

Dear Family and Friends,

Please join TEAM LAURA BETH and support my fundraiser this year to help the Muscular Dystrophy Association (MDA) find a cure for neuromuscular disease. It has been ten years since I was diagnosed with Friedreich's Ataxia, a rare progressive illness that continues to affect me. Your support will fund research to help stop progression of the disease and find a cure.

**This year, the MDA will return to Zoo Atlanta for a family reunion. The 2008 Walk of Hope to benefit the MDA will be held on Saturday October 4th. Last year our team donated over \$12500 at the MDA Walk of Hope. Over the last six years our participation in MDA Walks has raised approximately \$70,000 for research. 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" will go specifically to support Friedreich's Ataxia research.**



**Jerry Lewis MDA Telethon - September 1, 2008  
Laura Beth Jacquin Interview**

Many of you know that I began participating with the MDA in Massachusetts about 8 years ago. I was even named the MDA Goodwill Ambassador in Western Massachusetts and attended many fundraising events. This is the seventh year I have led a team at a MDA Walk event, and the third year in Georgia. Every year I try to improve on the fundraising results for the MDA, as well as SAM (Seek a Miracle) and FARA (Friedreich's Ataxia Research Alliance). These are the titles of two related organizations that specifically support research for my disease.

I am currently a senior at Berry College in Rome, GA, pursuing an Interdisciplinary Studies Major combining Education, Psychology, Art, and Family Studies. I hope to graduate next fall with my degree in "Children and Social Development," and to one day work with kids. I live on campus in an accessible dorm room and 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 buildings, and I am able to be somewhat independent. Learning to cope with a progressive neuromuscular disease can be difficult because I must continuously adjust my daily life to compensate for the progression of the disease. Luckily, I have tons of great friends at Berry that are willing to give me a hand whenever I need help. I did not show many symptoms at all when I was diagnosed with FA at age 11. Since then my muscles have become progressively weaker and my balance has deteriorated, preventing me from continuing with dancing and gymnastics. I was able to walk entering the 11th grade, but I began using a wheelchair about 6 years ago.

Your donation to the MDA helps their patients in so many ways. The MDA supports the purchase of medical equipment such as wheelchairs and provides medical and community service programs. One of my favorite benefits is the week of MDA summer camp presented to every child with MD between the ages of 6 and 17. For one week, kids with neuromuscular diseases get to spend time with their friends, ride horses, go fishing and swimming, and – my favorite – ride a zip line on 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. One of my favorite parts is watching all the kids who are affected by muscular dystrophy enjoying a week of busy activities without having to worry about anything.

Most critically, your donations to the MDA provide grant money for scientific research to find a cure for 43 neuromuscular diseases. We are on the threshold of developing approved treatments for Friedreich's Ataxia. There are several medicines that are in clinical trials this year or slated for trials in 2009, and I intend in participating if able. These clinical studies cost in the millions of dollars each, and the MDA and their allies need our help to fund them. At the National Institute of Health (NIH) in Washington and in Europe, phase III clinical trials with idebenone (a medication which significantly reduces the negative affects on the heart) are concluding. The MDA, FARA, and the National Ataxia Foundation just announced a 1.125 million dollar research grant to develop and select a histone deacetylase (HDAC) inhibitor candidate for human clinical trials. Hopefully this inhibitor will treat some of the symptoms of Friedreich's Ataxia.

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**

# 2008 MDA Walk of Hope



Zoo Atlanta, Atlanta, GA - Saturday October 4, 2008  
Registration- 8:30 AM Walk- 10:00 AM Awards & Lunch- 11:30

Please join **Team Laura Beth** at the Zoo & 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 - tel. 770-425-6444  
Make checks payable to "MDA Seek A Miracle" or donate on-online at:

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

select make a donation, sponsor a team & select Team Laura Beth

Thank you for your support

Related links:

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

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

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

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

And view a special video about Friedreich's Ataxia at:

[http://www.curefa.org/fara\\_a.mov](http://www.curefa.org/fara_a.mov)

**Laura Beth, family & friends at the 2007 MDA Walk of Hope**

