone by the wayside. Like many of you I start off strong and then stuff happens. Oh well, maybe next year I'll drop that muffin top.

On a personal note, I'm doing very well. I continue chemo treatments every 3 weeks for another 6 months. Fortunately my hair is returning and darned if I didn't go from being a wavy blonde to a curly brunette! The cancer community offers many programs; yoga, (there is a gentle yoga for MS) tai chi, dancing, and monthly art therapy classes. I love the art therapy. Each class I think, gee I wish we could offer this to the MS community because it's such a great way to express feelings and tap into the creative side. So if you're interested in an art and crafts class here at the MSSP give me a call at 503.297.9544.

Another thing we're working on is updating our website with a brand new look. Whew, what a project that has been! I naively thought it would be a simple project – wrong. It's taken a lot of time, thought and manpower but the end product will be something we can all be proud of. I want to thank everyone working on this project. Well, that's all for now.

Thank You! To This Year's *Blues4MS* Corporate Sponsors

See Page 10 for more information



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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: 4/01/2013.

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.

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FYI

Books of Interest About Life with Multiple Sclerosis

Turning Toward the Light – Marguerite Dearborn

My Story – A collection of Inspirational Voices – Liz Pearl

Perfect Misfortune – Allan Flood

CD – ADA Technical Assistance covers these topics

ADA Regulations

ADA Standards for Accessible Design

Technical Assistance Manuals

TA Documents

Stress Reduction Clinic at Hillsboro Yoga

Mindful Adaptive Yoga in chair

How they teach Therapeutic Yoga

Mindfulness-Based Stress Reduction (MBSR) and more

Housing Connections

Need a resource finding rentals within the Portland/Vancouver metro area? Try visiting www.HousingConnections.org. They have many different ways you can search such as price per month, accessibility, location, income based, number of bedrooms, etc. They also have the ability to post a property for those who have rental units. This service is free through the 211Info, Portland Housing Bureau, and Clark County Department of Community Services

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MSSP Equipment Closet

Manual wheelchairs needed call 503.297.9544

Mark These Dates

Event/Activity	Date	RSVP
Acupuncture	Open Mondays 10-2:00 pm	503.297.9544
Blues 4 MS	3/3/13 3:00-9:00 pm	None required Aladdin Theatre Visit www.blues4MS.org
Spring Workshop	5/11/13 11:30-3:30 pm	Required by 5/1/13 503.297.9544
Picnic	6/22/13 11:30-3:30 pm	Required by 6/15/13 Oaks Park 503.297.9544

Reducing Distress

Peace of mind can be an effective tool when facing Multiple Sclerosis. Here are some distress-reducing tips:

Understand distress is normal. Everyone has struggled on this journey. The experience of distress and anxiety is not a failure on your part. It is normal.

Learn about your type of MS. Much of the anxiety at diagnosis comes from lack of knowledge. Make a list of questions before each appointment. If you don't understand what your doctor is telling you, ask them to clarify or elaborate.

Speak up. MS can affect your mental health. It takes more courage to talk about your problems and accept help than it does to avoid them.

Prioritize and focus. Work with a social worker, speech, physical and/or occupational therapist(s) to identify problems that need to be addressed immediately and issues that can wait. Then focus on finding solutions.

Pull from previous life experiences. How have you dealt with difficult times in the past? What gives you comfort and support?

Do things you enjoy. Integrating pleasurable activities into the day can really help. Even small things, like gardening, or lunch with friends, can help you feel better.

Delegate tasks. Lighten your load by letting other people help. Family and friends can help with meals, running errands and taking you to medical appointments.

Try new things. Even if a coping technique like relaxation or yoga is unfamiliar, give it a try. If it's not for you try something else.



Advancements in MS Treatment 2013 - Workshop by Candyce Hayes

We are proud to welcome Allergan as a sponsor of our May 11, 2013 workshop. The event will be held at the Crowne Plaza Hotel at 1441 NE 2nd Ave., Portland, Oregon 97232 from 1:00-3:30. Refreshments will be served. We welcome two speaker: Karny Jacoby, MD, a Urologist from Seattle, will talk about urinary incontinence; and Jade Nelson will address Navigating the Health System (see page 5 for full details).

Comfort and Joy-Christmas Party Review - By Robin Blue

The challenges that we face as one year closes and another begins seemed to feel just a little sweeter and full of hope inside the Montavilla United Methodist Church on Saturday, December 15th, 2012. The annual Christmas party was full of warm cheer and plenty of comfort and joy. As I walked into a busy room of volunteers led by Marcia it was like entering Santa's workshop. Marcia directed over 30 volunteers during two shifts. Tables were decorated with ornaments and candles and the stage was set with lights and a tree. From the opposite side of the room I could smell the food cooking. Noelle and Anna busily prepared the turkey banquet!

