

Friends and Family

The Montel Williams MS Foundation Newsletter

volume III edition I

Asking for Help



Dear Friends,

For many of us with MS, asking for help is a difficult thing to do. Our illness takes so much from us, that we struggle to maintain our independence, our last shred of who we were before our diagnosis. The sentiment is understandable, but the results, poor. I know because I have been there. Learning to ask for help has been a process for me. As I say these days, illness is not weakness, nor is asking for help.

In this issue of Friends and Family, we share a column about how to integrate MS into your marriage and family life, written by a therapist whose own family has been touched by this illness. This piece addresses the fine line between telling your loved ones about your symptoms

and getting them to *understand* that you have different abilities and challenges because of the illness.

We also introduce you to a brave soldier in the fight against MS, Jennifer Woods, a young mother who has turned her MS diagnosis into a reason to make her stamp on disability law. I hope that Jennifer's fighting spirit and her wisdom will inspire you and give you and your loved ones important tools in your own MS journeys.

We are heading into the summer season doing two wonderful fund-raising events, one that enlists the support of country music great, Hal Ketchum, and one that introduces a talented new painter, Samantha Keely Smith, to the world. We have garnered the commitment of so many generous individuals who are working diligently to make these events successful. I hope that you will join us when and where you can.

Montel.

New Grants

Since January 2005, the Foundation has granted \$126,200 to the following projects:
Cell-Based Therapies Stem Cell Research Program and Molecular Neurobiology of MS
Principal Investigator: Dr. Stephen G. Waxman
Research Facility: VA Connecticut Healthcare System at Yale

Goals include understanding the molecular basis for remissions so that they may be induced, developing effective treatments that will prevent further neurological loss in people with MS, and restoring lost functions.

Identifying Metabolic Markers

Principal Investigator: Dr. Hugo Moser
Research Facility: Kennedy Krieger Institute at Johns Hopkins University

This study is to identify metabolic markers that predict lesion formation and progression in a potentially pathogenetic capacity. This will allow early detection for timely institution of therapy, and provide clues for identifying newer treatments and allow rapid evaluation of these new therapies.

Genetics

Principal Investigator: Dr. Tomas Olsson
Research Facility: Karolinska Sjukhuset, Stockholm, Sweden

This project will use epidemiological research to investigate the multifactorial nature of the MS disease process, by linking individuals' medical and other records with those of their parents, grandparents and siblings.

Activation and Differentiation of CNS Stem Cells in MS-like Autoimmune Lesions

Principal Investigator: Dr. Lou Brudin
Research Facility: Karolinska Hospital, Stockholm, Sweden

This project addresses the possible activation and differentiation of central nervous system stem cells following such immunological insults of MS characterized by spinal cord pathology. Dr. Brudin's observations may provide a clue to the mechanisms of neuroregeneration.

The Nancy Davis Center Without Walls

A collaboration of physicians, scientists and clinicians at six top MS institutions on research programs and therapeutic approaches to eradicate MS.

SPECIAL GIFT

In solidarity with the stellar work being done at the Accelerated Cure Project for Multiple Sclerosis, which is dedicated to curing MS by determining its causes, the Foundation has made a special gift of \$2,000, which will be matched by another foundation.

True Survivor: Jennifer Woods

Jennifer Woods is an attorney with the Indiana Protection and Advocacy Services who has parlayed her MS diagnosis at the tender age of 21 into a lifelong commitment to disability law. A wife and mother of twin four-year-old girls, Jennifer recently took a few hours from a busy morning to share with Friends and Family how she stays committed – and optimistic.



Friends and Family: How were you diagnosed with MS?

Jennifer Woods: During my senior year at Columbia University, I had the flu, double vision, spasticity in my legs and numbness all over. I started going to doctors, but was not getting any answers. At one point I could hardly see. The primary care physician on campus sent me to a neurologist who in turn sent me for a spinal tap and an MRI. Plaques showed up on the MRI, and I was told that I *probably* had MS.

FF: How did you react to this diagnosis?

JW: I thought that my life was over. I returned home to Indianapolis, and spent the next month in bed. I read in the encyclopedia that people with MS live for 22 years after diagnosis—at 21 that was not a good prognosis. But eventually the symptoms went away. I was convinced that I had only 22 years to live, but felt I felt okay.

FF: Why did you decide to specialize in disability law?

JW: I returned to New York City and began working at the National MS Society, assisting with the administration of the AmeriCorps national volunteer project. Seeing people with more visible disabilities scared me, but I realized that they were the same people inside who they were before the diagnosis.

Another turning point came when I volunteered for a legal services day, and learned about discrimination affecting people with MS. I was fascinated with the progress made through the Americans with Disabilities Act (ADA), but amazed by the remaining obstacles. I started thinking about law school, and chose Georgetown because DC was the heart of the disability-rights movement.

