

THANK-YOU GIFTS

Montel Dog Tag

Make a fashion statement and be charitable with the Montel Williams diamond-tip engraved two-sided dog tag. Montel's image is on one side, and the slogan "Mountain Get Out of My Way!" is on the other. The tag measures 1.9 inches by 1.4 inches, is made of rhodium and nickel, and comes with a 17.5-inch chain. It can be yours for a minimum gift of \$20.



MS Musicfest CD

MS Musicfest, the brainchild of rocker and humanitarian Jeff Cezosie, was an all-day summerfest in Staten Island, NY, featuring local rock performances and headlined by Kevin Martin (former lead singer of Candlebox) and the Hiwatts to benefit the Foundation. Get your MS Musicfest commemorative CD today for a minimum gift of \$15*.



*Please visit www.montelms.org to qualify for your gift, or indicate your choice of gift on the return envelope attached to this newsletter.

Note: The opinions reflected in this newsletter belong to the individuals represented and not the Foundation.

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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.

The Montel Williams MS Foundation
331 West 57th Street, PMB #420
New York, NY 10019



EIGHT-YEAR-OLD FIGHTER

Briana Landis seems just like your average 8-year-old-girl. She is smart, charming, and funny. She loves to play baseball, basketball, and soccer and to care for her baby sister (pictured below). The only difference between Briana and her classmates is that Briana has multiple sclerosis.

Briana began experiencing severe headaches at age 4. After about a year of testing, doctors finally diagnosed her with MS. With this diagnosis, she found a new mission in life – to travel throughout her community to raise money for and awareness of MS. She signed up for the MS walk and completed the 5-mile course with a group of 43 friends, raising approximately \$5,000 for MS in the process.



As a result of this outstanding achievement, Briana was named a national winner of the Kohl's Kids Who Care award, and received a \$5,000 scholarship along with a \$1,000 donation to a charity of her choice. We here at The Montel Williams MS Foundation are honored to receive this special gift.

Briana continues her fight to defeat MS. She raised an additional \$5,000 in 2005 and hopes to do the same again this year. We applaud Briana for turning her adversity into a platform to end the illness. With people like her, we will defeat MS.

WHEN MS HURTS THE MOST: MS AND CHILDREN



Children and MS. That very phrase makes me shudder. All parents with MS worry not only about the emotional impact of the illness on our children but also about the possibility, however slight, that any one of our children might one day utter the dreaded words "I have MS." That is the nightmare of every parent who lives with this illness. *I know.*

As we in the MS community—one of survivors and their loved ones—are aware, MS has been fast encroaching into "nontraditional" populations. Children have been added to the mix, along with men and people of color, defying our popular perceptions about what MS looks like.

We are honored to hear from a variety of people who know all too well about how children are affected by MS. In this issue, we feature an 8-year-old who has turned her MS diagnosis into an opportunity to educate the public and raise awareness about the illness. We speak with a teenager who is both battling MS and dealing with the aftermath of Hurricane Katrina. We also talk to the adult daughter of a woman with MS who has written a book about coping with the illness from a child's perspective.

In addition to these voices, one of the world's leading MS pediatricians, Dr. Lauren Krupp, has taken some time to talk to us about the National Pediatric Multiple Sclerosis Center at Stony Brook, in New York, and what we can learn about MS from children who are living with this illness.

While we can draw strength from the extraordinary people whom we feature in this issue, their stories serve as reminders of how far we have to go in our battle to end MS. Thank you for your ongoing commitment.

Montel B. Williams

ALSO IN THIS ISSUE:

- **Teen Battles MS**
- **Pediatric MS Specialist**
- **When MS Affects a Child's Loved One**

TRUE SURVIVOR: BATTLE AGAINST A PERSONAL HURRICANE

Chelsea Perniciaro is a typical teenager who has always loved sports and played for numerous teams. At age 13, however, Chelsea's life took a turn for the worse. In the span of a couple of years, she was hospitalized with a mystery illness, diagnosed with MS, and then endured Hurricane Katrina's assault on her hometown of Gulfport, Louisiana. Friends and Family recently caught up with Chelsea, who is now 16, and spoke with her about living with MS.

