

Carter's Update July 2009

It has been quite a long time since our last update. We didn't go to Montreal in June as scheduled because Mike was sick. After getting everyone's schedules coordinated, we had to wait a whole month before we could make it out there and it ended up being 17 weeks between our trips. By the time we got home from Montreal, we started moving into our new house in Milestone and then computer problems have prevented me from doing the write-up since then. Anyhow, all is well even though life has changed quite a bit for our family this summer.

Carter never showed any signs of being uncomfortable while he lasted such a long time between treatments. We flew from Regina to Toronto on July 13 and Carter was anxious to get off the plane and stretch his legs in the airport while we waited for our next plane to Montreal. He made his way all around our area of the airport with his walker and visited with everyone he saw on his way. We caught our next plane to Montreal, landed in the early evening and made our way to the hotel with no problems.



The next morning, Carter walked to the nurse's station to show off his newly acquired skills. They were quite excited to see how well he was doing since he had just taken his very first steps on our last trip out. He doesn't need any support from us anymore and can go quite a distance before he needs a rest. His IV access was quick and easy that morning. He got started on his treatment while we were down in the clinic waiting to see Dr. Fassier and he was very brave as he let Anik hook him up!



Carter treats his IV pole like an old pal and greeted it with a, "Hi pole, missed you!" He had to get a few x-rays and then got his bone can done, which showed that his bone density had returned to the same level he was at before it dropped way down after surgery. We are glad it has gone right back up and he has been so active since getting his cast removed that it's really not a big surprise, but still a nice relief.



We met with Dr. Fassier to review the x-rays and confirm that his hip and femur rod are still looking good. Everything looked great and Carter was so proud to walk to Dr. Fassier and show off how well he's doing. He left his walker and held onto Dr. Fassier's fingers and took quite a few steps to get to him. We were so happy to hear that everything has healed well and Carter can continue to work on his walking without another rodding surgery for the other leg in the near future. We have been

monitoring Carter's spine since scoliosis is a common characteristic of OI. Dr. Fassier took a look at Carter's back this trip and referred us to see the spine specialist a couple days later.



Carter has become quite steady on his feet and can stand independently for quite a while. He is really our little Superman!



He had so much fun in the playroom while we were there and enjoyed a bingo afternoon with the Shriners and a visit from Santa the next day. We loved having Christmas in July and although it may not look like it in the picture, Carter really did like Santa and did a craft with him after pictures were done.



We were lucky enough to be at the hospital at the same time as Charlie and his family again! It was really nice to have people to visit with at night in the hotel and to see around the hospital during the day. Carter had such a great time with them and had many belly laughs to prove it!



We had always been nervous about holding onto Carter's fingers as he walked. His little wrists seems so fragile and they 'pop' often, but after seeing Dr. Fassier hold his fingers to walk, we started doing it a lot more often. The photo below was taken right outside our hotel after we came back from our walk. It was the first time we went for a walk and Carter actually walked. It was a great feeling and a good opportunity for a family picture!!



Sadly, our appointment with the spine specialist did not go so well and we found out the curve in Carter's spine has already progressed to 50 degrees. It is quite a worry with all the complications that can occur with scoliosis and he will now be watched very closely. Spine surgery is likely in the not so distant future, but Carter was molded for a back brace to wear 23hrs/day to hopefully slow the progression of the curve. It has not been proven that the brace will stop the progression or really even slow it down, but we have been very vigilant with him wearing it at all times except to bathe or swim.

Although the first week was very hard, Carter has been his amazing self and has never complained since then. It took him a couple days to regain his balance to sit independently, crawl and about a week before he could pull to stand again. It was very difficult to watch him struggle as he had been doing so well before the brace. It has now been about 6 weeks with the brace and Carter is running around the house with his walker and took his first independent steps a few days ago. He let go of the coffee table and took 7 steps on his first try to get where he wanted to go. He can now take about 10-12 steps on his own to go from one place to another. It is such a thrill to see him walking around, whether it be on his own or with his walker! We are so proud of him!!



We go back to Montreal at the end of October and are really hoping for some good news about Carter's back this time. We know the curve won't be corrected with the brace, but we would really like him to get older before he faces a spinal surgery. They would likely place a growing rod in his spine to straighten it. The rod does extend to accommodate growth, but it is not telescoping like the rod in his femur. They have to do surgery about every 6 months to lengthen the rod so we are not looking forward to that possibility. They would hope to do that until he has finished growing and then the spine could be fused at that time. Fusion stops all growth so best case scenario would be waiting until he was a lot older before they have to do that. These are all scary possibilities, but we know the doctors will make the best decisions they can for him.