

CARTER'S AMAZING JOURNEY - JANUARY 2010

Carter was scheduled for his annual OI Conference with his team this trip. We have only had one conference with his team and it was in January, 2008. Since he had surgery last year and was casted for 3 months around this time so there was no need to meet about making a plan for him.

When it is your time for conference, they do a set of x-rays, bone density scan, and evaluations by physiotherapy and occupational therapy before you meet with everybody. This gives them a good idea of everything that is going on with your child and allows everyone to contribute to coming up with the plan for your child for the coming year. Our first day at the hospital on January 5 was also the same day as his conference so we were very busy that morning getting all of those things done as well as getting him hooked up to his IV. It all went smoothly and we waited our turn in the playroom to get called in for Carter's conference. While we were waiting, we had a good time playing with another little boy with OI who was on his first trip to the hospital. Ethan is 9 months old and needs one of his femurs rodded soon as it is bent at a 90 degree angle. His family had come from Cincinnati to see Dr. Fassier and hopefully get rodded on this same trip. Everyone in the OI world wants to see this man and have their children treated by him. Not only is he an amazing surgeon, he's an equally amazing man that Carter has grown to love! Carter took off into the conference room yelling, "Fassier, Fassier, look, I'm walking!".



During our conference, we decided that Carter will stay on a 3-day treatment of Aredia, but will now receive it every four months. There is a new drug they are trying out with some patients that is a 1-day treatment every six months, but since the Aredia has worked so well for Carter, we are going to stick with that for now. It only means one extra trip a year now that he is stretched out to four month intervals and it not only continues to increase his bone density, but also completely relieves him of all the constant bone pain. While looking at the x-rays of Carter's legs, Dr. Fassier told us that the left hip and femur he operated on last year looks great and the rod continues to expand well as Carter grows. That was such good news and we were so happy to hear that his hip is still stable since he has been walking. As we started to look at the right leg and how that femur had started to bow a little more, Dr. Fassier also pointed out that Carter's pelvis was on a bit of a diagonal. When he rodded

the left femur last year, he had to shorten it to get it straight. That had left the right femur quite a bit longer and so it was pushing the pelvis upward on that side to compensate when Carter was standing. This had also led to his spine curving more into the pelvis and his scoliosis getting worse. This discovery meant that Carter would be needing surgery to shorten his right femur which in turn would level his pelvis and hopefully (fingers crossed) help his spine straighten out a bit at the same time. His right hip was in the socket, but just barely so it would need a little tweak as well to place it in a better position. We asked if it would be need to done in the next few months and Dr. Fassier shocked us by saying, "No, how about next week?". The other little guy from Cincinnati wasn't going to be able to have his surgery the following week and since they had OR time booked already for him, they were going to give it to Carter instead. We jumped at the chance to get it done right away and felt really lucky that all the stars were lined up in our favour for Carter to get the surgery he needed.



This meant that when his treatment was finished on January 7, we would have six days off before his surgery on the 13th. Mike was able to give blood on one of the days so the hospital would have it on hand for surgery if Carter lost a lot of blood again. This surgery was only expected to take a couple hours as opposed to the six hour surgery last year. Without the major hip complications, he probably wouldn't need blood, but we wanted to have it there just in case. We also spent a lot of our time in the pool at the hotel getting Carter as strong as possible before his surgery. He was only going to be casted for 3 weeks, but would still lose a lot of muscle. He doesn't know he's exercising or doing physio....he just has a great time!



We also went to the Biodome again to see all the animals they have in different habitats. Carter really liked the monkeys, macaws, penguins and the beavers. Caillou was also there the same day as we were so that was a bit hit with Carter!



After we had spent the weekend touring around Montreal a bit, we went back to the hospital on the Monday before Carter's surgery. He did some water therapy in the pool with Stephanie. She gave us some great ideas for strengthening his back muscles and some things to do for his legs after surgery. Notice who's getting the hugs....and it's not mom!



Carter also got to make a cast for a doll that would show him what he was going to have on his leg in a couple days. Angie from the playroom took him through all the steps of surgery with his doll and then they put a long leg backslab on the doll's right leg, just like Carter would have.



The next day, Carter had to do a hand function test with his occupational therapist, Marie-Elaine. At his conference, there was talk of his finger laxity. His fingers can bend every which way which is not normal even for most OI kids. There is only one other girl like Carter and she not only had the super lax fingers she has the same hip and spine issues as Carter. We joke that they should have been twins since they are the only two the hospital has ever seen with these same characteristics. The hand function test showed that he needs to build up some strength in his fingers to prepare him not only for printing, but also for doing things like doing up buttons and snaps. Now at home, he has to do things like working with playdough or squeezing the trigger on a water bottle.



That afternoon, our Shriner driver was kind enough to drive us down to the Science Centre at the Old Port. We were running out of things to do before surgery so it was fun to go spend the afternoon down there and catch an IMAX movie at the same time.



We had to be at the hospital very early the morning of Carter's surgery since he was the first one scheduled that day. We took him up to the operating room floor about 7:30 after we had washed him with the disinfectant sponge and changed him into the gown that he doesn't like at all. We sat with him until it was time to go in and his favourite x-ray/imaging tech, "Auntie Donna", was able to come out of the OR and she carried him in instead of us passing him off to a nurse that he doesn't know.

