

# THE CHILDHOOD CANCER JOURNEY

**AT TEN MONTHS  
OLD, RYLA WAS  
DIAGNOSED WITH  
AN OPTIC PATHWAY  
GLIOMA**

It's a rare, slow-growing brain tumour that arises in or around the optic nerve, which connects the eye to the brain. As the tumour progresses, it presses on the optic nerve, causing a child's vision to worsen and, in rare cases, may cause blindness.



## FAMILY SUPPORT

# When Your Baby Has a Brain Tumour

**Even though I was a new parent, I had this intuition that something wasn't right with my baby girl.** Ryla's head seemed too big for her body when I compared her to other babies. She also developed "café au lait" spots on her body which I assumed were just birthmarks but were actually a sign of an underlying condition. At six months old, Ryla was diagnosed with neurofibromatosis, a rare genetic disorder that typically causes benign, slow-growing tumours on nerve tissue.

At ten months old, I noticed Ryla's eye wasn't tracking correctly. Our pediatrician didn't see anything unusual, but he knew we needed to monitor Ryla closely because of her diagnosis, so he referred her to a pediatric ophthalmologist. Ryla's condition changed quickly over the next month, and we ended up at SickKids before we even got to the appointment.

It started on Christmas day at my parents' house. Ryla's left eye was swollen and wouldn't stop watering.



A few days later, she woke up from a nap, and we were shocked to see her eye had gone from blue to brown. My husband, Rob, and I rushed her to Credit Valley Hospital and then to emergency at SickKids.

Ryla had a mass compressing her optic nerve, causing proptosis (bulging) and blood leaking into her eye. She needed an ultrasound and an MRI to uncover what the mass was and its exact location. The wait was excruciating for us and very uncomfortable for Ryla, who went 24 hours on IV nutrients only.

Finally, at 11 p.m. on New Year's Eve, Ryla got her MRI, and a few hours later, we were told our baby had an inoperable brain tumour.

We were sent home with the knowledge that the next step would be chemotherapy, but because the quick growth of Ryla's tumour was atypical, it would need to be evaluated by the tumour board at SickKids to determine the best course of treatment.

RM

*“We had to do something special for Ryla’s first birthday because we thought it might be the only one we would get to celebrate.”*

Typically, this type of tumour would not get biopsied because the procedure can cause blindness, but since her condition changed so quickly, the hospital staff felt the tumour was aggressive and wanted to know what they were dealing with. An optic nerve surgeon explained that he would try to go between the bone and eye to do the biopsy but warned us that he might need to remove some of her bone to get a clear path to the tumour.

**We had to do something special for Ryla’s first birthday because we thought it might be the only one we would get to celebrate.**

Ryla’s birthday occurred just a few days after the diagnosis and before the biopsy. We would not have made a big fuss because she was so young, but now that her future was uncertain, we couldn’t let it go by without marking the day.

While driving from Toronto to our home in Streetsville, our friends and family rallied to decorate the house, and we had a huge celebration. It was incredibly touching to see the beginning of our support network forming.



LAST YEAR,  
**POGO REIMBURSED  
FAMILIES \$391,440 FOR FOOD  
AND \$92,064 FOR CHILDCARE**



*"It is an unimaginable decision to make to take out part of your child's body."*

It took about two weeks, but the biopsy showed that the cancer was not as aggressive as they had feared. Ryla was approved for a clinical trial that included weekly chemotherapy at the hospital, but the results were not promising for her. She was approved for a second clinical trial involving a daily oral medication, but they had to alter the recommended dose to try to avoid any damage to her liver. It worked! Her tumour stabilized as long as she was on the medication, but started to grow again when the clinical trial ended. Luckily, she has been granted compassionate access to the clinical trial chemo which she continues today.

"It was hard to hear that Ryla was blind in one eye, but when the doctors told us they couldn't resect the tumour to prevent it from spreading to her right eye, it was devastating. Removing her left eye will make her more comfortable, but we need to rely on the chemotherapy to protect the vision she has. It makes her future uncertain."

-Rob McCormack



As life shattering as this has been for us over the last 4.5 years, Ryla takes it (mostly) in stride. She is an inquisitive, smart, sassy kid. Ryla is always happy to go to the POGO Satellite Clinic at Credit Valley Hospital near our house—she loves the toys, and the staff make her feel like a superstar. She has even learned to advocate for herself—letting them know that she doesn't want eye drops if they aren't necessary and asking for the child life specialist when she feels vulnerable.

