

Carter's Journey – January 2008

We have been getting pretty comfortable in our trips to Montreal so when we had a few surprises this time, we were not completely prepared. Our large suitcase never made the trip with us and instead ended up in Ottawa. West Jet staff was great in assuring us that they would have it at our hotel as soon as possible. It arrived in Montreal about midnight and by the next morning we had it in our hotel room. Although we escaped the freezing temperatures of Saskatchewan for a few days, it was still chilly in Montreal. We stayed warm in our hotel most evenings instead of going out, but since we did not have everything we needed on our first night, we bundled Carter up and walked to the mall to get some supplies and groceries.



Carter had to make it an extra two weeks without treatment with holidays and scheduling issues going on. He did incredibly well at home and wasn't grouchy and still slept great! After we got to Montreal, it was a different story and he cried at the drop of a hat. Thank goodness his treatment kicked in right away and he was feeling good again. Since there was going to be OI conferences scheduled for a few families that Tuesday, we got to meet a few new kids and some we had seen before. Carter's roommate at the hospital was a 2 year old girl who also has OI. The two of them enjoyed playing together and popping hundreds of bubbles in the playroom.



When you are at the hospital for your OI conference, the patient must get a full body set of x-rays done as well as the usual bone density scan. Carter had not had any x-rays for about 11 months so we were a little out of practice...which is a good thing I guess. They had to take quite a few and since Carter does not appreciate being held down, he didn't enjoy the experience very much. While we were moving him around to get pictures of different body parts, his IV pump started beeping and displaying weird messages. Our nurse came down from upstairs to figure out what was going on. Every time they went to take an x-ray, she would have to leave the room and then come back to get things going again. This made the whole process extra long and we were glad when the end of the day came. Our conference with all of the doctors, therapists, etc took place on the second afternoon of treatment. We were expecting to sit around a table with everyone as they shared their information. However, when we walked into the room everybody was standing at the front of the room chatting and looking at Carter's x-rays on the walls. It was rather informal and was a little less intimidating than what we expected.

Carter's bone density has now gone up by 70% and his teeth look like they are going to be fine. One article has stated that those diagnosed with severe OI have an 80% chance of also having DI (dentinogenesis imperfecta), which results in grey or brownish teeth that are very brittle. Carter has four teeth and the doctor thought they looked totally normal so we were glad to hear that. Receiving treatment early on may have played a part in this.

A couple of Carter's fractures had appeared to be healing crooked during his x-rays last year, but seemed to have straightened out a bit since then. We had assumed that he would need surgery to rod and straighten his one femur before he could try standing. There are no immediate plans for surgery to put rods in and the doctor would like to wait until Carter is pulling himself up first. Our other orthopedic concern has been Carter's dislocated hip. It is still definitely out of place and Carter's hip sockets also looked a little funny on the x-rays. We will be going to the Montreal Children's Hospital on our next trip to have an MRI done on his hips. If the doctor there is not sure about putting Carter under general anaesthetic yet, we will wait until our following trip. He will have to be put under as he will have to stay still for a long period of time and it can be quite scary for kids. The MRI should give the doctors more of an idea of what is going on with Carter's hips. He still does not seem to be experiencing any pain in his hips and they figure he will be able to stand with them the way they are. It was amazing and extremely overwhelming to have all of Carter's team in the same room at the same time focusing completely and totally on him. As you can see in the picture, he took part in his conference as

well. Carter's IV couldn't be saved by the end of that second day and at the end of his treatment, the flush started leaking into his hand so they took it out. We were just thankful that he had gotten his full dose already for that day and they would not have to do a new IV until the next morning.



We figure that Carter may have played a part in his IV coming out so he got to go swimming that night! Two of the other kids with OI were also in the pool so we had an awesome time. I had a great conversation with one other mom whose son is now about 10. We feel such a connection to those who can actually understand and identify with our situation. The unspoken bond between the kids and the families is something we truly cherish. Carter continues to love the water!



Day 3 of treatment went smoothly as the nurses had no trouble starting a new IV and got things going right away. As Carter gets older we are really appreciating the playroom, "Le Parc". He already seems to look forward to going to play and with no shortage of toys or park workers that have endless smiles and energy, he loves to spend all his time there. He had a couple great physio sessions to try and show off a few new things he's doing. His physiotherapist, Stephanie, had never seen him up on all fours before so we were excited to show her that.



We booked the dates for our next few trips since we know he'll need to be there every eight weeks. This will continue until December when it will likely change to every twelve weeks. Carter liked watching all the planes at the airport when we were waiting to leave. Our flight to Winnipeg was fairly empty so we got to move around a bit and Carter played in his own row for a little while. All our flights were good and we headed back to Estevan as soon as we landed in Regina. It's nice to get home to our own beds and Carter smiled again as soon as we got into the house and into his room even though it was midnight.



Carter usually starts doing something new a few days after we get home from Montreal. He must feel stronger and starts trying out new things. He's started kneeling a bit and finding his balance that way. It's pretty neat for us to see him get up like that. Although we don't have any definite plans for surgeries in the coming year and we didn't come home with any solid answers of what's going to happen, it was still a very positive trip overall. Of course we didn't want to hear that something else might be going on with his hips, but finding these things out sooner rather than later is always best. We are just so thankful that Carter has the right people taking care of him and we know they will do whatever it takes to provide him with the best possible future!

