

Friends and Family

The Montel Williams MS Foundation Newsletter

volume 11 edition 2

Give Any Way You Can



Dear Friends,

I continue to be touched by the letters, e-mails and calls that I receive from so many of you from across the country. Each one renews me and lets me know that I am on the right path in my mission to end MS. In your correspondence you share with me your stories of living with MS, or of supporting and wanting to learn how to support a loved one with this debilitating disease.

In this issue we talk to a tenacious MS survivor, Denise Coleman, who has beaten back tremendous health and personal challenges to forge a full life for herself. I hope you will draw as much inspiration from her story as I have.

And speaking of inspiration, my pledge to donate 100% of contributions from individuals to research toward a cure has moved many of you not only to hold all charities to a higher standard, but also to donate to this foundation. I am always surprised and touched when I get notes of apology with the donations, like the one from a senior citizen, a mother from Little Rock, Arkansas, who cares for an adult daughter debilitated by MS. "I wish it could be more," she writes of her gift, "but

I am on a fixed income." While I encourage each of you to give as much as you can, as often as you can, and to spread the news about the work that we do, no one need apologize for the size of their donation to this foundation. We honor each contribution as the gift that it is, as the step that it is toward ending this disease.

In this issue of the newsletter, we also share with you the many opportunities that there are to donate to the Foundation, from the summer-long fund-raiser that we did with Brunswick Bowling & Billiards, to the annual corporate party that my employees and colleagues from Paramount Domestic Television have turned into a fund-raiser for the Foundation, now for the second year in a row. And there are many more of you who work with your respective communities to do events that are both fun and meaningful for the Foundation. A few of these events are documented on the following pages. I thank each and every one of you from the bottom of my heart. This poem, by two donors, sums up all your efforts best:

*May this small donation
Act like a drop of rain
Flowing towards the ocean
Of other donations.
Let it find its level
And may you find a cure
May God give you strength to endure.*

—Rev. Dr. Angela S. Heil & Rev. Ralph Heil

Montel B. Williams

New Grant

This May The Montel Williams MS Foundation made a grant of \$25,000 to The Nancy Davis Center Without Walls, for its consortium of MS research scientists. This brings our total grants to \$603,000.

First Montel Williams MS Foundation Clinical Fellow Works on Clinical Trials for MS Drugs

Menaka DeSilva, M.D., served as the 2004-2005 Montel B. Williams Fellow of Clinical Neuroimmunology at the University of California at Irvine. He completed his neurology residency at the University of California at Irvine prior to accepting the fellowship. He was involved in various clinical trials including the Neurocrine Bioscience (NBI-5788) study, the Berlex ABOVE and BEYOND studies, the Cleveland Clinic/Biogen-Idec ACT trial, the Teva ACHIEVE trial, and the Biogen-Idec Antegren/Avonex trial. He was involved in the trial design, application process and clinical examinations. Dr. DeSilva was instrumental in obtaining computer hardware and software in which he was able to perform serial neurocognitive tests on multiple sclerosis patients. He helped organize the computer database developed to follow multiple sclerosis patients over time and to record their response to therapy. Dr. DeSilva also assisted Dr. Michael J. Olek, Assistant Professor of Neurology and Director of the Multiple Sclerosis Center at the University of California at Irvine, in compiling a new book on multiple sclerosis of which he is the editor. The book, *Multiple Sclerosis: Etiology, Diagnosis, and New Treatment Strategies*, was released by Humana Press in October of 2004.

True Survivor: Denise Coleman



Denise Coleman is a mother, former college and non-profit administrator, author, lecturer, pain management advocate and a true MS survivor. She spent a morning recently sharing her inspiring story with Friends and Family newsletter. A Long Island native, she resides in New York City.

Friends and Family: How long have you had pain?

Denise Coleman: I've had back pain for 41 years. By the time I'd become an adult, I'd had four major spinal surgeries.

FF: What precipitated your diagnosis with MS?

DC: I was experiencing numbness, my balance had become terrible, I was falling, my eyes were blurred, and I was overwhelmingly fatigued. All the doctors said that it was nerve damage due to my surgeries. It wasn't until 1997, after my current neurologist ordered an MRI, that I was diagnosed with the illness.

FF: How did you cope with the diagnosis?

DC: I hated to be ill, but the diagnosis validated how I felt. I finally knew that I wasn't crazy. People will tell you that there is no pain with MS. That is nonsense!

FF: How do you manage the pain?

