



Charlotte Perkins
2015 Jingle Bell Run/Walk
Youth Honoree
Chicago, IL

Charlotte's story as told by her mom:

May 21, 2014 our perfect world of four healthy babies came crashing down. Brian, Charlotte and I were driving to Lurie's to meet with the head of oncology. We were expecting to learn that our sweet baby girl had Leukemia. This is how everything unfolded.

In March, we noticed some changes in Charlotte's personality. She became very needy/clingy and wanted to be held. Slowly she started regressing in her walking to the point that she would not stand in her crib. We would carry her to her chair for breakfast and then to the couch, all while James, her twin brother, was climbing out of his crib and jumping over the couch. In April, she began running fevers at night; with Motrin they would quickly go down, (I thought she must have been getting her two-year molars). In hindsight, we constantly ask ourselves how we did not realize sooner that something was not right. The weekend before she was admitted I was out of town and Brian said that she literally refused to walk. That Tuesday night, her fever spiked to 104-degrees, and that was the breaking point. I brought her to the pediatrician the next morning. I explained the symptoms and learned she had lost two pounds in one month. They ran blood work and immediately found out that she was severely anemic. They took a closer look. Many areas of her blood were abnormal and had many characteristics of Leukemia.

The next thing we knew, my sister-in-law Laura, my sister Katie and my dear friend Christina were all at our house taking care of the boys, while Brian and I were headed to Lurie's. The boys are Charlotte's twin brother James, Jack who is two-and-a-half years older than she is and her biggest advocate, and finally baby brother William, who is just 14 months younger than Charlotte. With all these brothers Charlotte has no choice other than being one tough little girl.

After several more tests and what seemed like an eternity, she was admitted and diagnosed with systemic juvenile idiopathic arthritis (JIA). We felt so relieved that we did not have a child with cancer, but had no idea what a long and difficult journey we would still in fact have. For the next four days, Charlotte underwent more tests and was on IV steroids. She responded well and was sent home with a laundry list of medications, including a daily injection.

Charlie's (our nickname for Charlotte) health improved quickly and we began weaning her off steroids only to end up back in the ER, 10 days later with another 104-degree fever. Back on the steroids she went. She is on four different medications, including two injections, one of which is the chemotherapy drug, Methotrexate.

Who knew that kids got arthritis? Not me, and I certainly didn't know that 300,000 children have JIA. There are several types of JA. Systemic is the most severe and the hardest to treat, it affects her whole body. It's a lot of trial and error, figuring out what meds work best for her. She was much happier, however, her blood was still significantly abnormal;

she continued to have a lot of inflammation and often woke up saying, “mommy feet.” Before her shot she would say, “No shot, no shot” and “mean daddy.”

After seven months of trial and error of many drugs, it was time for a change as her health was not where we knew it could be. In December 2014, we began taking her down to Lurie’s, every other week for an IV infusion of yet another drug called Actemra. Her health improved drastically, very quickly and in January, she went into medicated remission.

Slowly, we have increased the time between infusions and to date, she gets it once a month in addition to her weekly Methotrexate injections. We thank you for reading Charlotte’s story. We are so blessed that we have so many amazing people in our lives that love our babies like their own.

Charlie, her family and friends are true Champions of Yes! They are celebrating Charlie’s everyday victories, and they are supporting a very courageous and brave little fighter! We are thrilled to recognize Charlotte Perkins as the 2015 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.