



Our Story

UNILATERAL CATARACT

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This is a picture of
me when I was born!
I was born on April
2nd, 2001 and was
6.10 pounds!



Hi! I am Juan and this is my mom, Sandra. This booklet is about our story - my experience with unilateral congenital cataract. Our journey begins with my parents finding out about my diagnosis and caring for me as I grew up. Towards the end of this booklet, I'll tell you what my life's like now.

My mom has always wanted to share our experience and successful journey. One day she came across the idea of a booklet. She wanted to write our experience in the hopes that this booklet will one day help other families who are dealing with the same thing.

My mom talked to me about it and we decided that we both wanted to go ahead with the idea. We wondered how we would be able to go about this. We then talked to Dr. Jane Gardiner, one of my ophthalmologists at B.C. Children's Hospital, hoping that she would be able to help us make this idea come true. A week later, she contacted us saying that the hospital would like to help her create this booklet!

**In those early days
of patching, Juan
would often rip the
patch off before we
could stop him.**



A DIAGNOSIS OF A CONGENITAL CATARACT WAS CONFIRMED

Juan's due date was April 19th 2001. On the early morning of April 1st, my labor started and after a normal pregnancy, Juan was born on April 2nd at 7:11 p.m. at BC Women's Hospital.

Everything went well and we left the Hospital two days later. Juan was our first child and we were thrilled to finally meet him and share our lives with him. Both grandmothers came from Colombia to help us with their grandson and we all were living a dream.

At first, Juan's every waking moment was a feeding moment. He was losing weight quite fast because it was difficult to wake him up. Other than that, everything seemed fine with him.

When Juan was 7 days old, we had his first visit to our family doctor. Normally, a reddish reflection can be seen when the doctor shines a light in a healthy eye.

Our family doctor noticed that there was something wrong with this "red reflex" in Juan's left eye.

He called one of his colleagues to make sure and they both agreed that Juan had to be seen by a pediatrician as soon as possible. Dr. Lee called Dr. N. Bhanji, who agreed to see us right away. We got to his office at the end of the day. Afterwards, Dr. Bhanji spoke to Dr. Gardiner, the ophthalmologist, about Juan's case. We were sad and surprised about the unexpected news of something being wrong with our baby.

Next day, at 8 days old, Juan was seen by Dr. J. Gardiner in the morning, who confirmed the diagnosis of unilateral congenital cataract. She then arranged an appointment with Dr. C. Lyons for the same day. Dr. Lyons was the surgeon who was going to operate on him.

WHAT IS UNILATERAL CATARACT?

A cataract is a cloudy lens. The lens is responsible for focusing light onto the back of the eye or the retina. If the lens is cloudy, light cannot get to the retina and vision will not develop in the eye. Unilateral means that he had the problem in just one eye. Congenital means that he was born with it (unlike the cataracts that people get with aging). <http://www.aapos.org/terms/conditions/31>

Dr. J. Gardiner

**Juan's first
patched eye
bunny toy.**



WHAT IS A CATARACT SURGERY

We felt our world collapsing with the news of our baby having a unilateral congenital cataract. My mom, Juan's grandmother, had also had a congenital cataract on her left eye. She could not help but feel guilty about her only grandson, at the time, having the same condition, even in the same eye. My husband, Arturo, and I, immediately started to seek advice from ophthalmologists that we knew in Colombia, our home country. They told us that they were going to explore with the pediatric ophthalmologists to find out who they would recommend for our baby's surgery. To our relief, it was Dr. Lyons who was recommended.

In the meantime we attended the first appointment with Dr. Lyons and his fellow student at the time was Dr. Ospina. Dr. Ospina is an ophthalmologist from Colombia who became a friend and was a great support during the whole process and into Juan's early childhood. At that appointment we decided to go through with the surgery as soon as possible. The surgery got booked for next day. The surgery took place on April 11, 2001, when Juan was only 9 days old. Dr. Lyons informed

us about the surgery process. He explained that he would not put intra-ocular lenses in newborn infant eyes, preferring to wait until the eye has grown to adult size (at age 2 years).

