

Friends and Family

The Montel Williams MS Foundation Newsletter

volume III edition 2

Keeping On



Dear Friends,

This has been a year of peaks and valleys for those of us living with MS. The promising drug Tysabri was pulled from the market in February following the related death of two individuals. It is our hope that it will be reintroduced soon following some more extensive testing by researchers.

In May our friends at Karolinska Institute announced that they have identified an MS gene, in part because of funding they have received from The Montel Williams MS Foundation, funding from you. I hope that you will hold onto this bright spot in our MS journey. We at the Foundation couldn't have gotten there without your commitment. We will keep you up to date as the ramifications of this terrific finding become more palpable in the upcoming months.

In the meantime, I continue to do my best to take care of myself and to manage the

aspects of this illness that are in my control. Everyone who knows me knows that I chase snow all over the world. I have spent much of the summer snowboarding in the mountains of South America.

I have terrible pain in my feet, but I find that snowboarding forces me to focus on my lower extremities, improving the electrical messages between my brain and my feet. The more I snowboard, the better my feet feel, and the more natural my walking becomes.

In this issue of *Friends and Family*, we share with you the stories of some courageous soldiers in the battle against MS. These individuals have taken it upon themselves to use physical fitness as a way to combat MS. Everyone fights this illness in the best way for his or her



individual needs. This is their choice. May their choice inspire you.

MS Gene Is Identified!

The Montel Williams MS Foundation is a Funder of the Karolinska Research Responsible for the Finding

The Karolinska Institute in Sweden has mapped several genome regions of importance for inflammation in the nervous system, and has identified MHC2TA as a gene associated with increased susceptibility to MS, rheumatoid arthritis and myocardial infarction. This finding, published in the May 2005 edition of *Nature Genetics*, may spur the development of more selective, targeted therapies for people living with MS. The Montel Williams MS Foundation is a funder of this research.

Congratulations to principal researcher Dr. Tomas Olsson and his team at Karolinska.

New MS Drugs on the Horizon

Daclizumab

Biogen Idec has partnered with Protein Design Labs in the manufacturing and development of a Phase II drug, Daclizumab, for the treatment of multiple sclerosis.

Tovaxin

Interim results for the Pharma Frontiers drug, Tovaxin in two MS Phase I/ II trials, have concluded that that drug is safe and well tolerable and has demonstrated improvements in MS patients.

Although both drugs would still require extensive testing and government approval, they represent hope for MS survivors and their families.

True Survivor: Michelle Theall

Michelle Theall is Editor in Chief and founder of *Dandelion Magazine*, the only women's adventure and outdoor sports magazine. She received her MS diagnosis shortly after she launched *Dandelion*. Having built a career around health and fitness, Michelle chose to incorporate this knowledge in managing her MS. Michelle recently spent an afternoon with *Friends and Family* newsletter sharing how her determination to stay active has helped her manage her MS.

Friends and Family: What triggered your diagnosis?

Michelle Theall: I've been a runner since I was 10 years old and competed in the 800M at the college Division I level on scholarship. At 35 years old, I was still running, mostly on the trails in Colorado for fun. I started tripping and falling. I twisted my left ankle, then the right, skidded into a cactus hind-quarters first, and slid on my chest down an embankment all in the same month. Even my friends would warn me about curbs and steps. Next, my left pinky and ring finger began tingling. Then, I had urinary urgency with hesitance. I headed for the doctor.

FF: How did you respond to your diagnosis?

MT: I researched about MS online and in books, but really didn't find anything that reflected *my* experience. Everyone had a different story to tell. So, I started to gauge the seriousness of my disease by the way outsiders responded to it. I told everyone I knew that I had been diagnosed, and then scrutinized their reactions to see how dire my situation really was. The response that stuck with me was from Mariel Hemingway. We were putting her on the very first cover of *Dandelion* because she had just authored a yoga book. We were sitting in the grass together between rolls of film when I told her I'd been diagnosed with MS. She looked at me and said, "You have beautiful eyes." What I heard was "You are not your disease, or your potential disability, or your level of fitness. You are beautiful inside and out." And, if that's what you choose for people to see, that's what will radiate from you.

FF: What was your initial perception of MS?

