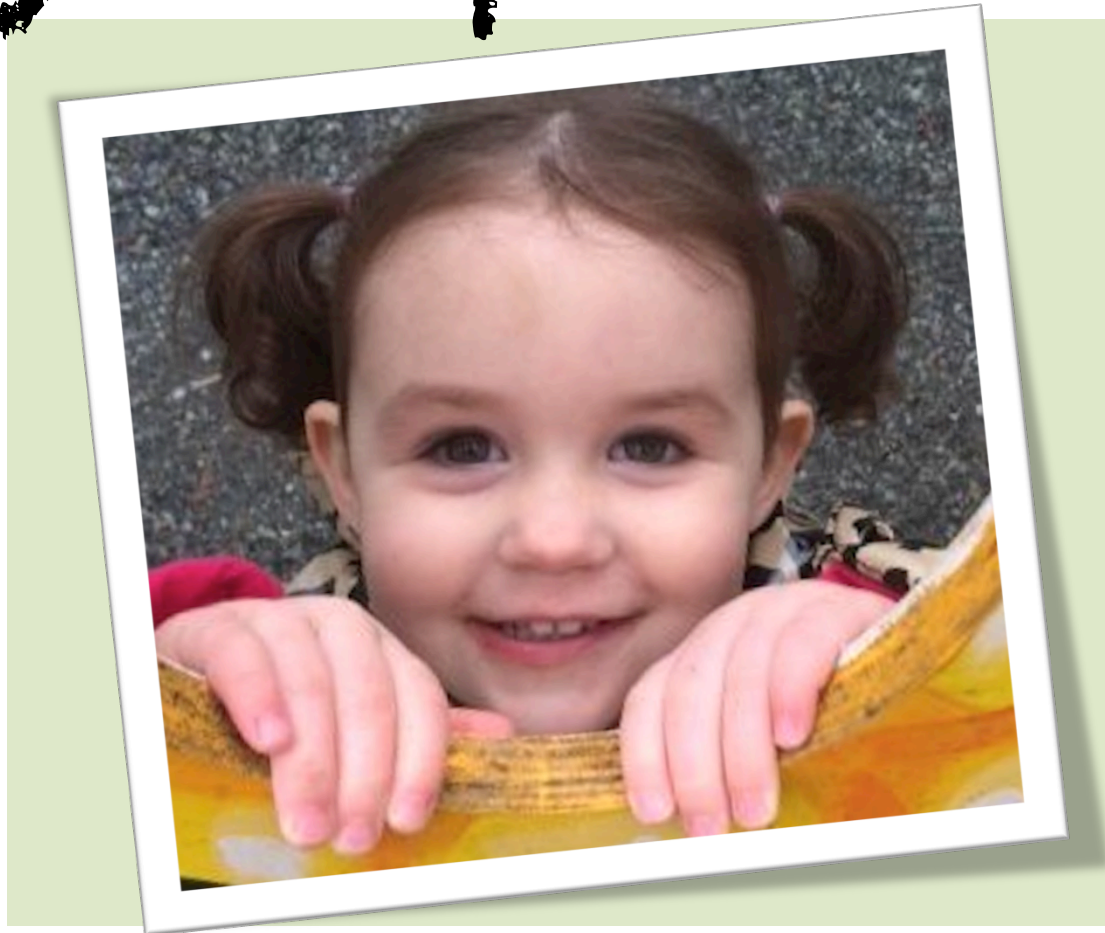


Maya's Special Eye



MICROPHTHALMIA



Department of Pediatric Ophthalmology





Hello, my name is Paula and this is my daughter Maya. Maya was born with severe complex microphthalmia on her left side. Microphthalmia is a developmental disorder of the eye in which one or both eyes are abnormally small. In Maya's case her "little eye" is very tiny and her eyelid would not open without a conformer or prosthesis (artificial eye) in the eye socket.

When Maya's second prosthesis was made, I decided to create a book to show all the steps on our journey and how her prosthesis was made. I thought it could be helpful for other parents and also our family and friends so they could better understand the process of creating and getting a prosthesis, as well as Maya's condition. We shared the book with our ocularist, Mr. Rob Drennan, and pediatric ophthalmologist, Dr. Jane Gardiner, and are now honoured to be a part of this project.

It was very scary for us as parents finding out that Maya's eye hadn't developed. The first year of our journey had a lot of difficult days. Now, Maya is doing wonderfully. This is our journey through the first few years of Maya's life.