Throughout the day, 120 clients along with their family members and friends joined in the festivities. The event began with Executive Director Candyce Hayes introducing the Rose City Banjolliers as the day's first entertainment. They strummed and played familiar Christmas carols and everyone sang along. The Banjolliers performed while guests checked in and settled into their tables. Upon arrival guests received gift bags donated by the MSSP, local businesses and individuals. Later a couple of raffles were held.



The second shift of volunteers arrived and made sure all the guests were tended to and comfortable. No one had an empty cup of joy all afternoon! The day wound down with the wonderful music of blues guitarist Robbie Laws. Board member Art Richards graced the stage and played with Laws bringing the Christmas party to a peaceful close. We hope everyone enjoyed the day and will plan to attend a future MSSP event.



Don't Accept the Status Quo



In healthcare and other life issues don't always accept the first answer. Sharon and Michael Giddings learned this upon receiving a letter from TriMet saying he needed to come in for a reevaluation. The evaluation resulted in Michael (and 30 other disabled clients) losing their ability to ride the LIFT program based on weight restrictions.

Sharon went to work first calling TriMet to get a clarification and when she couldn't get a resolution she contacted the media. KGW Channel 8 took an interest in the story and did some great investigation. Long story short, TriMet wasn't allowed to restrict riders based on weight. Unfortunately Mike passed away on November 5, 2012. He is deeply missed.

Navigating the Health Insurance System by Jade Nelson



My name is Jade, and I'm a senior at Portland State University. My major is in Community Health and my minor is in Aging Services. I'm taking a class that focuses on being an effective change agent which means I'm actively making a difference in my community. I was diagnosed with epilepsy in 1987. Since then I've had brain surgery, been on multiple medications, and visited more doctors that I can begin to count. I've had the opportunity to experience the healthcare system at its best and worst.

For the last 15 years I've learned how to navigate the healthcare system, including verbal appeals to insurance companies, filing state complaints, and finding medication coverage when I couldn't afford my medication. As part of my class I'm going to be a speaker during the MSSP's May 11, 2013 workshop.

Advocacy Tool Box - Pilot Training by Jade Nelson

A pilot training will be held on March 30, 2013 at the MSSP office from 10 am to 1 pm. The training is open to 8-10 people and will cover:

- Creating an appeal for denied healthcare coverage
- How to write a letter requesting a grievance appeal
- How to file a state complaint
- How to write a formal letter stating a need for medication assistance, and much more.

The pilot training is for people struggling with these issues. I'm excited to share my knowledge to make the journey a little bit easier. I'm just one person with a neurological disorder but there are millions trying to find their way. I believe this training will offer a light at the end of a sometimes overwhelming tunnel. Call the office at 503.297.9544 or email programs@msoregon.org to register. The deadline to register for the pilot study is March 15, 2013.

Charity as Beneficiary of Traditional IRA or Retirement Plan

by Gaylin Frye



What is it?

Naming a beneficiary for your traditional IRA or employer-sponsored retirement plan may be one of the most important financial decisions you ever make. The beneficiary (or beneficiaries) you name will receive the funds remaining in your IRA or plan after you die, so you should certainly consider your loved ones' future needs. However, choosing the right beneficiary is often more complicated than that. Your choice could have an impact in one or more of the following areas:

- The size of the annual required minimum distributions (RMDs) that you must take from the IRA or plan during your lifetime
- The rate at which the funds must be distributed from the IRA or plan after your death
- The combined federal estate tax liability of you and your spouse (assuming you are married and expect estate tax to be an issue for one or both of you)

Your first thought may be to designate your spouse, child, grandchild, or other loved one as beneficiary of your IRA or retirement plan. Naming one or more of these individuals is common, and often makes sense for a number of reasons. However, your beneficiary choices are not limited to individual people. Another option may be to designate one or more charities as beneficiary of your IRA or retirement plan. Naming a charity can allow you to provide for an organization you believe in, and it can also result in significant income tax and estate planning benefits.

Caution: This discussion applies only to traditional IRAs and employer-sponsored retirement plans. Choosing a beneficiary for a Roth IRA involves different considerations. **Naming a charity as beneficiary will not affect required minimum distributions during your life.** Under federal law, you must begin taking annual required minimum distributions (RMDs) from your traditional IRA and most employer-sponsored retirement plans (including 401(k)s, 403(b)s, 457(b)s, SEPs, and SIMPLE plans) by April 1 of the calendar year following the calendar year in which you reach age 70½ (your "required beginning date"). With employer-sponsored retirement plans, you can delay your first distribution from your current employer's plan until April 1 of the calendar year following the calendar year in which you retire if you retire after age 70½, you are still participating in the employer's plan, and you own 5 percent or less of the employer.