DC: My neurologist's practice includes an integrative pain management specialist. Now I work with professionals who understand pain. I have an intrathecal morphine pump, which deals with much of the pain. It has given me a new lease on life.

FF: How do you as a patient get your physician to work with you on pain management?

DC: If a doctor can't spend a few minutes to talk to you about how your pain is changing or not, whether it is burning or stabbing, and how it is affecting your life, then he or she is ineffective. If the doctor doesn't ask, tell him or her anyway. Make sure that you are heard!

FF: What's your advice for MS survivors who want to explain their pain to doubting loved ones?

DC: I share with friends and loved ones good books that describe how pain affects someone else's life, like *Climbing Higher*. You have to be able to explain that it is not that you don't want to be with your loved ones, you have no choice. There are times that you just need to lie down, or you are in the hospital a lot, or you cannot participate in the same activities, or maybe you are just in a lousy mood! So it is your responsibility to explain your situation to the people around you—not so that they will fully understand your pain and sensations, but so that they can better understand that you need assistance and why. Those of us in pain must realize that our loved ones may even get angry and miss an old friend. Well guess what? So do we!

FF: Your personal life has thrown you quite a few wrenches as well. How did you end up on welfare?

DC: I was a young divorced mother with a disability and no college degree, so I went on welfare. Back then you were not allowed to go to college if you were on welfare, so I took the county to court and I won.

After college, I got a job at State University of New York at Stony Brook and did my Master's at night. Since then, I have worked with women who are struggling to get out of the system. Being on public assistance taught me a lot about the human experience.

FF: You were Executive Director of The Stony Brook Foundation, and have had illustrious positions in fundraising and administration at the National Alliance for Research on Schizophrenia & Depression, at Fairleigh Dickinson University and at Bank Street College. What ended your career?

DC: In 1998 I went out on disability. It was the hardest thing I'd ever done. My daughter was grown. My career was over. I no longer had the responsibilities and pressures, as well as the human contact, that came with them. After six months, I knew that if I didn't do something, I was going to get really depressed. So I wrote a mystery called *A Loyal Client*, which I am trying to get published.

FF: What was the impetus for the founding of the Chronic Pain Awareness Project, and what are its goals?

DC: Two weeks after September 11, 2001, began 16 months of strife for me. I started falling more than usual, and broke several bones, including my right hip, which was eventually replaced. I was wheelchair bound and afraid to walk. On top of that, I was beginning to experience cognitive loss for the first time.

That's when I created the Chronic Pain Awareness Project. If I did not do something to help others, everything that I had been through would have been a waste. I know that God put me here for a reason. I decided to focus on transitions, how people adapt physically and emotionally to their new lives. People with chronic pain have to reevaluate their goals based on what they can do in the context of pain.

The Chronic Pain Awareness Project comprises a public awareness component; public speaking engagements and seminars; and a medical model, including an educational program for medical professionals on communicating with chronic pain patients. I ultimately want to impact medical education so that chronic pain and pain management are taught in medical schools and hospitals across disciplines, not just as a specialty.

FF: What is the secret to your perseverance?

DC: Sometimes I'm angered by the many interruptions I've had in reaching my goals, but I've learned not to give up. I have also been fortunate to have a wonderful daughter who has been a motivating force my whole adult life. And a good sense of humor doesn't hurt; sometimes you just have to laugh at yourself.

FF: What is the Hang in There Group?

DC: Hang in There includes 18 women from across the country, from their mid 30's to mid-60's, who have MS. We e-mail each other every day, sharing stories about what this dreadful disease, the MonSter, is doing to our families and us, information about our therapies, our doctors, our symptoms, what works and what doesn't. Most of all, we offer a level of support that someone who does not experience the pain and anguish, both physical and emotional, cannot offer.

From The Hang In There Group

"I am a fighter and I'm stubborn. I won't let the MonSter win but sometimes it gets the upper hand."—**Teri Svehla, IL**

"I am in constant pain, but I still live every day to the fullest my body allows. I thank God for every day that I have with my husband and son." —**Marlene Dixon, AL**

"No one can SEE how unsteady I may be, unless I fall. There is no way to get "normal" people to understand, that is why we need MS groups to keep us all from going insane!"—**Micky Brown, TN**

Summer Fundraisers

"Strike Down MS" Summer



Montel signs a bowling ball at Brunswick Zone Lone Tree, in CO.

July 10, 2004 marked Family Day for The Montel Williams MS Foundation's first ever national fundraising event, Strike Down MS Summer. Together with 106 Brunswick bowling centers across the U.S., supporters bowled all summer long to raise funds for research toward a cure for MS. We would like to thank everyone who participated.