The reason is that it is very difficult to predict what size the eye will grow to and therefore what power lens needs to be inserted at the time of the surgery, whereas if you wait until the eye has grown (age 2) then you know what power lens is necessary for appropriate focus.

Dr. C. Lyons

Over 3 hours passed from the time we gave our baby to the nurse before entering to the operating room until we could see him again, even though the surgery itself lasted approximately 1 hour. It was a success. I knew from then that my work was going to be long and challenging.

The surgery was hardest on us, although he did not seem to have any discomfort at all. I had to put a drop in his eye very often.

It was very
challenging to wear
glasses as a very
sleepy baby!



WHY DO WE NEED TO PATCH? HOW DO CONTACT LENSES WORK?

The stress generated by the whole situation was very hard on our family. On the very day that we left the hospital we went to see Gary Winthrope and Noel Brown. Gary was going to be the person working with Juan regarding his contact lens and Noel was helping us with Juan's prescription glasses, the first week after the surgery Juan was fit with very thick prescription glasses



and we started patching the good eye to stimulate visual development in his left eye.

The glasses and contact lens help to focus the light on the retina as a normal clear lens in an eye does. The patching forces the brain to use the eye which was disadvantaged by having a cataract. It stimulates visual development. The patching is to treat a condition called amblyopia. <http://www.aapos.org/terms/conditions/21>

Dr. J. Gardiner

I started patching his right eye, a couple of days after the surgery. As soon as he was awake I would put his glasses and the patch on his right eye every other day, for the whole day. I did not realize at that time that by patching his better eye, I was giving my baby Juan probably the best gift I could have ever given.

Only about 1/5 to 1/4 of the children with unilateral congenital cataract develop good vision even with early surgery.

Dr. C. Lyons

This is my 6 month
old baby picture,
wearing my big
glasses.



AFTER THE SURGERY

A week after the surgery, Juan was put under general anesthesia again because the doctors wanted to check his eye pressure and glasses prescription and make sure everything was good inside Juan's little eye. That procedure happened every six months for the next 5 years.

This was to make sure that Juan did not develop glaucoma (high eye pressure) or retina problems which can happen after cataract surgery. Now, with better tools to check eye pressure in babies, we don't need to do examinations under anaesthesia as often.

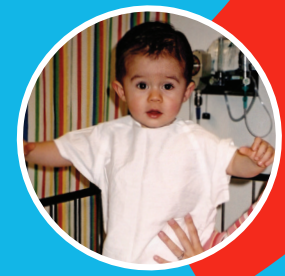
Dr. J. Gardiner

In June 2001, at almost 2 months of age, he was fit with his soft contact lens – silicone based and I was trained on how to put it in and take it out. His glasses were not as thick and we continued to patch his good eye every other day .

Juan still wore glasses with the contact lens, but they were not as thick because most of the focusing power was in the contact lens.

Dr. J. Gardiner

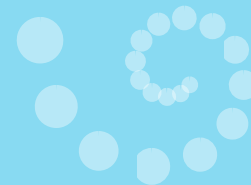


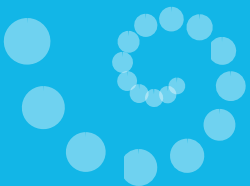




My mom would put in the contact lens as soon as I woke up. She would also wait until I was asleep to remove it because she was afraid of hurting me if I moved. She would use a little instrument with a suction cup and I did not even notice. She would also change my patch every time I got it wet by crying.

Guess what? I also needed another surgery for an inguinal hernia repair when I was a month old. That was my third general anesthesia in my first month.





