



In February of 2009 I received a call from a mother of a two and a half-year old son who was in the process of being diagnosed. Mom told me her son was going through some testing but his doctor was almost sure he had Duchenne Muscular Dystrophy. Mom was very distressed and we both cried on the phone on that first conversation that lasted well over one hour.

Mom told me that once her son was asleep, she was spending hours watching and crying over him knowing that the diagnosis of Duchenne was going to take him from her too soon. Mom was very depressed and had a very difficult time accepting that diagnosis.

When I searched our peer supporter data base I only found parents with teenage children who were already showing the debilitating signs of the disease. I knew a conversation with any of these parents was going to depress this mom even more. I decided to find a parent with a younger child.

With the help of the Parent Project program at the Muscular Dystrophy Association I was put in touch with a mom in Arizona who had an eight-year old with the same diagnosis. This mom became the peer supporter for the mom in Pennsylvania.

When I talked to Mom in Arizona, she told me of all the research being done with new drugs for Duchenne. She said, her son was receiving an experimental treatment at a clinic in Utah and the results were very promising. Arizona mom said, since the child in question here was younger than three, he had an excellent chance of getting the newest drugs and treatments. The match was made.

A couple of weeks later I contacted the mom here to do her “follow up”. It was amazing to see the transformation! That first conversation with her, which was filled with sadness and despair, seemed to be eons away from what I was hearing. I was thrilled to hear a complete new mom at the other end of the phone. Mom told me her peer supporter had been amazing, she had been full of information and directions of where to go with her son for treatments. Mom said, “My peer supporter gave me hope, which was what I needed the most.” Mom became very involved with the Muscular Dystrophy Association and she began doing fundraisers to support research for Duchenne’s. I often get e-mails with announcements of car washes, bake sales, etc. with all the proceeds going to MDA. I know I did not change her son’s diagnosis but I know I made a difference on the life of this mom. Instead of mourning the death of her son years before his actual passing, this mom is focusing on how to help him stay well.

Six months after that first call, this mom contacted me and became a peer supporter herself.