Annual Corporate Party

September 18, 2004 marked the 4th Annual Staff Party for The Montel Williams Show in Katonah, NY, and the second such event to benefit The Montel Williams MS Foundation. The staff raised over \$5,000 for MS research. Thanks to those companies

whose donations made the event a resounding success: Yorktown Beer & Soda, Suburban Wine & Liquor Store Inc., Inserra Supermarkets, Route 66, D. Bertoline & Sons, Manhattan Beer, Oak Beverages, Strokos and New York Party Works.

Top row (left to right): Joe Pryor, Director of Security Affairs; Gwen Clark, Production Accountant; Rob Salanca, Cameraman.

Middle row (left to right): Helaine Tabacoff, Production Assistant; Will Parker, Security; Nicole Mata, Travel Coordinator; Jessica Disimone, Production Assistant.

Bottom row (left to right): Dan Cotoia, Executive Assistant; Anthony D'Amato, Production Assistant.



Fundraisers' Corner

Every month, Montel receives letters from people who have found fun and clever ways to take the initiative to raise funds for MS research. Many people have so much fun, they make their event annual!

Annual Angels:

Jonathon J. Sosnowski, of Scotia, NY, raised \$5,430.00 when his jewelry store, Schenectady Mayfair Jewelers And Silversmiths, held its annual golf tournament. To date, they have raised a total of \$12,953.00 for the Foundation!

Dana Nichols, of Lawrenceburg, KY, raised \$2,041.51 when her friends and family competed in their annual lawn and garden tractor-pulling contest. To date, they have raised a total of \$3,402.71 for the cause!

New Champions:



Brad and Nikki Kinzer, of Tigard, OR, raised \$15,316.00 when they designed their own MS Walk with a group of friends and loved ones during their anniversary celebrations.

Meg Stezzi, of Marlton, NJ, raised \$2,078.00 when the Cosmetology Class of the Rizzieri Aveda School for Beauty and Wellness did a Hair Show.

Dayna Zisis, of Bohemia, NY, raised \$1,000 through bake sales with the hard work of her students at Branford Hall Career Institute.

Companies Donate to the Foundation



Freshflowercard Raises Funds for the Foundation Every Time You Order

Make your order of autumn flowers handcrafted into a personalized mini-fresh flower arrangement and set into a 3-dimensional card. Your item will be delivered overnight in a sturdy yet elegant gold and black gift box by freshflowercard. Freshflowercard donates a portion of each purchase to The Foundation. To order visit: www.freshflowercard.com OR phone (M-F 9-5pm PST) 1-877-443-7374. Choose MS Research, and *** Code: MW 113004 to receive a free butterfly.*** Pictured: Come Rumba With Me.

American Express Gives You 3 Easy Ways to Donate to The Montel Williams MS Foundation

Log onto <http://amex.justgive.org/giving/donate.jsp?charityId=4429&> to do any of the following: 1) Earn one Membership Rewards® 1 point for every dollar you donate when you charge your contribution to an eligible, enrolled Card. 2) Make a monthly or annual recurring donation. 3) Redeem points in increments of 1,000, 5,000, and 10,000—the Foundation receives \$5 for every 1,000 points redeemed.

Save The Dates

“STAND UP AGAINST MS” COMEDY FUNDRAISER features stand-up comics competing to raise funds for MS. The monthly contests will be held at The New York Improv at 318 West 53rd Street on October 27th, November 17th, January 12th, February 11th and March 9th, all at 9p.m. Tickets are \$12. The NY Improv will donate \$10 from every ticket sold to the Foundation. To make a reservation or for more information, please call 212-757-2323, or log onto www.newyorkimprov.com for tickets.



For more information on Rebif,
please call 1-877-447-3243

Fight MS With Your Gift

Your gift could double if your company has a matching gift program. Please ask your human resources office for the appropriate forms and guidelines.

Please consider continuing the fight against MS for as long as it takes to find a cure. Consider including a bequest to The Montel Williams MS Foundation in your will.

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A copy of the latest Financial Report and Registration filed by this organization may be obtained by sending a self-addressed, stamped envelope to: The Montel Williams MS Foundation, 331 West 57th Street, PMB #420, New York, NY 10019, or by contacting the New York Office of the Attorney General, Department of Law, Charities Bureau, 120 Broadway, New York, NY 10271. Registration with the Attorney General does not imply an endorsement.

PERMIT NO.

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