MT: The disease was unpredictable and unique to each individual. No matter how many others I met with the disease, I felt alone, but I vowed I would not go down quietly.

FF: How did your knowledge of health and fitness influence the way you chose to manage your MS?

MT: MS is a marathon and not a sprint. I wouldn't win any victories overnight. I had to adopt new habits and a new lifestyle. As active as I am, I knew there were still things in my control that would better my health than I wasn't doing. I had gained 20 pounds since college. My fatigued muscles deserved better than to haul around any extra weight. I gave up chocolate and alcohol. I also researched supplements to help my muscle cramps and soreness (Potassium, Magnesium/Calcium, and [Methul Sulfonyl Methane] MSM for my connective tissue pain). For energy, I upped my B vitamins. I tried different types of massage until I found Myofascial Release deep tissue work that helped my stiff and stuck muscles to glide over one another. Finally, I started playing basketball to make sure I was sending quick stop

and start, eye-hand coordination signals out from my brain to my body. I lifted weights, slowly, to maintain control of each movement. I ran. And, when I couldn't, I walked. Anything to send a variety of signals out to my body.

FF: Why is it so important for you to stay active?

MT: I still consider myself an athlete. It's an integral part of who I am. But, it would be important whether I had MS or not. I've got two books coming out in Fall 2006 as part of the Little Kick in the Butt book series by Fulcrum Press. One is *30-Days to Better Health* and the other is *30-Days to Getting Back in Shape*. They're written for everyone. There are certain things about our health we can control to help us live our lives to the fullest. I'm an ironic fitness and health spokesperson now because I'm battling this progressive disease that has no cure. But to me, it makes all the sense in the world. I will be as active as possible until the day I leave this earth.

If I'm in a scooter one day, that's fine too.

I'm going to paint it purple, turbo-charge the engine, put all-terrain tires on it, and add streamers to the handlebars.

FF: What made you decide to climb Mt. Kilimanjaro?

MT: When I was first diagnosed, I panicked. I have a lot of dreams I want to fulfill and many of them are on foot with a backpack. Africa is a magical place. I wanted to go on safari, and when a friend put together a trip including the Kili climb, I couldn't say no.

FF: You have always pushed your body to its limits. How difficult was it for you to stop before reaching the top of the mountain?

MT: I'm the kind of person who has to see what's around the next corner. But my body told me to stop. With MS, I think

about the reward. Is whatever I'm doing worth the cost to my body? The answer at the last base camp of Kilimanjaro was no. My goal had been not to be the weakest member of our team. I hadn't wanted to hold anyone back. In the end, only 6 of our 10 team members went to the summit. I watched their headlamps zigzag up the mountain at midnight. I could see every star in the sky. My only thought was that stopping was okay. Where I am standing at any particular moment is the top of the world.

FF: What is your advice in staying active for others who have been diagnosed with MS and are affected by mobility?

MT: There is immense reward in even the smallest of advances in your health and mobility. If you can lift your legs 5 times, then try for 6. If you can kick laps in a pool, but can't move your arms, try to increase your distance each month. Make your legs and heart as strong as they can be. If you can work yourself up to walking a *mile with a cane*, then the aisle of the grocery store might be a piece of cake for you for five more years. If you've gained a few extra pounds, change your diet to lose them. Take small steps within your control to improve little by little, or to keep what you have. Don't give up! Everything you try to do physically tells your brain to send a signal. Sending signals will keep you healthy and strong for as long as possible. Train your body for daily living at whatever level of ability you can. Above all, remind yourself that you are a beautiful person and so much more than your MS or your mobility.



Finding My Strength in Weights

By Lisa Powell
as told to *Friends and Family*

I was diagnosed with MS in 2001 after experiencing symptoms for over a year. It was like the room was spinning and I had to hold on to the wall to walk.

Twice I was misdiagnosed with middle-ear infections and given antibiotics.

When I lost the feeling in my hands and feet, I was misdiagnosed with nerve root infraction and given anti-inflammatories.

I eventually lost my sight, and was diagnosed with nystagmus. A neurologist confirmed that I had MS. I didn't work for months.

Once I started taking the right medications and my condition stabilized, I got a part-time job. But I still had balance problems and it was difficult getting around. I didn't tell my coworkers at first. I wouldn't even get up to go to the bathroom if people were around; I didn't want them to see how I walked.

