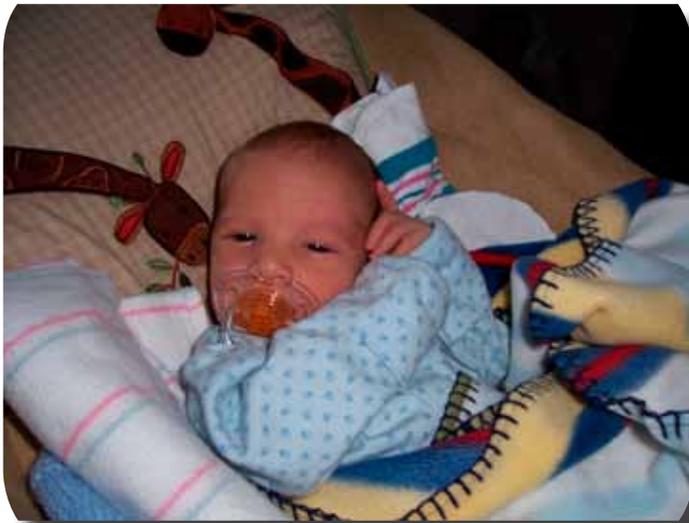


# The Jack and Hunter MacKay Story

## Birth

Jack and Hunter were born at Concord Hospital in New Hampshire on February 20, 2008 via caesarian section at 36 weeks gestation. Both were very good weight and height for being 4 weeks early. Jack was 6 pounds 3 ounces and 19 ½ inches long. Hunter was 5 pounds 15 ounces and 19 ¼ inches long. After the first couple days of the boys not being interested in eating they were giving feeding tubes though their noses. At the hospital they were given breast milk mixed with a high calorie formula to help with growth and weight gain. Being that they were early they needed a bit more calories to get them to grow. After two weeks in the hospital and finally some weight gain after a small loss they were able to come home.



*Jack*



*Hunter*

## The Initial Sign

We first started to notice a bump in Hunter's back then in Jack's back at about six months old. We kind of shoved it off at first thinking it was due to the fact that they were twins and in cramped quarters. We were already receiving early intervention from a local company due to Hunter also being diagnosed with Torticollis (he would favor his head to the left) again thinking that this diagnosis was also related to be a twin. The physical therapist added the back problem to her list of stretches.

At about 1 year of age we started bring Hunter to a pediatric orthopedic for both issues. Jack did not go with Hunter as we were still in denial and blaming the condition on cramped quarters for nine months. After about one year of seeing this orthopedic and not being happy with him for personal reason we received another referral, both boys this time, for a pediatric orthopedic out of Dartmouth Hitchcock Medical Center in Lebanon, New Hampshire. With the first appointment he had a feeling something was seriously wrong. At this appointment both boys were two years one month, they could not stand or walk unassisted, they were diagnosed with kyphosis, thick joints, and a short neck. Our now current orthopedic referred us to a neurologist. At our neurologist appointment were we given bags and directions for collecting urine on both Jack and Hunter. We dropped off our samples at our local lab in Concord and within one week the neurologist call us and asked if we could come up to Lebanon that afternoon to see her and not bring the children.



*Jack*



*Hunter*

## **Diagnosis and our reaction.**

We received the diagnosis that both our boys had Morquio Syndrome on June 10, 2008 from our Neurologist in her office with her nurse. I knew that there was something wrong with the boys. I was looking for an answer of ok this is what is wrong and this is how were fix it and they will be back to normal in a few weeks. That was not the answer we got that afternoon. She handed us several sheet of papers with information about the Syndrome and the National MPS Society information. I'm not sure what part of the information hit us harder but I can tell you that it was very overwhelming. Not only did we have one child with this but we have two. Our little surprise of on your pregnant again so soon to oh it's twins to oh and they aren't "healthy" was like a nightmare come true.

I wouldn't let myself digest it all and fall apart. I refused to think about that could happen in twenty years let alone one year down the road. Ok what do we do first? What is the treatment? You mean there is currently nothing that can help my children except surgeries? The doctor then suggested we be admitted to the hospital and receive all the testing needed. Of course what was going to be just a couple days of testing turned into a 2 week stay.

## **Surgery**

Our first surgery was the spinal fusion. Hunter went on June 18<sup>th</sup> and Jack went on June 22<sup>nd</sup>. Both went very well. The surgeons removed c1 and fused the occiput to c2. Both also received a metal rod that helped with the fusion. Because of this rod we were lucky enough not to have the have the boys in a halo and only a c- collar. We are currently going on our six month with the collars and hopeful by the time you all are reading this the collars will come off. They are also currently scheduled for ear tubes. We hope this will help their speech.

*Hunter*



*Jack*

## **Morquio Community**

After we left the hospital from our first 2 weeks, I went right to the computer and became a member of the MPS Society. From there I received a phone call from them and gave them my email address and my new Morquio family began. I feel blessed to have these people to talk to, to cry to, and to share my boys' success. Because these people are the ones who can truly understand what my children are going through. Although we have not had this diagnosis for more than 6 months yet I feel as though I can also help those who are newly diagnosed. I want to be a part of this community and help in any way I can and I believe that those whom I have met can see that. I hope to make a difference in my boys' lives and all the others that I can.

## **Our current situation**

Right now we are scheduled for ear tubes this week. We also are having CT scans to check on the spinal fusion with the hopes that we will have their collars off by Christmas! I am guessing our next step is keeping an eye on the orthopedic stand point of their situation focusing on their hips and kyphosis. I hate to think about the next surgery and that they will have to have

more but I know it will inevitable.

We are also in transition from Early Intervention to pre-school. They will start preschool in February and I think it will be a nice change for them to be with other children and getting the chance to learn in a school setting. With leaving early intervention comes with getting their new equipment. At this point we have on loan a stander and walker from our early intervention company and will need to return it once they are no longer being taken care of by them. We have already tried out new walkers and chair and are being ordered. I can't wait till we have two walkers so they aren't fighting over one walker!

I am also in the process of creating the Jack and Hunter MacKay Fund. This fund is being set up to help us pay for any medical help of any kind for the future and also to help with further research of the disease and hope of a cure by donating to the MPS Society and the Carol Ann Foundation.

## **Our expectations**

Right now our expectations are to hold off any major surgeries for at least a year or two. We hope that with this spinal fusion they will gain strength and learn how to finally walk unassisted. Also we hope that the ear tubes will help with their speech and can learn to speak more clearly so when they go to school everyone will be able to understand them and not just us. I really almost don't have too many expectations beyond this winter. This diagnosis is still very new to us and even though I have done my research and very well prepared for the future I try not to look too far into it. I try to only look a year or two into the future and work on that.