Under the final IRS regulations on minimum required distributions issued in April 2002, your choice of beneficiary generally will not affect the calculation of your RMDs during your lifetime. An important exception exists, though, if your spouse is your sole designated beneficiary for the entire distribution year, and he or she is more than 10 years younger than you.

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Charity as Beneficiary of Traditional IRA or Retirement Plan

by Gaylin Frye

Under the final regulations, having a charity as beneficiary will generally result in limited options (and the fastest possible payout) for required post-death distributions. However, a charity generally pays no income tax on distributions. See below for more information on these issues.

Caution: The calculation of RMDs is complex, as are the related tax and estate planning issues. For more information, consult a tax professional.

Advantages of naming a charity as beneficiary

A charity will not pay income tax on post-death distributions

Like distributions taken during your lifetime, required post-death distributions from a traditional IRA or retirement plan are taxable (to the extent that a distribution represents pretax or tax-deductible contributions, and investment earnings). Consequently, your beneficiary will generally be subject to federal income tax on any distribution that he or she receives from the inherited IRA or plan. (State income tax may also apply.) The post-death distributions will be taxable according to the beneficiary's federal income tax bracket. By contrast, if you named a charity as of January 7, 2013 see disclaimer at end of this article.

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To learn more about these programs call the MSSP office 503.297.9544.

On meeting Dr. Swank by Paula-Noel Macfie, PhD



The very first multiple sclerosis support group I went to in the spring of 2001, I had no idea what was about to unfold in my life. I had just spent the past seven years in graduate school with indigenous elders and healers and completing my doctoral dissertation. I was diagnosed with MS in August of 2001, just three months after graduating with my PhD.

Going into the “world of MS,” I listened to the others in the support group who were diagnosed with MS. They spent almost all of their time talking about the various drugs they were trying out, many of them not working or semi-working, with sub-symptoms as side effects from the drugs. It was all too much for me. I knew after seeing tribal brain surgery in graduate school that the western way of approaching a disease like MS was not one that allows for any sort of cure or healing. After I shared this in the group, a woman

leaned over to me and said, “If you are not going to take the prescription drugs for MS, then you need to meet Dr. Swank. Here is his phone number.”

I went with my dad later that spring to Dr. Swank’s house, with an invitation from his wife Leanna. The moment I met him, I could see such a spark in his eye and was so touched by his gracious and light-hearted manner. He reminded me of so many of the wise indigenous elders, whose knowledge was shared with every slight and subtle comment he made. I ended up spending the next two years visiting with Dr. Swank, taking notes for him, reading his research and usually ending up eating lunch with him at the Skyline Café.

During lunch, he would recount his days in the war or at the Montreal Neurological Institute. He enjoyed sharing stories of his upbringing in Camas. He always made me feel at ease. I enjoyed the retelling of his stories the most, because I knew I was in the presence of an historical and important researcher. He taught me the most valuable tool I’ve ever been taught – how to be in the presence of another person and listen to them, truly hear them and offer the listening back in the wisest of exactly needed advice. This made him such a special man to me. He was accessible and open. I realized early on that there were not many doctors, nor human beings like him.

Every single day I was with him, he would say, “It is diet, rest and exercise. This is the base of all nutritional diseases like multiple sclerosis.” I would often ask him why he called MS a nutritional disease. He would get out his notebook and draw pictures of the capillaries in the body, the path of food through the organs and visually show how through lack of a proper diet, people like myself with MS, starve our bodies with improper fat. He also adamantly explained how our body will rely on itself for its needs if we do not provide for it what it needs. He always insisted on MS being related to the vascular system (he invented blood filters), starting with the small intestine/liver contributing to poorly digested fats and/or lack of proper fats. Circulation and nutrition seemed to me to be a key to finding balance with this disease.

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On meeting Dr. Swank by Paula-Noel Macfie, PhD

What I feel was his greatest accomplishment among the many accolades he received in his life, is that he has truly helped so many people with multiple sclerosis understand that this disease can be slowed down, and in some cases reversed with diet, rest and exercise. Proper nutrition is the key for MS. Getting daily naps is a key. He always said that even if I “lie down for 20 minutes, my body will have an opportunity to recharge. Everyone needs a recharge daily.” He insisted on walking a mile a day, and did so until the last time that I saw him.

