

Dear Friends and Family,

I would like to ask for your support in helping the Muscular Dystrophy Association (MDA) find a cure for neuromuscular disease. Nine years ago I was diagnosed with Friedreich's Ataxia, a rare progressive illness that along with over 40 other neuromuscular diseases is supported by the MDA.

On November 10th, at Zoo Atlanta, the MDA will hold the 2007 Walk of Hope to benefit the Muscular Dystrophy Association. Last year my team raised \$7097 at the MDA Walk of Hope in Georgia. I would appreciate your support again this year with a donation and joining me at the Walk. All donations designated as "MDA Seek-A-Miracle" go specifically to support Friedreich's Ataxia research.

I began participating with the MDA in Massachusetts by volunteering for fundraising events. I was the MDA Goodwill Ambassador in Western Massachusetts for two years. This is the sixth year I have led a team at a MDA Walk event, the second year in Georgia. Every year I try to improve on fundraising efforts for the MDA, as well as SAM (Seek a Miracle) and FARA (Friedreich's Ataxia Research Alliance), two related organizations that specifically support research for my disease.

Learning to cope with a progressive neuromuscular disease is not easy, but I get tons of love and support from my family and friends. I was eleven years old when I was diagnosed with a neuromuscular disease, and at the time I hardly thought about a disease for which I did not have noticeable symptoms. After a couple of years I started to feel my muscles become weaker and my balance became too difficult to continue with dancing and gymnastics. I was still able to walk entering the 11th grade, but because of heart complications I began using a wheelchair part time. Today, I use a wheelchair all the time, and a power chair at college. I am currently in my junior year at Berry College in Rome, GA, where I live on campus, in an accessible dorm room. I have a power wheelchair that helps me get to classes and school events. Student services provide me with automatic door openers to get in and out of buildings, and I have many great friends who help me every day at school. I am pursuing an Interdisciplinary Studies Major combining Education, Psychology, and Family Studies. I hope to one day work with children in a school setting.

Donations to the MDA help their patients in many ways. The MDA supports the purchase of medical equipment such as wheelchairs and provides medical and community service programs. Each summer, the MDA sends children ages 6 to 21 to special camps throughout the U.S.A., including the one I attend in Rutledge, Georgia. For one week, kids with neuromuscular diseases get to spend time with their friends, go swimming and fishing, ride horses and zip down a ropes course. I love the Georgia MDA camp because it is so much fun to be able to participate in activities that I would normally not be able to do. But one of my favorite parts is seeing all the kids who are affected by muscular dystrophy enjoying a week having fun like any other kid. Even though I'm older now and you don't often see kids my age going to camp, my college friends that have muscular dystrophy tell me that MDA camp is the highlight of their year.

Most critically, your donations to the MDA provide grant money for scientific research to find a cure for neuromuscular diseases. We are on the threshold of developing approved treatments for Friedreich's Ataxia. There are four medicines that are in clinical trials this year and two medicines slated for trials in 2008. These clinical studies cost in the millions of dollars each, and the MDA and SAM need our help to fund them. At the National Institute of Health (NIH) in Washington and in Europe, phase III clinical trials with idebenone are beginning. A phase II clinical trial with a related drug called Mitoquinone is targeted to commence next year in Australia, UCLA, University of Texas, and Emory in Atlanta. A class of compounds called Histone Deacetylase (HDAC) inhibitors discovered by The Scripps Research Institute in California obtained a commercial licensing agreement based on promising preclinical results. A compound called EPI-A0001 has begun trials in Europe and an iron chelator called Deferiprone is being clinically tested to remove excessive iron accumulation from the body. Earlier this year it was reported that scientists in Madrid had successfully treated mice with Friedreich's Ataxia by transferring genes for the missing frataxin protein into their nervous systems, which resulted in functional recovery that was "surprisingly complete."

I have many friends with muscular dystrophy, and it hurts me to know that they struggle every day with life threatening diseases. I feel that it is my obligation to be an advocate for these people as well as for all of their families and friends. Fortunately, I wasn't diagnosed with my disease until I was in middle school, but a lot of kids start to show symptoms at a very young age. Whenever I want to give up trying, I remind myself that I had twelve years to be a kid – I played sports, I danced, I was a gymnast – some children have to learn to grow up before they even get to be a kid, and that is so unfair. I want to give people affected the hope to keep fighting and looking for a cure because I know that with God's help, someday muscular dystrophy won't affect anyone's life. I can't wait for that day.

Love, **Laura Beth Jacquin**



2007 MDA Walk of Hope



Zoo Atlanta, Atlanta, GA - Saturday November 10, 2007
Registration- 8:30 AM Walk- 10:00 AM Awards & Lunch- 11:30



The Honorary Walk Chairperson is Keisha Williams of CW Atlanta

Please join **Team Laura Beth** at the Zoo or support her with a donation
Collect \$100 in donations to receive free entrance to the Zoo and a Walk tee-shirt

Contact John & Patricia & Laura Beth Jacquin @ 770-425-6444
Make checks payable to "MDA Seek A Miracle"

Thank you for your support

Related links:

<http://www.mdawalkofhope.org/>

<http://www.mdausa.org/>

<http://www.seekamiracle.org/>

<http://www.curefa.org/>

<http://www.fortnet.org/fapg/fevents.htm>



Laura Beth, family & friends at the 2006 MDA Walk of Hope