



Ashley Frankel

2012 Indianapolis Jingle Bell Run Child Honoree

Ashley Brook Frankel was born in November 2003. She was a happy baby, "well loved" by her Mother, Father and Nana. Her Nana came to live with her when she was only three months old so that her parents could work and Ashley would not have to go to daycare. Her Nana helped bring out her creative side. They were always doing crafts and working in the garden to teach Ashley about nature. Ashley thrived with all of the love and attention from her family.

Sometime after she turned one, she woke up crying every morning. We didn't know why it was happening, but it didn't seem right. Since she couldn't talk yet, she was unable to tell us why she was crying. Right around her second birthday, we went on a trip to California. On our last day there, we woke up early to start packing for the trip home and noticed that Ashley was limping. I called her over to look at her ankle and saw that it was swollen. As soon as we arrived back home I phoned her pediatrician and was able to get her an appointment immediately, but her pediatrician was out of the office that week, so she saw another pediatrician in the same practice. He checked her out and said he thought she probably had a sprained ankle but wanted to send her for an x-ray to make certain it wasn't broken. We took her for an x-ray that same day and learned that it was not broken. The pediatrician told us to watch her for the next couple of weeks and her ankle should get better. He said if it got worse to call back.

After about two weeks it got worse and Ashley couldn't walk without limping. We called back and were able to get right in with her regular pediatrician. She asked a couple of questions, examined Ashley's ankle and told us she thought Ashley had Juvenile Rheumatoid Arthritis. We didn't even know children could get arthritis. The Doctor told us we should take her immediately to the hospital to get tests in order to confirm her diagnosis. When we left the Doctor's office we went straight to the hospital for the lab work. We were contacted the very next day with the news that Ashley had all the markers for JRA and that we should schedule an appointment at Riley Hospital the next week. We scheduled the appointment and met Dr. Ballinger.

Dr. Ballinger was amazing and was able to put us at ease right away. The holidays were upon us at that time and we went to Colorado to visit my family for Christmas. Ashley was limping and clearly in pain the entire time. She refused to take any medicine to help with the pain. We felt so

helpless. I called Thuy (the nurse at Riley) to ask what we should do. She told me we needed to be concerned about permanent joint damage since Ashley would not take anything to help make her feel better or to treat the arthritis. When we went back to Riley we discussed all the possible options we could try. One of the first procedures we tried was joint injections. Since Ashley was barely two years old the Doctor recommended we put her under general anesthesia since she had to be perfectly still in order to inject her joints in just the right place. There was no guarantee that the injections would work. When Ashley awoke from the procedure she was crying so hard because she was disoriented from the anesthesia. It broke our hearts to hear her crying like that. The very next day she was able to walk without limping. We were so excited. It lasted only a week before all her same symptoms returned. She had arthritis in five joints - both ankles, both knees and her right wrist. She was just learning to hold a pencil and crayons, but because of the arthritis in her wrist it made it very difficult for her to even try.

Since the injections didn't work we started medicating her. We had to hide it in a piece of chocolate since she still refused to take any type of medicine. Godiva chocolates actually made special pieces of chocolate for us when we explained what we needed so that it was easier to put the medicine in it. The chocolate looked like little volcanoes and that's when Ashley's life long love of chocolate began! She took the medicine for several months and we definitely noticed a difference, but it was clear that it did not ease her pain completely. Dr. Ballinger and Thuy recommended we add a different type of injections into our regimen to completely take away all of Ashley's symptoms so she could have a normal childhood. I was very opposed to the new treatment plan, since this certain type of medicine could only be injected. I did not want to give my 2-year-old daughter a shot twice a week. I was kindly told that I either needed to give her the injections or she would be crippled. I went to Riley the next week to be trained on how to give her the injections. It was so hard the first several months. Ashley's dad had to hold her down while I gave her the injection. We all hated it. Even though she fought and threw a fit every time she had to get the shot. We always told her how brave she was and rewarded her with a piece of chocolate.

Eventually, she stopped fighting and learned to take it in stride. She started asking if she could help prepare the shot. I let her help as much as she could for a two year old. After a couple of months Dr. Ballinger wanted to try taking her off the oral medicine and just give her the injections. She did fine without the oral medicine, so she never took it again. She was doing really well, so after two years of getting the injections, Dr. Ballinger suggested we try taking her off the medicine altogether and that there was a chance that her arthritis would be gone. We were scared but also excited that she would no longer have to have the shots. We stopped giving her the injections and within two weeks the arthritis was raging again - just as strongly as when she was first diagnosed. It was devastating.

Ashley has been getting injections now for five years. She has had so much physical therapy that she's stronger than most adults. She is so brave - physically and emotionally. If you did not know she has arthritis you could not tell by looking at her. We're told there's a good chance that she will outgrow the JRA, but there's also a chance she will have it for the rest of her life. She does not remember a time that she did not have arthritis. She wears it as a badge of courage. We have taught her to be proud of the fact that she has overcome so much. She is an amazing little girl and we are so proud of her.

Ashley is 7 years old. She enjoys most outdoor activities, playing with friends and family, reading, doing math problems and taking dance lessons. We still go to Riley every three months, so we try to make it a fun day instead of something she will dread. Everyone at Riley is amazing, especially Dr. Ballinger and Thuy Beam. We feel so fortunate to have them so close. We have high hopes that Ashley will eventually outgrow the arthritis, but we also know that if she does not outgrow it she will be fine. She is a strong, happy, healthy girl who will become a strong, happy, healthy woman.