On August 16, 2012 Maya was born after a normal pregnancy and labour. After two years of trying for a baby, we were overjoyed. We were thrilled to have a 7 pound 11 ounce little girl.



Maya was born with a very special condition called microphthalmia. This is where one of her eyes was underdeveloped and appears smaller than the other.

After the doctor examined Maya, he mentioned that he was a bit concerned about her left eye as it hadn't opened. We assumed it was swollen from delivery. Her ear was also quite bent.

A few hours later a pediatrician came in to see us. He tried to open her eye but couldn't get it exposed enough to see anything. They thought it was possible that her eye was recessed but couldn't be sure.

A nurse at the hospital mentioned to us that there was a possibility that she could be blind on that side. As upsetting as that was to hear, I kept remembering that comment. We waited and worried each day as her eye still wasn't opening.

One week later, when Maya was eight days old, we went to British Columbia (BC) Children's Hospital. Our first stop was in the Radiology Department where they did an ultrasound of both eyes.

They looked at her right side first, we could see a properly formed eye. However, when they examined the left side, there was only a small bit of tissue, the size of a pea. That's when we knew something was very wrong.

I was glad that the nurse had mentioned that she could be blind on her left side; it helped prepare me for what was to come.

INITIAL DIAGNOSIS OF MICROPTHALMIA WAS CONFIRMED

After the ultrasound, we headed to our appointment with Dr. Jane Gardiner, a pediatric ophthalmologist at BC Children's Hospital. This is when we learned that Maya's left eye didn't develop.

Dr. Gardiner told us that Maya's left eye did not form properly, it was small and she had a severe cataract. She had what was called Microphthalmia and would never be able to see out of her left eye. There was no option for a transplant (only corneas can be transplanted, not whole eyes.)



We were devastated. We had never heard of Microphthalmia. I didn't know it was possible for an eye to just not develop. We had so many questions and so many fears. How would this affect her quality of life? What could we expect in the days and weeks ahead?

An appointment was set up in two weeks with Mr. Robert Drennan, an ocularist at Marie Allen Ocularist Ltd. An ocularist specializes in fitting and fabricating artificial eyes and conformers for people born without or have lost their eyes. Together with his lab assistant, Ms. Lavene Noren, they would help us set up a treatment plan for Maya. In order for her left eye to look more normal and in order for her eye socket to grow properly, she would need a prosthetic (artificial) eye.

WHAT IS MICROPTHALMIA?

'Micro' means small. 'Ophthalmos' means eye. Literally microphthalmia means small eye. It is a condition where one or both eyes do not develop properly in the womb. At the most severe end of the spectrum is anophthalmia where there is no eye tissue at all and at the mildest end of of the spectrum are small, but normally functioning eyes. Patients with microphthalmia may also have cataracts (cloudy lens), small corneas, abnormal or missing parts of the iris (coloured part of the eye) and disorganized retina (lining of the back of the eye). It can occur in isolation or in association with other congenital abnormalities.

- Dr. J. Gardiner MD, FRCSC



When Maya was three weeks old, we went to visit an ophthalmologist, who specializes in making and fitting eye prosthesis.

We met Rob and Lavene, who came up with a treatment plan.



OUR VISIT TO THE OCULARIST

There is not much information out there on microphthalmia. Our first appointment with the ocularist helped prepare us for what was to come.

Our first step was to enlarge Maya's eye socket. To do this we would need to put something called a conformer into the eye socket. We decided that it was in Maya's best interest not to waste any time.

Maya's ocularist, Rob, put her first conformer in her left eye socket. It was about the size of a grain of rice. We booked a second appointment to come back in three weeks and replace it with a larger one.

The thought of putting something in and out of Maya's eye socket was terrifying to me in the beginning. I did not know if I would be strong enough to do it. Rob was key to teaching us how and helped us gain the knowledge and strength to do this.

We went back for our second appointment. We watched and learned as Rob and Lavene took the first conformer out. Then they used a special tool to take an impression of the shape of her eye socket. From the impression, Rob made a custom conformer for Maya.

It was important that it fit perfectly to get the best results possible. In the beginning this was quite a difficult process, she was so little and the eye socket was so small. As she grew it became a lot easier.

Microphthalmia is just one of the many conditions which require an ocular prosthesis. Other conditions include eye cancers (retinoblastoma, melanoma) where the eye needs to be removed. Also, after trauma or multiple surgeries, an eye may become shrunk (phthisical) and deformed, and fitting a prosthetic eye can provide an excellent cosmetic result.