The road has been and continues to be very rocky. As Ryla got older, she started to grasp that other kids don't have to go to the hospital all the time.

And when she started school, it became starkly apparent to her that she looks different from everyone else. Her classmates would ask, **"Why do you have one big eye and one little eye?"** **Arvinder, our POGO Interlink Nurse, came to Ryla's school and explained to her class that everyone is unique.** Some people look different because they have different colour hair, eyes or skin. She taught the students how to ask Ryla questions that wouldn't make her feel bad, and Ryla feels more comfortable and loves going to school. Arvinder also advocated for a special needs EA in the classroom and a therapist for Ryla.

We are very grateful for everything  
POGO has done for our family.



POGO has been with our family from the start. When Ryla was diagnosed, a POGO Interlink Nurse was assigned to help us navigate the challenges ahead. I have been on maternity leave and critical illness leave since Ryla was born, so our income has decreased significantly, but our expenses have increased. When you spend several days in a row at the hospital, you buy food and other things that you wouldn't have to if you were at home. Our POGO Interlink Nurse pointed us to resources like the POGO Financial Assistance Program to help pay for out-of-pocket costs. And having a POGO Satellite Clinic so close to home cuts down on the cost of gas and, more importantly, helps us maintain some semblance of regular life. When Ryla has a fever, the POGO Satellite Clinic is our first stop. This minimizes the disruption in our lives and allows us more family time.

**We are not out of the woods yet. Ryla's second surgery has not been scheduled yet, and we don't know what post-surgery will look like, but we know our POGO supports will help us get through it.**

## SURVIVOR CARE

# When Your Brain Tumour Can't Be Cured

*The story below is an abridged version of a speech Maryam gave (virtually) from her hospital bed to an audience at a fundraising event benefitting POGO. To watch her entire speech, scan the QR code at the end of her story.*

I was diagnosed with cancer when I was just four years old, but what is surprising to most people is that I still live with a tumour in my brain stem.

Removing the tumour has never been an option because of its location. That kind of surgery could cause severe side effects or even death.

Every few years, depending on the growth of the tumour, I undergo whatever suitable treatment is available. I also have a magnetic device with a hollow tube called a shunt running from my head to my stomach. The shunt helps to relieve the pressure on my brain by draining the fluid from the cysts surrounding the solid tumour and redirecting it to my stomach, where it can be reabsorbed.

I have spent most of my life in and out of SickKids. This is all I have ever known...until recently.

In February, I completed a course of radiation at the Princess Margaret Cancer Centre. This was my first transition from the children's hospital into adult care. The move felt like losing my second home and all the people I have gotten to know over the first 14 years of treatment. People like my POGO Interlink Nurse Cory, who was my rock and my comfort person. She coordinated conversations with my peers at school, helped me access accommodations, introduced me to resources, and made navigating school, life and treatments possible for my younger self.