Dr. Fassier said it would be a couple hours so we went downstairs, had breakfast and sat around watching TV. After 3 hours, we were wondering if there were complications again, but soon after that Dr. Fassier came down to find us and said that everything went really well. It took a bit longer because the first rod that he put in got bent while he was putting the second part of it in. Luckily he had an extra rod there, removed the bent one and inserted the new one instead. Carter didn't need to receive any blood during the surgery and he had already started to wake up in recovery. He would be so much better off if he would just sleep after surgery for a little while, but he always wakes up minutes after getting to recovery and turns into a little fighter. Dr. Fassier also told us that he decided to have an A-frame cast put on Carter since there was a risk of his femur rotating around the rod and ending up with his foot turned in or out. An A-frame is a lot different than the long leg back slab we had thought he would have. Both legs have to be casted because a bar is placed between the legs for stability. The good part is that the casts only went up to the tops of his thighs so he would be able to sit up normally. We went up to see him in recovery and were able to take him back to his room fairly quickly after he woke up since he was doing quite well.



He had a cottle in the OR for pain control. A cottle is like an epidural, but they just give the medication into the back and remove the needle instead of leaving it in for future doses. It left him numb from the waist down for 8-10 hours so he was quite wide awake and happy for that time. He was eating really well a couple hours after surgery and was even talking on the phone. When it came near the time for the cottle to be wearing off, they started him on a morphine drip which kept him comfortable during the night. The next day he didn't eat as much and started to have some muscle spasms so he got a couple doses of valium throughout the day with his morphine. We did get to take him down to the park to play, but since it was still too painful to move him around, we just took his bed with us!



The second day after surgery, Carter's hemoglobin was low and with the level he was at, we wouldn't be allowed to fly home. The tricky thing was that he was too low to fly, but his numbers were too high to normally qualify for a blood transfusion. Luckily, we still had the blood that Mike had donated in case Carter needed it during surgery. The doctors gave the go ahead to give the blood to Carter since it would be thrown away if he didn't use it and we were so glad they did. He got a lot more energy, colour in his cheeks, and a better appetite not long after the transfusion finished. We had to wait until the next day to find out if it had boosted his numbers high enough to go home. The next day, his blood tests showed that his hemoglobin had gone from 8.2 to 12.1 so he had improved a ton! You have to be at 9.0 to fly so he was cleared to go home. We took him back to the hotel that afternoon and got some practice handling him with his new cast. It was a little awkward, especially since most of his incision was on the outside of his cast and it still hurt quite a bit when it was touched. He had only been on morphine for about 24hrs after surgery before we switched to Tylenol with codeine. He got a prescription for that so we were able to control his pain fairly well at the hotel and even managed supper out in a restaurant that night! The owner of the restaurant bought us drinks...well, you know you've been there a lot when...!! It was our 18th trip and we go to the same restaurant once every trip with a little boy that either has an IV in his head/hand or some sort of cast. I guess we must be memorable!



Although the A-frame cast isn't as bad as last year's spica, it still presented a big problem for dressing since it has the bar between his legs. Luckily, one of the men on the maintenance crew in charge of linens, took a couple pair of Carter's pants, cut them down the sides and sewed in Velcro. We were so thankful he did that for us! The pants worked out great and were really easy to put on and take off. Since Carter is potty trained this year, we were especially glad they were easy to take off and his cast allowed him to sit normally so he could still use the potty.



We had great flights home and Carter was amazing! He either slept or happily played the entire time. We had an incredible welcoming committee waiting for us at the airport in Regina...not only our families, but members of the Shriners Drum Corps! They played a great selection of Disney songs that Carter especially enjoyed. It was so neat to see them there supporting us.



After getting home, it didn't take too long to get used to life with Carter's cast. He only needed Tylenol and codeine at night to help him sleep and rarely asked for us to take his A (cast) off. He was back to his little mischievous self in no time, getting into all kinds of trouble in all different kinds of ways! He could crawl around on his tummy dragging his cast behind him and started rolling himself over a few days after we got home. Since he had been independently walking before this surgery, we had been worried that he would be really upset at his loss of mobility, but he just found a different way to do things.



The cast only needed to be on for 3 weeks and then we decided to go to Saskatoon to have it removed. Dr. Fassier was okay with having Dr. Dzus do the x-rays and cast removal there so we decided to save a trip to Montreal. They removed the cast on February 3 and took a couple of x-rays that showed that healing had begun. There are still gaps between the pieces of his femur bone where Dr. Fassier had cut through it in 2 places, however it is stabilized inside the bone by the rod so he didn't have to be completely healed to get the cast off. We just have to make sure he takes it slow so the rest of the healing can happen over the next few weeks. The x-rays also showed that the rod is in place and his hip is nicely in the socket in a much improved position. His legs also look to be the same length now so hopefully his pelvis will be evened out and stop the curve in his spine from progressing. A quick visit with the spine doctor on this trip showed that the brace was still holding the curve steady at around 31 degrees so we hope it will either stay there or maybe even get a bit better. We thought Carter deserved a little holiday after his ordeal so we took him to the spa in Moose Jaw for two nights to get his leg moving again in the water. It turned out to be great physio for him and he started standing in the pool the first time in. By the time we left, he was cruising along the ledges of the pool and standing in the water for extended periods of time. He is taking it slow with his walker at home, but it won't be long before he's running again!