

Hello

My name is Laura Beth Jacquin and I'm 19 years old. I am an Early Childhood Education major at Berry College in Rome, Georgia. I love going out with my friends, I really like going to the gym to work out, and I love to volunteer and work with kids.

About eight years ago, I was diagnosed with a neuromuscular disease called Friedreich's Ataxia (FA). Along with 43 other neuromuscular diseases, my progressive illness is covered by the Muscular Dystrophy Association (MDA). Learning to cope with my disease is not always easy, but I have a lot of love and support from my friends and family. I do my best to stay involved in the MDA and continue to raise money and hope for a cure.



When I was still very little, my mom introduced me to gymnastics. Sure, it was more of tumbling around, learning to grow out of that awkward balance stage that everyone goes through as a toddler, but I really enjoyed it. As I got older, I continued with gymnastics, and I also began to learn tap, jazz, and modern dancing. I think I had played most every sport that my friends were involved in by the time I was in middle school, but none of them really interested me. I loved dancing, and a dancer was what I wanted to be. Then it all stopped.

In sixth grade, I was diagnosed with FA – a disease that I had never heard of or had symptoms of. In fact, almost no regular doctor has even seen it because only one in 50,000 people have it. I'm not going to bother going into all of the details about genes and DNA, but only 1 in 90 people of European descent carries this rare form of Muscular Dystrophy. Their children only have a 25% chance of receiving the actual disease.

Being only eleven years old, I had much more to be worried about than some disease that I didn't even have symptoms of, and I continued my regular life. It was not until seventh grade that I started to feel my muscles become weaker and my balance became too difficult to remain a gymnast or a dancer any longer. I was able to continue walking into eleventh grade, but because of heart complications I began using a wheelchair part time. Today, I use a wheelchair all the time, and even though my balance has gotten to the point that I can no longer walk, I try to remain strong and I exercise all the time.

I became personally involved in volunteering and fundraising for the MDA about five years ago served as the western Massachusetts MDA Goodwill Ambassador for two years. Every year I try to be more successful in 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.

This is where you come in! On October 21st, at Pinckneyville Park in Norcross, Georgia, the MDA will hold the "Experian Walk of Hope" in order to raise money and awareness about Muscular Dystrophy. I have participated in four of these walks in Western MA. Last year more than 100 people gathered donations and walked with my team, and I would appreciate your support this year. I have never been a team captain for a walk in Georgia, so I would really like to be one of the largest fundraising teams. Therefore, all donations to the MDA designated as "*MDA Seek-A-Miracle*" go specifically to support Friedreich's Ataxia research. In the past my fundraising teams have raised over \$50,000 in total donations for the MDA/Seek-A-Miracle and FARA.

The MDA provides grant money to scientists for research to find a cure for neuromuscular diseases. Fundraising events hosted by the MDA donate to programs of worldwide research, comprehensive medical and community services, and ongoing professional and public health education. Also, each summer, the MDA pays to send children from ages 6 to 21 to MDA camps throughout America. For one week kids get to hang out with friends, ride horses, go swimming, have fun on a ropes course, and most importantly they have the childhood that maybe they don't get all year. Through donations, the MDA pays for this week as well as providing for support services, clinics, and financial aid for the purchase of medical equipment, such as wheelchairs.

I have many friends with Muscular Dystrophy and FA and it hurts me to know that they struggle every day. I feel that it is my job 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 are very young when they start to show symptoms. 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 little people have to learn to grow up before they even get to be a kid, and that isn't fair.

I want to give those that are affected the hope to keep fighting and looking for a cure because I know that with God's help someday Muscular Dystrophy won't be an issue in anyone's life. And I can't wait for that day.

Love,

Laura Beth Jacquin



Some of my 2005 Stride and Ride Team

Experian Walk of Hope

Pinckneyville Park
Norcross, GA

Saturday October 21, 2006

Registration- 8:30 AM

Walk- 10:00 AM

Rain or Shine

You may join **Team Laura Beth** by calling me at (413) 575-6804,
or send checks payable to "MDA Seek A Miracle" to my address:
3069 Addie Pond Way
Marietta, GA 30064

Walk donation envelopes and more information available
through the MDA at (770) 621-9800



My family and I at the 2002 MDA Stride and Ride