



Graci Diggs
2013 Jingle Bell Run/Walk Youth Honoree
Columbia, Missouri

Hello, my name is Anna Diggs. I am the mom of Graci Diggs who has suffered from juvenile rheumatoid arthritis (JRA) since she was 4 years old. I was asked to tell my story as a parent with a child with JRA. I hope this helps you understand that this is a severe disease. It doesn't always show itself on the outside but the inside of the body is truly sick. Here is our story.

On May 2, 2005 our family was blessed with this bundle of fire in which we named Graci. She was our little miracle due to the fact we had been told after the birth of our first daughter and the loss of three babies that we just weren't going to be able to have another child. So as you can imagine when Graci was born we were over joyed. From day one she was the most alert and strong willed little girl I had ever witnessed. That trait was with her from day one, and I believe it's the reason she handled her diagnosis so well.

On August 2, 2009, Graci woke up just like normal and was getting herself dressed as usual. She had to do everything on her own from an early age. I heard her cry my name but initially thought she was just aggravated while putting on her clothes. However, I quickly realized it was not her normal cry. As I rushed into her room, I saw her struggling to put on her shorts. I am not an enabling parent so I asked her what the problem was, she said, "I can't bend my knee to put on my shorts." At first I thought to myself she was just being silly; then as I leaned over to help her I got the biggest shock of my life. Her left knee was triple in size and bright red. It was very hot to the touch. I asked her if she had fallen as she was very active and loved to climb. She said no, and I didn't remember her falling. I took her in to show my husband Aaron and we agreed we should have it looked at right away. This was a Sunday morning so we had to take her to urgent care. We got no answers there. They wanted our family doctor to see her on Monday. So we did that. First thing Monday morning I called the office and they got her right in. He treated her for inflammation, knowing Graci rather well he figured she had tweaked it during her normal play. However, by Thursday of the same week she had lost total mobility. Back to his office we went. This time he was very concerned and sent us to a pediatric orthopedic that day. That same day we found ourselves traveling one hour away with a visit to the orthopedic doctor. This appointment went a little different as they took x-rays and drew blood. We were asked to wait on the blood results. Her x-rays resulted in nothing, but her blood work showed a positive ANA and several other things weren't normal. We were then referred to a rheumatologist the very next day.

The next doctor took several labs and found out her immune system was severely attacking her body in several ways. Her digestive system was not functioning properly, her blood pressure was high, her poor little system was under siege and it didn't know what to do. She was a sick little girl and it struck like a bolt of lightning. We would spend a lot of time in the doctor's office and at the hospital for tests over the next few months as several specialists worked to figure out what was going on in her body. The fluid in her knee had jellied and they couldn't draw it out with a needle so while doing an MRI they tried again with no success. This meant several weeks of grueling physical therapy. As the weeks went by we were told there could be a tumor causing the problem in her knee. We were told they were looking for

Cushing's disease, Crohn's disease, possible Celiac disease, and the list continues; but we still had no real answers. Finally after the specialist ruled out all the other possibilities we were told Graci had juvenile rheumatoid arthritis. Stunned at the whole roller coaster ride we had been on our first response was, thank God it's not life threatening, just altering. From that day forward, as a family, we never looked back. Graci took one day at a time. She was always excited to see her doctors and especially Vanessa in the lab. She never cries while having her blood drawn which is a lot. She is always a brave girl. She had a couple of small setbacks during the next couple of years but nothing major.

In 2012, the lightning strikes again; she was struck again in the same knee. This time the arthritis was meaner and more aggressive. The swelling, pain, and stiffness returned with a vengeance. We found ourselves making the multiple trips to the doctors. More visits to the hospital for MRI, draining's, biopsies, and injections. Graci was in 2nd grade at this time and could understand quite a bit more about what was going on. She found herself not able to keep up with her peers in PE class and at recess. As parents, Aaron and I could see her little spirit drifting from her at night when no one was around. She was feeling helpless and alone. As she and I lay in bed one night I asked her what she was thinking. She asked why this had to happen to her and if there was any other kids like her. I told her that God never gives us more than we can handle, and that he needs you to go through this because he has a plan for you. I knew there were other children out there but we had never seen or met any of the other patients at that time. With my heart aching I set out on the computer to find something that would help her and us as a family. My research unveiled just what Graci needed, the Jingle Bell Walk/Run. I showed it to her and asked if it would be something she would like to do. I had an idea of what it would entail as I had been involved in other charity work but I had no idea how it would affect her. I told her it would be a lot of work and she was going to have to do her part because this was her cause. In true Graci fashion the spark returned and our ideas starting bouncing off of each other. With the help of Donna Henderson our late start didn't set us back one bit.

We spent hours putting ribbons on jingle bells to sell. We designed shirts to sell. We created an event on Facebook and before we knew it the whole town was involved. Graci ended up with one of the largest teams for the Jingle Bell Walk/Run. She was also awarded 2nd place for fundraising and made it into the top ten in the region. She was so excited when she was able to turn in almost \$3,000 her first year as a participant. The day of the walk she was in a wheel chair but that wasn't going to stop her from participating. Along with her group she finished the race as she does on a daily basis. Graci has good and bad days. Mornings are always faced with stiffness, and long car rides are grueling for her. This never gets her down or makes her upset anymore. Graci has decided that JRA will not define her, nor will she let it keep her from the things she loves. She has to wear a brace on her knee but that doesn't slow her down a bit. Graci stays active playing softball, volleyball, swimming, and riding her bike. She loves playing with her friends who always know if she is lagging behind that she will catch up. Her JRA is under control at the moment with drugs, diet, and exercise. Graci understands that these changes had to be made in order for her to continue to do the things she loves, and that's a lot of things. Just ask anyone who knows her!

Graci was super excited this year as she found out she was selected to be the Columbia Jingle Bell Run/Walk youth honoree for 2013. Graci never does anything small so she tells me that her fundraising goal this year is \$4,000. Guess what, we started fundraising in June. We hosted a kickball tournament in which she played in and her Go, Go, Go, Graci team will be having a sand volleyball tournament and possibly a 5K glow run.

Graci has quickly become our hero, not only because she is so strong but because she has such a big heart. Even when she isn't having a great day she is always thinking of others.

Graci is our hero, too! We are proud to have her as our 2013 Jingle Bell Run/Walk Youth Honoree.

About the Arthritis Foundation

The Arthritis Foundation (www.arthritis.org) is committed to raising awareness and reducing the unacceptable impact of arthritis, which strikes one in every five adults and 300,000 children, and is the nation's leading cause of disability. To conquer this painful, debilitating disease, we support education, research, advocacy and other vital programs and services.