FF: How did you manage MS during your post-diagnosis period?

JW: When the physical symptoms of MS are latent, you have to think about what to do with your time. I wanted to use the law to be of service to people with disabilities. I graduated from law school, got married and had twins. Almost immediately after I gave birth, I had an exacerbation.

FF: What kinds of legal cases do you see at work?

JW: The agency advocates for individuals with developmental and physical disabilities, and mental illness. We help a fair number of MS survivors who use assistive technology such as scooters and gliders—equipment that insurance companies are less likely to cover. I determine whether an insurance company's policies are discriminatory, whether their categorizations are fair, and help individuals work through the appeals process.

FF: The ADA has been law for 15 years. Why are so many public places still inaccessible?

JW: Often older businesses have not been pushed to comply. It is not uncommon for the owners or administrators of facilities to incorrectly assume that their buildings are accessible. Through the Indiana Protection and Advocacy Services, I am heading a compliance project for the Help America Vote Act, passed after the 2000 elections, to make polling sites accessible. The legislation gives each state funds to document how polling places will be made accessible by January 2006. I must say that Indiana is doing well in developing its accessibility plan.

FF: What rights do employees with disabilities have?

JW: Employers must provide reasonable accommodations, and financial programs may be available to help small employers comply.

FF: How can individuals fight discrimination?

JW: For employment issues you should contact your local Equal Employment Opportunity Commission (EEOC). The Department of Justice has a complaint process for ADA issues, and each state has a protection and advocacy agency that is federally funded and mandated to respond to complaints about access.

FF: Why did you decide to run in the New York City Marathon?

JW: I wanted my girls to realize that you can set goals even if you have a major challenge. The marathon was even more of a challenge for me because I hate running. Last fall, I ran 26.2 miles the day after I turned 33! I was advised to wait a year so that I could train more for the marathon. But I am not sure what new challenges I will face in a year. MS is unpredictable. While you are healthy and can do it, go for it!

FF: How much have you told your daughters about your illness?

JW: My girls know that Mommy is sick once a week, and that Daddy takes care of Mommy, because he gives me my shots. I am a board member of Girls Inc., an organization dedicated to helping girls become "strong, smart and bold". Many of these girls have their own obstacles, but we teach them that they need to be brave enough to set goals and find creative ways to work with their challenges. I will approach my daughters with a similar philosophy. They will not have a negative, sad viewpoint of MS.

FF: We get lots of calls from young people who are diagnosed at some critical juncture in their life. What's your advice?

JW: Don't let MS stop you. Think about whether the challenges presented by the illness generate new ideas, new curiosities. I discovered an area of law that intrigued me as a result of having MS.

Fighting Back

There are myriad resources that you can access if you think that you are being discriminated against because of MS or any other kind of disability.

National Association of Protection and Advocacy Systems (NAPAS)

900 Second Street NE, Suite 211
Washington, DC 20002
Phone: (202)-408-9514
Fax: (202)-408-9520

Great Lakes Disability and Business Technical Assistance Center

1640 West Roosevelt Road
Chicago, IL 60608
312-413-1407 (Voice/TTY)
312-413-1856 (Fax)

U.S. Department of Justice

Civil Rights Division
950 Pennsylvania Avenue, NW
Disability Rights Section - NYAV
Washington, DC 20530
1-800-514-0301 or 1-800-514-0383 (TDD)

When MS Is A Third Wheel, Can The Marriage Be Saved?

**Connie Lenori, 33, a stay-at-home mother of two toddlers, called the Foundation office shortly after the re-release of Montel's Climbing Higher in January. Connie wanted to know if the book was going to be released on tape. Why? Because her husband, *Chad, 35, had shown her little empathy since her diagnosis with MS two years earlier. He had scoffed at her fatigue and the debilitating leg pain that sent her reeling, telling her that her symptoms were all in her head.*

She Says

Chad was the the perfect husband and father, until I was diagnosed with MS shortly after giving birth to my second baby. He pushes me away when I try to talk to him about how I feel. When I tried to show him *Climbing Higher*, he pushed that away, too. That's when I called Montel's foundation to find out if the book is on tape. I figure that when we are driving in the car, I can force him to listen to it. That's how desperate I am to show him that MS is real.



He Says

Connie was the sweetest person I had ever known, and it seemed like our honeymoon went on for years. But then it was as if she turned into an old woman overnight. She is resentful that I still hike and climb, which we used to do together. She says that she is always tired and painful and wants to talk about it all the time. What is the point? She even tried to show me Montel's book. What does that have to do with us? She has let her illness become a third person in this marriage. It controls everything.