Friends and Family: What was the chain of events leading up to your diagnosis?

Chelsea Perniciaro: I am not sure how it all began, but I do remember that nothing seemed to go right on the basketball court. I was very clumsy, and I could not seem to concentrate on schoolwork. I could not think or remember anything. And my eyesight was not that great either. Every week I seemed to be complaining about something different. During practice one evening there was weakness in my legs and I experienced a bad fall. An orthopedic doctor said it was growing pains and sent me home in a knee brace. Just walking the halls from class to class became a chore. I thought I was doing too much. I was beginning to believe that basketball just was not worth it; I was tired. I experienced another bad fall during practice, which was embarrassing. That was my last day on the court with my team.

FF: How did your symptoms progress?

CP: After I experienced blindness in my left eye, my parents knew something was seriously wrong. This would be the beginning of new challenges for me. I could barely even walk, and I was hospitalized. The doctor talked to my parents about Gambier Paralysis. I'll never forget that word – *paralysis*. Later that afternoon a team of doctors diagnosed me with one of two diseases: Either Acute Disseminated Encephalomyelitis (ADEM) or MS. The two illnesses are so similar in symptoms that it was hard to tell which one I had. Eventually I was diagnosed with MS.



FF: How did you react to the diagnosis?

CP: I thought I was going to die. I was so scared and it was horrible. But I just prayed to the Lord and asked Him to help me fight through it. Nancy Goldman from The Montel Williams MS Foundation wrote me a letter in which she quoted Montel: "You have MS, it does not have you." I live by that.

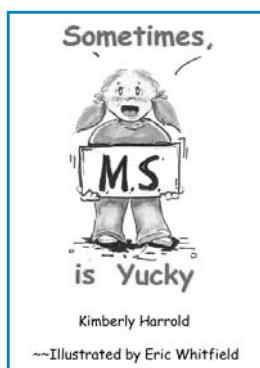
FF: How did you and your family fare during Hurricane Katrina?

CP: Our house was destroyed; it floated about 150 feet away from where it was supposed to be and broke off into lots of pieces. Thankfully, everyone in my family was physically okay. We had to start all over. My dad just built us a new house.

FF: How are you doing now?

CP: Occurrences of MS to me are like hurricanes. They begin to brew in a mysterious way. Some are stronger than others. When each one forms, I set up my barricade, prepare for the wind and ride it out. Although my first occurrence was a whammy, I've been riding this one out for more than five months. I am slowly coming back. I feel stronger every day. I have my barricade and no hurricane will break me down.

TALKING TO SMALL CHILDREN ABOUT MS



Sometimes MS Is Yucky is a children's book by Kimberly Harrold, the adult daughter of a woman with MS. The book, which targets 3- to 8-year-olds, includes touching lines such as "MS is hard to understand. Sometimes Mom's body hurts. Some days she feels good. Some days she feels bad. Sometimes MS is yucky. But always, Mommy loves me very much. This helps the yuckiness go away."

Says Kimberly: "I really wanted to help parents of children address the emotional issues of having a family member with MS. I grew up with a mom with MS, so I felt and still feel a need for resources targeting young children."

The book also includes a guide for parents and caregivers, with suggestions on how to explain to children MS symptoms, and exercises to help them manage the feelings of fear and anger brought about by the illness.

You can order *Sometimes MS Is Yucky* online for \$7.95 by visiting www.sciencehumanitiespress.com.

NEED ASSISTANCE PAYING FOR YOUR PRESCRIPTION MEDICINES?



Montel serves as the spokesperson for the Partnership for Prescription Assistance (PPA), a national program to help patients in need access prescription medications. It has helped more than two million uninsured and underinsured patients, but millions more can benefit.

For more information about the Partnership for Prescription Assistance, please visit its website at www.pparx.org or call 888-4-PPA-NOW (888-477-2669).

A CONVERSATION WITH DR. LAUREN KRUPP, DIRECTOR, NATIONAL PEDIATRIC MULTIPLE SCLEROSIS CENTER AT STONY BROOK

Friends and Family: How many children in the United States have MS?

Dr. Lauren Krupp: According to the NMSS, approximately 8,000 to 10,000 children have MS and another 10,000 to 15,000 have experienced what may be symptoms of MS.