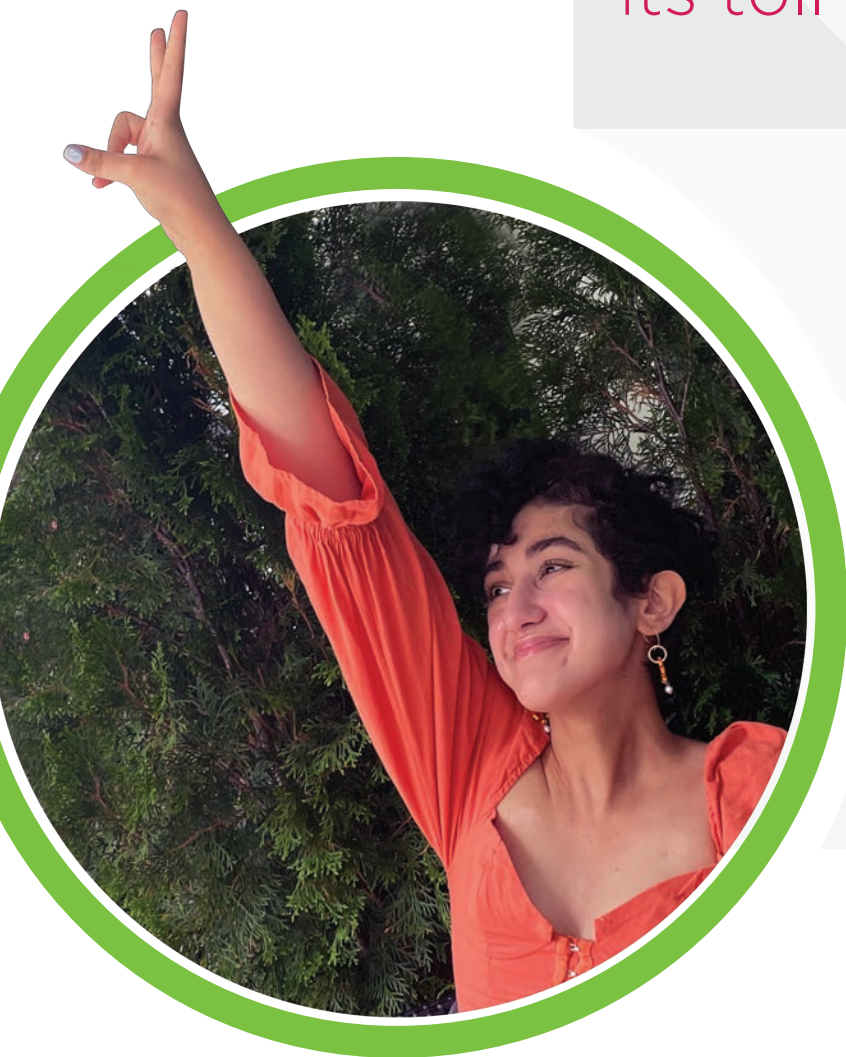
In the adult system, I don't have a Cory or a team of professionals working together under one roof to support me. While I am lucky because I attend a POGO AfterCare Clinic where all my health information is housed, it is not a one-stop shop. I must go to different hospitals for all the necessary monitoring, including regular MRIs, X-rays, blood work and occasional CT scans.

Seeing my family suffer because of my health issues was difficult. It was as though the weight of their stress was on my shoulders. By the time I reached my late teens, I was feeling like a burden. My whole life, I was taking, taking, taking, without the capacity to give.


**MK**



As you can imagine, all of this has taken its toll on my mental health.



Eventually, I sought counselling and was formally diagnosed with anxiety and depression. My counsellor taught me other ways to cope, and I can see that my life has value.

And when I started university, my POGO Interlink Nurse introduced me to another resource: my POGO Transitions Counsellor. She helped me navigate the university's disability services to access the accommodations I need. She also introduced me to scholarships specific to survivors of childhood cancer and continues to help me balance my ongoing health issues while going to school. All of this has been integral to my academic success and mental health.

**I know part of my life's purpose is to do something that makes a difference in the lives of kids with cancer, and it starts here by raising awareness of the challenges children and survivors face so that we can help them overcome them.**



In this video, Maryam Kraishi describes her cancer journey and struggle with mental health issues as a result of living with a brain tumour. Scan or click here to watch.

Last year, **104** POGO School and Work Transitions clients applied, attended, or were accepted to a post-secondary institution

# POGO

## ENSURES ACCESS TO **HIGH QUALITY, COORDINATED CARE & SUPPORT**

There are **eight POGO Satellite Clinics** bringing patient care closer to home in communities across Ontario. Each Clinic is linked to one of the province's five major hospitals with a specialized childhood cancer program. The centres work collaboratively to provide integrated, seamless care for children in treatment and their families.

**POGO Interlink Nurses** provide excellent nursing support to the young cancer patient; work with schools to educate and support staff and students about the special needs of the ill child and facilitate the child's return to the classroom; and help families identify useful resources and services in the community, including the POGO Financial Assistance Program.

The **POGO Financial Assistance Program\*** provides much-needed financial support to families for food while they are at the hospital, childcare for siblings at home and accommodation when they need to travel for treatment.

There are **seven POGO AfterCare Clinics** across Ontario monitoring survivors regularly for long-term effects from cancer treatment.

**POGO School and Work Transitions Counsellors\*** help survivors get the support and assistance they need to finish high school and move on to post-secondary education or work.

**POGO research\*** translates into improved care and better outcomes.

\*Donor-funded program

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#ChampionChildhoodCancerCare | #POGO4Kids

Charitable Registration #: 871067245RR0001



**POGO partners to achieve an excellent and integrated childhood cancer care system for children, youth, their families and survivors in Ontario and beyond.**

**Pediatric Oncology Group of Ontario**

480 University Avenue, Suite 1014

Toronto, Ontario M5G 1V2

416 592 1232 | 1 855 367 7646