The Therapist Says

It is understandable that Chad would feel resentment. In his desire to pretend that MS isn't a real disease though, in psychodynamic terms, he is in the defensive position of denial. Possibly Chad would feel too vulnerable and powerless if he were to fully allow himself to accept the devastation of MS and how radically it has affected his wife, and by extension their life together. Chad may not be able right now to grieve the loss of his wife as he'd like her to be, and accept the reality of their new situation.

Connie optimally wants Chad to understand what she is experiencing. She also needs to be aware that her husband is having a tough time in his own right. Would it be possible for Connie to be there, at the end of a hike, with a picnic lunch for the two of them to enjoy together? What interests do Connie and Chad have in common, or could develop together, that would be fun for them as a couple?

Accepting and changing old ways of being is not easy for anyone. Many people believe that it's best to pretend that everything is okay because if they really acknowledge what they're thinking and feeling, it will only make things worse. It is always an advantage to accept a situation as it is and to appreciate the feelings that come up.

Chad is expressing his feelings about how his wife's MS symptoms are affecting him, and Connie needs to be able to hear what her husband is saying. In time, Chad may be able to accept what is happening, but he is going to need Connie's help to do that first.

Daphne Leahy, CSW, a NY-based therapist in private practice, has a relative who is living with MS.

*** Names and some identifying circumstances changed to protect privacy.**

Editor's Note: Depression is an illness that is common among MS survivors due to their compromised central nervous systems, which can be devastating and potentially lethal despite being very treatable. Depression can also occur among caregivers, whose needs are often under-supported. In this case the therapist ruled out depression in both the MS survivor and her husband.

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.

Special Thanks

Psychic Sylvia Browne has partnered with the publishing firm, Hay House, to do a series of 19 lectures across the nation between February and December of 2005. Sylvia and Hay House are donating \$2 from each ticket sold over the duration of the tour to The Montel Williams MS Foundation. Hay House has already made two generous donations totaling \$75,000, and has collected an additional \$1,726 from participants of Sylvia's lectures.

Sylvia is also helping to raise funds through one of her latest books, *Animals on the Other Side*, which is available now for just \$16.95! Purchase your book through the link below and the Foundation will receive a \$5 donation for each book sold. You must order through this link, www.angelbea.com/montel.html, or call 1-800-570-8689 and tell the operator you heard about the book through Montel.

Animals on the Other Side explains for pet owners of all ages what animals experience when they pass over. So far, Montel's supporters have already raised over \$12,500 for MS research by purchasing this book.

Generous Grant From FEDEX

FedEx has made a generous donation in the amount of \$50,000 to the Foundation. Our thanks to William G. Margaritis, Corporate Vice President, Worldwide Communications & Investor Relations and Rose Jackson Flenorl, Manager, Global Community Relations & Philanthropy, for facilitating this grant.

Wyndham Casa Marina Resort in Key West, Florida (www.wyndham.com) donated a land package for two for a 3-nights/4-days stay at their resort. Thanks in part to their donation, we were able to raise over \$5,000 from employees of *The Montel Williams Show* and award this trip to the staff member who secured the highest amount of donations at our Annual Corporate Party. Congratulations Robin Patterson!

On A High Note...

Paul Nicholas, a young aspiring musician with MS, has just completed his first album entitled *Remember Me Forever*. Paul will donate 10% of sales from his album to The Montel Williams MS Foundation. Please visit <http://creativeforce.com/webstore/> to order. Thank you, Paul!



Events

Rites Of Passage

The Montel Williams MS Foundation will present Samantha Keely Smith's vivid paintings at a major exhibit entitled *Rites of Passage* at ACA Galleries on 529 West 20th Street in Manhattan. The exhibit will be open to the public on Saturday, June 4, 2005 and continue through July 15, 2005. A portion of the proceeds from *Rites of Passage* will be donated to The Montel Williams MS Foundation. For more information on the exhibition, and to buy a limited-edition catalogue for \$20, please see www.montelms.org.

Jam Against MS

Montel will join country music star Hal Ketchum in song during a series of concert tour dates from June 18 to July 16, 2005. Proceeds from the concerts will be donated to The Montel Williams MS Foundation. These are the venues and dates: TRUMP 29 SPOTLIGHT CASINO – Coachella, CA – June 18 • ISLE OF CAPRI – Lake Charles, LA – June 25 • ISLE OF CAPRI – Bossier City, LA – July 14 • ORIENTAL THEATER – Denver, CO – July 15 • TEXAS STATION CASINO – Las Vegas – July 16 • ISLE OF CAPRI – Biloxi, MS – July 17. For more information, please visit www.montelms.org.

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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.

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