FF: Can children be born with MS?

LK: No, it is an acquired disease. Children, like adults, may be born with a predisposition to the disease.

FF: How many children worldwide have MS?

LK: Three to 5 percent of the 2.5 million people in the world who have MS are children.

FF: What is your reaction to headlines such as PEDIATRIC MS: A SILENT EPIDEMIC? Are they hyperbole?

LK: Yes, because we do not have enough epidemiology studies for the past and present to say it is an epidemic.

FF: Do children typically exhibit an array of symptoms that is similar to those of adults?

LK: Yes.

FF: What was the impetus for founding the National Pediatric MS Center?

LK: A young, beautiful girl who got MS and experienced a very rough course was presented to us. We were extremely frustrated that there was so little known about how best to help her. We became determined that when the next kid came to us we would know more and be better prepared to assist the child and the family.

FF: How many children does the center currently serve and what is the age range?

LK: We have seen close to 200 children at our center between the ages of 3 and 17.

FF: MS is typically thought of as a "woman's disease." Does its foray into the pediatric population also signify a foray into other "nontraditional populations"?

LK: Yes, there is a surprisingly large number of Hispanics, African Americans, and first-generation Americans who are suffering with the disease whose parents were born in countries that traditionally do not have MS.

FF: What can research into children living with MS potentially offer to the adult population of MS patients?

LK: The National Pediatric Multiple Sclerosis Center is advancing research that could potentially make a huge difference in the lives of both children and adults with MS. Our goal is to apply our findings in identifying the biological changes in children with MS and to ultimately find a cure for this disabling disease.

FF: Tell us a bit about the Centers of Excellence and what its impact is.

LK: To further understanding and awareness of pediatric MS, the NMSS is providing \$13.5 million over the next five years to six regional pediatric MS centers that will focus on treatment and research. The centers, at the University of Alabama in Birmingham; State University of New York at Buffalo; the Mayo Clinic in Rochester, Minn.; the National Pediatric Multiple Sclerosis Center at Stony Brook University Hospital in Long Island; the Massachusetts General Hospital for Children in Boston; and the University of California in San Francisco, will pool their data in an effort to establish the first national database of pediatric MS cases. Researchers say the database will lead to more clinical trials involving children, who are often treated for MS with medicines that are approved for use in adults but haven't been rigorously studied in children. I am the leader of this network of centers. The goal is to treat as many children as possible and to set the standard for comprehensive care for pediatric MS, including medical diagnosis and treatment, rehabilitation, psychosocial issues and educational components. The centers will create the framework to conduct critical research – both to understand childhood MS and to unlock the mysteries of MS in adults.

FF: Do you have any advice for parents who are caring for children with MS?

LK: Yes. If possible, have your child seen at one of the Pediatric MS Centers of Excellence. Please visit www.pediatricmscenter.org for more information on the centers. It is also important to encourage your child to remain on therapy even though no symptoms are appearing.



FUNDING ANGELS

Hay House Publishers supported the Foundation throughout our last fiscal year with a gift of \$125,000, our largest single gift ever. We are deeply indebted to Louise Hay and Reid Tracy.

FedEx Corporation recently renewed its support with a generous \$50,000 donation. Thanks to Bill Margaritis and Rose Jackson Flenorl for facilitating this gift once again.

Kimberly Dolan of Dolan's Deli and Bar organized her fourth annual golf tournament for MS research. Thanks to everyone's support, she was able to raise more than \$8,000 during one event. Kimberly has already geared up for this year's tournament, slated for fall 2006.

Ron Wood, CEO of Modern Engineering, organized a golf tournament in honor of the wife of one of his employees, who is living with MS. Thanks to Ron's efforts, the company raised \$5,000 for MS research.

Thanks to the generosity of all of our supporters, we can continue making strides in our battle against MS.

EVENTS



Annual Bike-a-thon

Join us Saturday, September 30, for a 20-mile event to benefit MS research in and around Sag Harbor, NY. The bike-a-thon is open to people of all abilities, and each rider is encouraged to ride at a pace that is personally comfortable. For more information or to register as a cyclist, please visit www.montelms.org.