Then one day I heard Montel Williams say on the radio that strength training helped his MS. I kept asking my doctor about strength training, and because we keep the lines of communication open, he eventually okayed the workouts. But he warned me to stay hydrated and to avoid overexertion. (My doctor answers all my questions, and if I feel strongly about something he disagrees with, we come up with a compromise, a safe way to do it.) He also gave me some of the best advice ever: *Listen to your body.*



But before I could get could begin exercising I was hospitalized with an exacerbation.

When I was discharged the left side of my body was completely numb. My former boss called me at home in Queens, NY, and asked

me to come back to work. I explained to him that I had been working somewhere else part-time, that I had MS, and that I had just been hospitalized.

He said, "Cut to the chase, can you make it or not?" My house was now in arrears and I needed the money. I said, "As soon as I can walk I will call you!"

Despite the numbness, I went back to both jobs. As it turns out, a new coworker had just become a licensed personal trainer, and he offered to work with me for free. He didn't know anything about MS, but he researched the illness to prepare for me.

I had never been to a gym before in my life and I almost didn't go back after my first day of training. My parents raised me that I could do anything I put my mind to, but this was the first time that I ever thought that something was too hard. Sometimes the trainer would send me home, or he would restrict my workout because I was just too weak or off balance.

Strength training helped alleviate the horrible feeling that my muscles were falling apart.

I began to feel strong and my muscles started to take shape. After six months the trainer said "I'm proud of you, you're getting stronger, you don't need me anymore." Now I work out on my own.

One day when I was leaving the gym, I met Darin Kaye [a member of the Foundation's development committee]. He saw me training hard and recommended Montel's books, *Body Change* and *Climbing Higher*.

When I read *Climbing Higher* I realized that my excruciating foot pain is related to MS. Calf exercises help my feet now, much, I imagine, as snowboarding helps Montel. Strength training has also improved my balance. I would trip over my feet or gravitate to one side of my body. It can be very difficult to center myself sometimes, but if I stand on something unstable like a balance ball, and do weights, it centers me almost instantly.

I train 5 days a week, 2 1/2 hours a day before work. It takes a lot of effort, but if I cut something out of my routine, I feel it. Medicines can help manage MS, but for how long? Since beginning strength training I have not missed a day of work. I had an episode with spasticity in one arm and poor balance a few months ago. I calmed down, breathed, relaxed, and accepted it. In the morning I was weaker, but I went to the gym.

You have to decide what works for you, and if that is strength training, parks departments have free gyms if you can't afford club membership, or you can buy affordable free weights from sporting or discount stores. At the end of the day your health is your best personal investment.

Montel recently received this compelling letter. Its words speak for itself.

Dear Mr. Williams,
Eight years after my initial diagnosis, I'm still going strong in a career that most would consider out of the question for someone with MS.

I am a personal trainer and co-own a fitness center called ThirdPower Fitness in Washington, DC. While we cater to people of all shapes and sizes, I focus on working with clients who have special needs, MS included. I truly believe that getting physically stronger will help people feel more secure and empower them to take on challenges they otherwise may not step up to.

In the last year, the disease has worked its way through my body, leaving my legs without much strength. Though I still teach classes, train clients and workout, now I must adapt my routine to new realities . . . depending on how much function my legs have that day. But if my experiences with MS have taught me anything, it's that it is never too late to turn it all round. It can be done, by anyone, in any condition, at any age. The first step is to take a step.

Julia Lundeen
Washington, DC



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.

Triathlete William Nystrom

William was diagnosed with MS 13 years ago at age 27, after finishing the Dipsea Trial race from Mill Valley to Stinson Beach, CA. His first symptoms were loss of feeling/numbness and decreased mobility from his waist down. But he made one promise to himself: "No one is ever going to look at me and know that I am sick." Says William, "My neurologist encouraged my training and healthy lifestyle. He is convinced that I manage my condition so well (although I still experience numbness in my hands, feet and knees) directly because of my activities."



Note: the opinions reflected in this newsletter belong to the individuals represented and not the Foundation. Physical activity cannot take the place of a treatment regimen and should never be done without consultation with your health professional(s).

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