JUAN'S EARLY CHILDHOOD

As Juan grew, managing the lens and glasses became normal daily activities for us. Juan was a lovely toddler. He loved books (he is an avid reader now!), coloring, and playing outside. I was very strict following his patching schedule. It did not matter if that day he had a birthday party, a social event, or if it was a very hot day. Patching was our number one priority. He was very cautious with his movements.

We saw Dr. Lyons and later Dr. Gardiner every three months for about 5 or 6 years and often we had to change the prescription on the lens or on the glasses or sometimes on both. Therefore we became frequent customers at Robert's and Browns where both opticians were. I have to admit that it broke my heart sometimes

when I knew photographs were going to be taken when he was wearing his eye patch. Again over and over, I reminded myself that patching was the key for a healthy and happy future of his vision.

His patching schedule was at first every other day for a whole day until Juan was 3 years old, then it was reduced to 6 hours, by the time he was 4 we went down to 2 hours every day; in 2007 at the age of 6, Dr. Gardiner recommended to increase the patching again to 4 hours a day, because there had been a drop in his vision since last appointment. In late 2007, we went to 2 hours per day again. By 2008, when Juan was 7, we were doing 1 hour every day. We were told in August 2008 that we could stop patching, at the age of 7.



PRESCHOOL

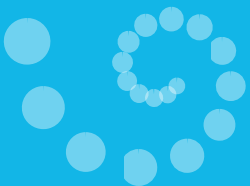
The most difficult stage was between 18 to 30 months of age. I got kicked and punched many times when trying to put his contact lens in and his eye patch on. However, I was determined that he needed to learn that it was part of our routine and that I was not going to give up or lose the battle. By the time he was 3 years old, he did not resist anymore and was more or less cooperating.

Just a month before his 3rd birthday, Juan was going to start preschool and I was concerned about the reaction or comments of the other kids to his eye patch. I was also a bit worried about his fine motor skills performance and his own safety on the days he used the eye patch. This was because if his glasses were dirty or if for some reason he took them off, I felt his vision would be very limited, but it seems that I worried for no reason, he seemed to manage just fine even when that happened. By that point (since 2003), Juan was

using bifocal glasses, with a very visible line. I wanted to prepare Juan. I started talking to him about what had happened in his past and why he used an eye patch and glasses. I tried as much as I could to prepare him for the questions or comments I thought he was going to get. To my relief, he did not come home once with a negative feeling about it. The teachers did a great job and helped him tremendously with his work.

I remember one of his classmates wanted to wear an eye patch to school. He told his mom that he wanted to be a pirate like Juan. I was a witness of the curiosity of other kids towards Juan's patch. The most common questions or comments were: *Why do you have just one eye? Why do you have a band aid on your eye?*

Juan was very easy going about it and explained that he had surgery when he was a baby and that he had the eye patch so he could exercise his eye.



KINDERGARTEN IN THE "BIG SCHOOL"

I want to assure you that this was enough for the majority of kids and they kept playing. Every now and then when kids wanted to know more, he will take them by the hand and bring them to me. He would say *“Mommy, can you explain more about my eye? I really want to play!”*

I often saw curious children that wanted to know or understand why a little boy had an eye patch but saw their parents trying to distract them or to quiet them. I found this to be unfortunate. If Juan saw this happen, he would often jump in immediately and say that it was okay. He would explain that it was just an eye patch. He would point to his left eye and explain that the patch will help that eye get better. He did everything a preschooler likes to do. He spent hours

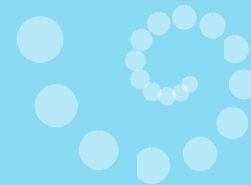
in playgrounds playing with friends, enjoyed the beach, learned how to ski, started playing soccer, and went swimming without a parent in the pool. I would like to mention that swimming was the only time he would remove his contact lens and of course glasses. He also started biking with training wheels, although, he never felt very safe on his bike and did not want us to take the training wheels off for long time.

