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THE CHILDHOOD CANCER JOURNEY

Ellie was diagnosed with rhabdomyosarcoma at age 10. Rhabdomyosarcoma is a rare cancer that often starts in the head and neck. When three surgeries on her face and concurrent chemo didn't eliminate all the cancer cells, Ellie was sent to Jacksonville, Florida, for proton therapy—precision radiation that significantly limits radiation to nearby organs.

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I could tell immediately something was wrong when the nurse entered the room. It was his energy, the way his eyes darted between me and the screen; I sensed the air in the room shift. At that exact moment, I felt my world start to fracture.

-Samantha Taylor

POGO

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

**FOR KIDS WITH CANCER
FOR NOW, FOR LIFE.**

CANCER WAS HARD BUT IT DIDN'T BREAK ME

When I was eight, I found a bump on my face, sort of like a rock under my skin, with a red rash. The doctor called it lipoma (a benign tumour) and said I could leave it or have a plastic surgeon remove it. Once the bump started growing, I didn't like how it looked and asked my parents if I could have it removed.

The surgery was scary, but I was excited about sleepover camp coming up, so I focused on that to get through. When I returned from camp, my parents sat me down and told me the bump was actually something called a tumour and that we had an appointment at the hospital the next day to talk about how to treat it.

When we got there, I was told to hang out with the child life specialist while my parents met with the doctor. The next thing I knew, my parents and the doctor came into the room, sat me down and told me I had cancer. The doctor said that even though it was very scary to hear, I would get through it, and I believed her.

I had two more surgeries on my face, and once my scar healed, I started chemotherapy.



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“There was a point while Ellie was getting chemo that her oncologist pulled me into a small room. She let me know that Ellie's biopsy indicated she may have a genetic mutation that would make her chemo-resistant—meaning her treatment would definitely fail. At that moment, my flesh turned to armour.

The only thing I could think of was that I had to be stronger than I ever imagined I could be. I returned to Ellie's side and texted my husband, Ley, sitting two feet away, the news that our daughter might not make it through this and that our son, Oakley, might also have the mutation. I had to watch his face react to the news. We didn't tell the kids what was going on, but for the next seven weeks while we waited for the lab results from the U.S., we grieved Ellie—relieving her pain with warm baths every hour, creating a cozy home environment, gripping as tight as we could to every single day. **When I finally got the phone call that the test had come out clear, my knees gave way, and I collapsed, crying. I was so relieved.”**

- Samantha Taylor



[Scan or click here to watch a snapshot of Ellie's cancer journey.](#)

During my chemotherapy, I took lots of baths (I was obsessed with bath bombs), and my family spent all our time together watching movies in our PJs, playing games and sitting on the couch by the fire. Being with my family got me through it.

The surgeries did not get all of the cancer out of my face, and my whole family was sent to Jacksonville, Florida, for two months so I could have proton therapy. It was winter at home but warm there, so I could swim—which was great. The clinic had a coffee cart, and I became the barista, making coffee and hot chocolate for everyone.

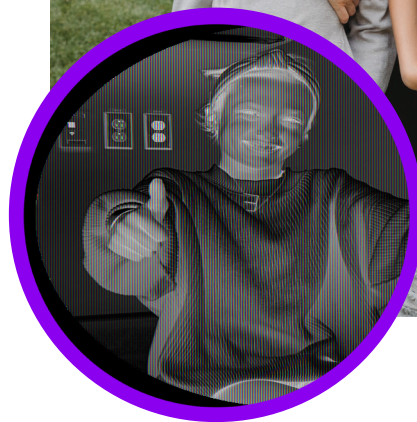
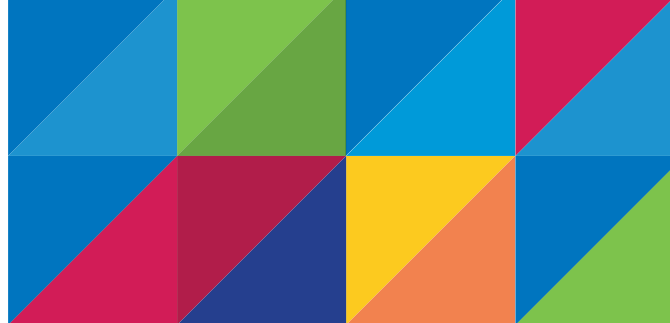
We met a lot of other families at the proton clinic, and I loved interacting and playing with the younger kids—like a child life specialist. I tried to calm and reassure them that the laser doesn't hurt. I helped them feel brave about their treatment. I even made a video about how “low stress” radiation therapy is. It made me feel like I was really making a difference.

When we came back to Canada, I continued my chemo treatment at the POGO Satellite Clinic at Credit Valley Hospital. The clinic was warm and inviting, with big windows and a fairy garden outside. My nurse, Lindsay, was THE BEST. She was always gentle; she let me do things my way and never once rushed me. If I needed her to repeat things 10,000 times, she did. We did crafts and jokes and wheelchair races. Even my brother got to play with the child life specialist. I found it very comforting to go somewhere where everyone knows what you like, and they let you take some control.

Having cancer was a big deal, and it was scary, but I found ways to get through it with the help of my family and all the doctors and nurses along the way, especially at the POGO Satellite Clinic.

The POGO Financial Assistance Program reimburses families for out-of-pocket costs associated with their child's treatment in Ontario, as well as out-of-province or out-of-country, provided their physician in Ontario approves the treatment plan.

**LAST YEAR, POGO PROVIDED
\$720,000 TO 796 FAMILIES
ACROSS ONTARIO**



LIFE ADVICE FROM ELLIE

When I found out I had cancer, I didn't tell anyone because I felt embarrassed. When I finally returned to finish Grade 6, I wore a wig, but that was uncomfortable, and I thought I looked weird. On the first day of Grade 7, I got the courage not to wear my wig, and I walked into school with my short hair. I got so many compliments 😊. **Now I know. You should never be insecure; you just need to be yourself.**

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