



Scleroderma Society of Ontario
136 Kenilworth Avenue North, Hamilton, Ontario, L8H 4R8
Toll Free: 1-888-776-7776
www.sclerodermaontario.ca

Colby's Story - A Mother's Tear

by Jamie Boal

My son Colby was diagnosed with Linear Scleroderma last year at the age of 3. He was a VERY active little guy and never had any health problems.

Colby was outside playing one day and started complaining that his foot hurt, so we took him to the local hospital. They did x-rays and it showed that Colby has fractured his foot but they couldn't put a cast on due to swelling. We babied him all night, poor little guy was hurt, the next morning my husband and I awoke to Colby jumping on our bed, we were pretty shocked (we knew he had a high pain tolerance, but god!!) The whole day he was fine. After a week or so had passed I noticed a discolouration on his left arm. I brought him to the doctor and he told me just to wash him with this stuff called Salsin Blue?? It never went away. During this time he had fallen again and hurt his knee, so once again off to the hospital, but a different one of course! They did x-rays again and asked tons of questions but the doctor recommended that we take him into The Children's Hospital of Eastern Ontario (CHEO) for a better opinion. So we did! As the doctor there looked him over and did more x-rays, more blood work and bent his little leg every which way (at this time Colby was laughing at the pain) he wanted us to wait at the hospital to see a rheumatologist. After a few hours we were able to see her and my panic mode (mom's mode) started, I called my husband, my Mom and Dad and my friend Arnie. I just didn't know what to do. Here is a healthy little boy who drives you nuts every day because he is so active sitting there watching the doctors looking at him with no idea what's going on. She looked him over, noticed the patches he had on his arm and said, "Oh No, Jesus" while shaking her head. My heart sank; she wanted him to go for a biopsy ASAP. I didn't know what to do, I felt helpless. When she said the word Scleroderma I was baffled, I had never heard of it. The first this she said to me



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was DO NOT go home and pull it up on the computer, but I did. It gave him no hope what so ever and I just wanted to die. I cried for days, why did this have to happen to my baby? The day came when he had the biopsy done. I sat in the waiting room holding his Special Teddy and cried. I met a lady in there whose daughter was in for day surgery also and she assured me everything would be ok. She had been through it before, only to find out that her 3 year old daughter had cancer and only a few weeks to live. Right then I felt lucky. Here she is comforting me when my son is in there for a biopsy and her daughter is fighting for her life. It put things in perspective. My son wasn't going to die, he was just going to have a big struggle but I would still have him to hug and kiss everyday. He came out of that small surgery fine, we went home like normal and all he complained about was the spot where his I.V. was. It took him a few days to get back to normal, but no complaints!! We finally found out for sure it was Linear Scleroderma a few weeks later. Then the battle began! He was put on Prednisone and Methotrexate and advised to take Folic Acid. We battled with him taking the liquid form of Prednisone, so they switched to the pills. He took his pills like a trooper. He was so swollen and puffy it was unbelievable. We started physiotherapy and it worked wonders. His one finger was bent all the time and they got it straight, his knee which was bad too has improved but not perfect! His ankle and the top of his foot is the worst. We then got news that our Doctor in Ottawa was leaving, we were sent to Toronto Sick Kid's Hospital. We went every 3 months, and then got to come back to Ottawa as they found a new Doctor!! Thank God! We meet the new Doctor a few weeks ago and he is great! I have a positive attitude when it comes to Co's disease, he will be fine, he acts the same, he never complains about pain, he does have headaches often but it doesn't stop him. Right now at this point there is nothing anyone can do, you work with the doctors who are caring for your baby, and be glad that you still have them!

Colby has come along way in the past year. I can honestly say that I am glad Co got



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this disease he is the strongest boy ever. I'm not sure if a lot of kids could handle what he has been through. Hopefully he will teach people about his disease when he is older, that's my one wish. He looks no different than any other little boy walking down the road but inside he is complete opposite. What a way to be. Wish we could all be like Colby!