- Dr. J. Gardiner MD, FRCSC

HOW DO EYE CONFORMERS WORK?

A conformer is a temporary therapeutic device, made of acrylic, which is placed in the eye socket. Starting very small, we increase the size of the conformer every 4-6 weeks. The conformers accommodate the growth and expansion of the socket until it is large enough to be fit with a full artificial eye with a painted iris that matches the other eye. Usually this is at about 1 year of age.

- Mr. R. Drennan BCO, BADO

We started using conformers to expand Maya's eye socket. We used a new conformer every 3-4 weeks.



We went back every three to four weeks to have the conformer replaced with a larger one. It was easy to tell when it was getting too small as Rob put a red dot on the top of it. When we could see the dot, we knew that the conformer was spinning.

After watching Rob and Lavene for the first few months, I decided it was time for me to try taking the conformer out. It got easier each time I did it.

Around the same time, as Maya was becoming more mobile, she started wearing glasses to protect her good eye. While it is sometimes challenging to get her to wear them, Dr. Gardiner has made us realize how important this is.



On the left are two out of Maya's eight conformers. They are numbers four and five.

MAYA'S FIRST PROSTHESIS

When Maya was seven months old, Rob and Lavene made her first painted prosthesis. As Maya's muscles surrounding her eye had developed, the prosthesis even moved. Not quite as much as her other eye, but it did move. The eyelids also closed and blinked like her normal eye. This was such an important day for us.



For seven months we would often be stopped and asked what was wrong with our daughter. It was really hard. We were so worried about what the future would be like for Maya. Would she be teased all the time? Once she had her prosthesis, all of those questions from people stopped. It was such a relief.

Maya was still growing so quickly at this age that we had to have the prosthesis enlarged every four weeks or so. We would go to Rob and Lavene first thing in the morning to have the prosthesis enlarged. By this time I was quite comfortable removing it myself. We would then leave for a few hours while they would add to the back and sides of the prosthesis. We would return in the afternoon to a prosthesis that would fit properly and not spin.



As Maya got bigger, we had the prosthesis enlarged.



Eventually we needed to have a new prosthesis made!

PROCEDURE AT BC CHILDREN'S HOSPITAL

At 15 months old, we couldn't get Maya to sit still for Rob to take a new impression of her eye socket. Rob and Dr. Gardiner decided that it would be a good time for Maya to be put under general anesthesia. This way Dr. Gardiner could check the health of the tissue in Maya's right socket (the healthy eye) and Rob could get a proper impression of the left socket (the special eye) so the new prosthesis would fit perfectly.

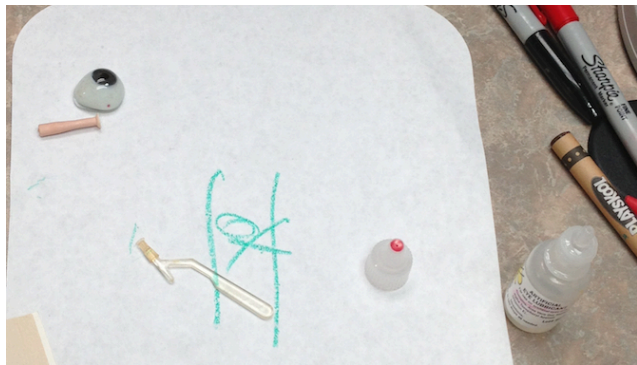
Her procedure went really well. As hard as it was, I got to hold her until she was asleep. Then the nurses came to get us before she was awake. This way, I was there when she went to sleep and again when she woke up. Maya did amazing.

Mr. Drennan and I took advantage of general anesthesia in the operating room at BC Children's Hospital, to get a very good mold of Maya's left eye socket. At the same time, I was able to take a very good look at the right eye and ensure that it was perfectly healthy.