Soon enough, he was 5 and ready for Kindergarten in the “big school.” The same worries arose for me again. This time it was not so much about his peers but about all the other children at school. I was afraid of the terrible stories you hear about bullying. I was worried about Juan having an emotionally negative reaction towards his glasses or patching.

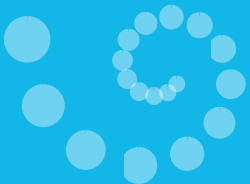




I was very happy about starting in my “big school” and wanted to have new glasses for my first day of school. I wanted to look like Harry Potter! My parents got me the glasses I wanted and I was very happy wearing them to school. My glasses at that point were bifocal with a very visible line but I could not care less because I was wearing my blue version of Harry Potter glasses.



**Juan with his
kindergarten
teacher**



Again to my surprise, Juan never had any negative experience regarding the use of his eye patch or glasses. On the contrary, I got very positive comments about how cute he looked with his glasses and how well he responded to inquiries about his patch from parents and children. He tended to move more carefully or run less the days he wore his patch to school but still played and worked like anybody else in his class.

Madame Clarke, his kindergarten teacher, remembers to this date Juan performing very well socially and academically. The only accommodation we needed was to select Juan's seating in the classroom. The only time Juan would get upset about comments of his glasses was when kids and even adults thought they were broken because the bifocal line, and that is when he started asking Dr. Gardiner for progressive lens. And it was not until March 2010 when he started finally wearing those lenses and he loves it.

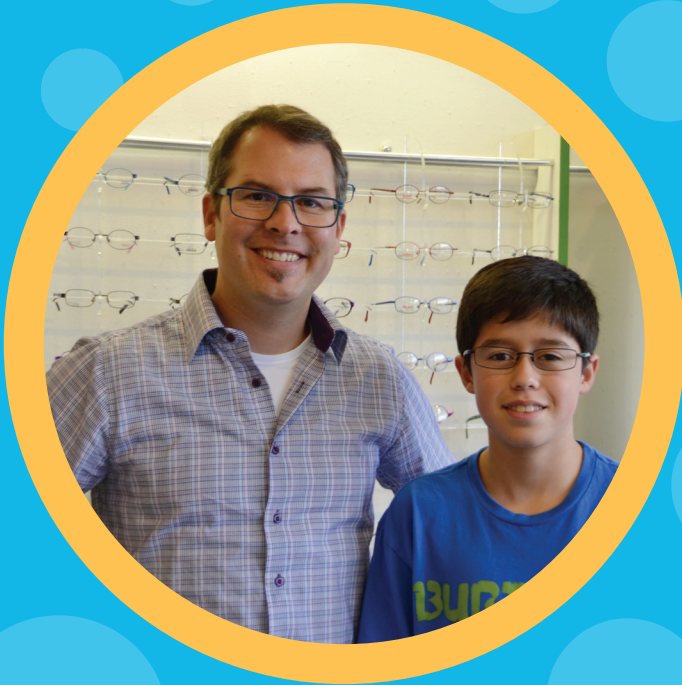
Juan is and has always been very protective of his contact lenses and especially of his glasses. As, Gary Winthrop says, Juan is exceptionally good in that regard Juan has never lost or damaged his contact lens or glasses.

Juan's little brother, Nicolas, was born in the summer of 2007. He liked to take off Juan's glasses every time Juan walked by or played with him. This would make Juan very frustrated. It was around this time when Juan's glasses needed to be adjusted frequently as they were always crooked and we had to see Ivan Ferenc very often.



My mini-collection
of all the pairs of
glasses i've
ever had.

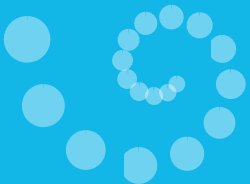




Since I can remember, I have always enjoyed choosing new glasses and I usually ask my brother for new glasses every other year for my birthday, knowing that the new glasses are coming from my parents though! Ivan, now at In Sight Optical, has been awesome in helping me choose new frames and I even had the chance to see and help cutting my own lens in his lab.