He left such a profound impression on my life and the path I have chosen to balance MS in my life. To this day, I have treated MS solely with Dr. Swank’s protocol, along with several herbs. I’ve had good days and not-so-good days like everyone else, yet I know that I have longevity and perseverance with the wisdom that Dr. Swank has imparted to me about living well while navigating multiple sclerosis. He always took time to eat proper food, rest, walk, nap, listen to inspiring music and take the time to make sure every single one of his patients was listened to. He has an impeccable reputation and has helped us live well by being the example. For Dr. Roy L. Swank, I hold his research and his timeless wisdom close to my heart, because that is where he said the opening is.

Dr. Swank established a foundation to continue his work. There is no listed telephone number but they can be reached by email at Swankmsdiet.org and Swank MS Foundation at PO Box 82254, Portland, OR 97282-0254

About Allergan

More than 2.5 million men and women in the US live with urinary incontinence due to a neurologic condition such as multiple sclerosis, spinal cord injury, Parkinson’s disease, or stroke.² These neurologic conditions can interfere with messages between the brain and bladder.¹ As a result, the bladder muscle may become overactive, leading to leakage of urine (urinary incontinence) that you cannot control.¹

When you think of Botox injections, you probably think of getting rid of unwanted wrinkles around the eyes or forehead, but recently the US Food and Drug Administration (FDA) approved using the injections to help patients with neurological conditions who suffer from incontinence, or an overactive bladder.

Botox injections paralyze the bladder muscle to prevent contractions that cause urgency to urinate or leak. Although medications and behavioral modifications are treatment options, many patients, especially the elderly, do not respond to these methods and need a more aggressive approach,

Understanding Urinary Incontinence Associated With Overactive Bladder Due to a Neurologic Condition

The bladder’s job is to store urine and release it at an appropriate time and place. For this to happen smoothly, the brain and the bladder must communicate properly. When the bladder is full, it sends a message to your brain, and you feel an urge to “go.”¹ Your brain sends a message back to your bladder, telling it to contract (tighten) and release urine.¹ The spinal cord carries the messages between the bladder and the brain.

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KEEPING OUR DOORS OPEN:

Mary Flower, Dave's Killer Granddaddies, Robbie Laws Band,
Terry Robb, Kevin Selfe & The Tornados, The Knuckleheads

BLUES 4 MS
a benefit concert for the Multiple Sclerosis Society of Portland
2013
www.blues4ms.org

Sunday, March 3rd 2013
3:00pm - 9:00pm

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More information on the event and the raffle at www.blues4ms.org.

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Cindy Plouff
Kaisa Carlson
Candyce Hayes
LouAnn Lindberg

All proceeds help fund programs and services that directly help those living with MS, their family members and caregivers in Oregon and SW Washington.

About Allergan

For people who do not have urinary leakage from overactive bladder associated with a neurologic condition, the decision to urinate is voluntary, or under a person's control.¹

Discover what's possible with BOTOX® (onabotulinumtoxinA)

Have you tried an anticholinergic medication for urinary incontinence related to your overactive bladder associated with a neurologic condition but still have leakage or cannot tolerate the side effects? BOTOX® is proven to significantly reduce the number of leakage episodes experienced by patients just like you.¹ BOTOX® patients had about 22 fewer leakage episodes each week (compared to about 13 fewer for placebo).

What results could I see?

BOTOX® (onabotulinumtoxinA) clinical studies included patients with urinary incontinence due to overactive bladder associated with a neurologic condition. They had all tried at least one medication for their urinary incontinence but did not experience the improvements they were hoping to see or could not tolerate the side effects. Before treatment with BOTOX®, patients in these studies had an average of 32 leakage episodes each week.¹

Six weeks after treatment with BOTOX®, patients experienced^{1,2}:

- About 22 fewer leakage episodes each week (compared to about 13 fewer for patients receiving placebo, an inactive medicine)
- Increased bladder capacity (the bladder could hold more urine)
- Decreased pressure in the bladder

Improvement that starts as soon as 2 weeks



As soon as 2 weeks—

that's when improvement can be seen.⁺⁺

Some patients experienced fewer leakage episodes compared with placebo as soon as 2 weeks after treatment with BOTOX®.²

About 10 months—

that's how long relief of urinary incontinence symptoms can last.

Based on clinical studies, the effects of treatment with BOTOX® can last for about 10 months.²

Individual results may vary.



For more information visit www.BotoxforIncontinence.com where you can listen to patient stories and find a Urologist near you.

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of Portland, Oregon, Inc.
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