- Dr. J. Gardiner MD, FRCSC



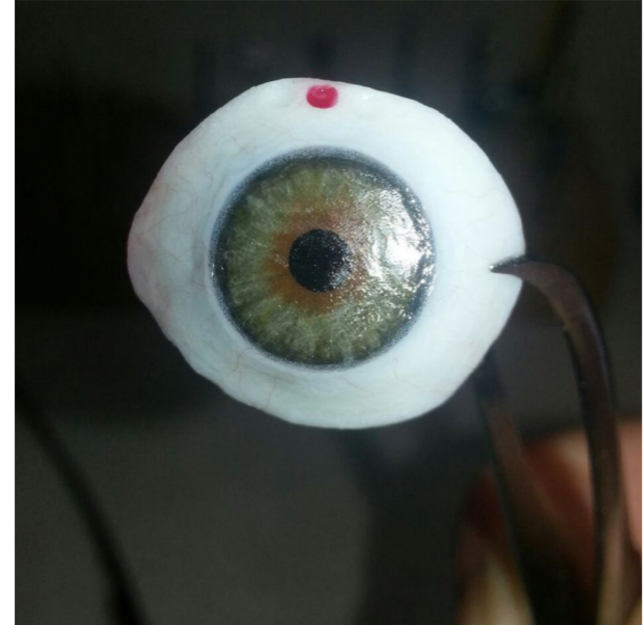
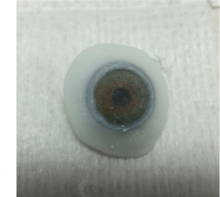
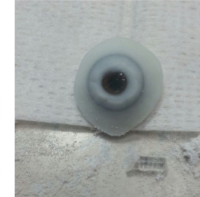
When Maya was 15 months old, we went to BC Children's Hospital. Maya had a procedure to make sure her healthy eye was okay and to take an impression of her socket for her new artificial eye!



These are pictures of the impression molds that the ocularist made while Maya was sleeping. They are used to create the shape of Maya's new eye.



A week later the base for her new eye was ready. We headed out to the ocularist's office. Rob located the pupil while Lavene painted Maya's beautiful eye color. It was so amazing to watch it all come together.

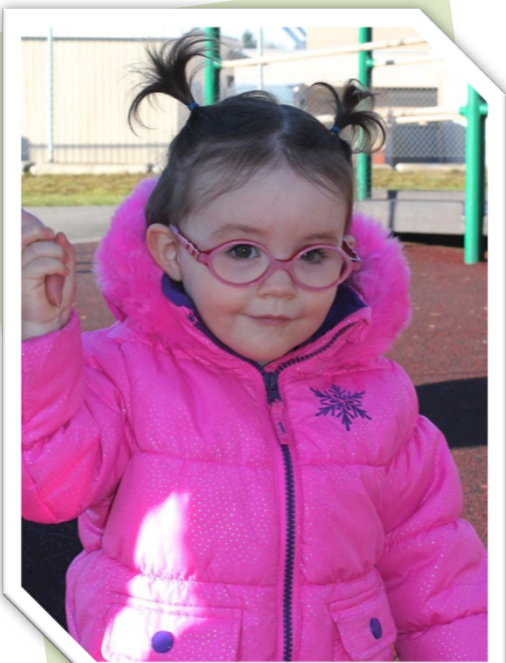


They created a beautiful new prosthesis for Maya.

CARING FOR THE PROSTHESIS

In the past year we have only had the prosthesis enlarged once. The majority of growth in the eye is in the first two years of life. We go every few months to have it properly cleaned and polished. I also remove it every month or so for cleaning.

It has now been a year since the second prosthesis was made and we have not had to get it enlarged.



Is it difficult for Maya to have the prosthesis placed into and removed from her eye socket?

Maya doesn't mind at all. Now that she is starting to understand, it is easy to get her prosthesis in and out. We also use lubricant drops or artificial tears, which allows the prosthesis to slide into the socket easier. The artificial tears can also help prevent protein build up on the prosthesis, which may cause irritation, for those who don't have sufficient natural tears.

How do you put it in?

Using your fingers to hold the upper lid open, slide the artificial eye up under the lid. Holding that position, you pull down the bottom lid to slide the eye into place. The ocularist will provide each patient a small silicone suction cup that attaches on to the prosthesis and acts like a handle.

Do you take the prosthesis out every night?

Not with Maya. We can go a couple of months without removing it to clean at home, but some prosthetics will need to be removed nightly. The ocularist will determine this for you.

Can she still close her eye normally?

Yes, in Maya's case she can but every case is different. Such cases are referred back to the ophthalmologist!

Why does Maya wear glasses?

Glasses are very important to protect Maya's healthy right eye. Even though she does not have prescription in them, the glasses protect her eyes from accidents which could happen.



It is amazing to think where we were over two and a half years ago. Maya has grown so much so fast in that short time. To see how far she's come and how well she's doing makes us so proud. Looking back on those first few months I wish that someone had told us how great she would be doing.

We are so lucky to have such an excellent support team on our side including doctors, ocularists, and infant development specialists. We can only hope that others with Maya's condition, or other conditions requiring a prosthetic eye, can get the help they need and continue to lead normal, productive lives.





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