Nicolas, my
little brother
wearing my
glasses

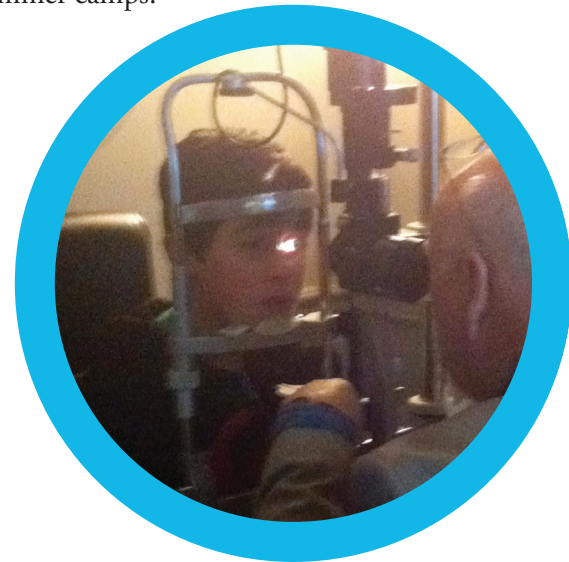


ACCIDENTS HAPPEN

I lost one of Juan's contacts once. It happened when I took it out of Juan's eye just before one of his swimming lessons. It slipped from my hand and fell into the drain. It was okay though because I always make sure to have a spare lens just in case. Accidents happen, so it's important to be prepared!

One day, I got a phone call from his Grade 1 teacher, Madame Legal. Juan had fallen at school. He was running and when he fell his forehead and nose were scraped. The worst part, for Juan, about this mishap was that his glasses became all twisted and scraped. I picked him up at school and he made me drive all the way to his optician's office to get his glasses fixed. Juan's main concern was fixing his glasses. It turned out that he has also broken his left wrist with the fall and had to wear a cast. However, he did not complain about that until the next day. He was mostly upset about his glasses.

All the way through elementary school, Juan did very well. He was a very good student. He enjoyed reading, playing soccer, swimming, and watching movies. His favorite activities were snowboarding and going to summer camps.







Right now I am in grade 7 and I just started to play Water Polo in the spring. I'm really enjoying it! I still love snowboarding and have an amazing group of friends. I have done every activity or sport I have wanted to try and don't feel that my eye, contact or glasses have been a limitation at all.

Sometimes I wonder if by having good 3D vision I would be better at the sports I like, especially now at playing Water Polo where I'm playing without my contact lens and without my glasses.

HOW IS 3D VISION AND OR DEPTH PERCEPTION AFFECTED?

3D vision develops when the 2 eyes are used at the same time to look at the same thing. Juan does use both eyes simultaneously to build a 3D image of the world around him, but his ability to do this is not as good as most people's. This is because he spent so much of his early childhood using only one eye at a time. This is the 'price' of developing a good acuity in the affected eye. In some children, some 3D vision does develop. Having one eye very de-focussed when he is not wearing a contact lens when swimming would also interfere with his depth perception a lot.

Dr. C. Lyons





This journey has not ended, as I still think about the possibility of having the surgery to put an intraocular lens in my eye, especially because I am spending a lot of my time in the water these days and it will be very convenient not to have to put my contact lens in. Also I know when I go to summer camps, my mom gets worried because I'm not wearing my contact nor my glasses at all for the whole week, even though we already checked with Dr. Gardiner and she did not seem to be too concerned about that.

Juan could have a secondary IOL implantation at any time. Generally, if a patient and his family are managing well with the contact lens then we just carry on. Although the secondary intra-ocular lens is convenient, does not subject the eye to contact-lens related complications such as infections and provides the patient with constant correction (even when swimming), there is a small risk involved (general anaesthetic, technical problems) so if everything is going well, why take more risk?

Dr. C. Lyons



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