

THE CHILDHOOD CANCER JOURNEY

THE VEENSTRA FAMILY

WHEN STELLA WAS JUST 18 MONTHS OLD, she had a fever that wouldn't go away. Her mother brought her to the emergency department not expecting the news she was about to receive.

After a series of tests, mom and Stella were in an ambulance headed to The Hospital for Sick Children in Toronto—dad and Stella's twin sister, Sophia, followed by car.

Due to COVID safety protocols in place across the province, only one parent was allowed in the hospital. Dad was sitting in his car on speakerphone when the doctors diagnosed Stella with acute lymphoblastic leukemia.

Photo by Naomi Lucienne Photography



FAMILY SUPPORT

Parenting Apart When Your Child has Cancer

BY SARA FRANSKY

At first, the doctors thought Stella's fever was due to a virus, but when they got the bloodwork back, her results showed that her hemoglobin and platelets were dangerously low and her white blood cells almost nonexistent. I have been working as a medical laboratory technologist for nine years, so I understood the numbers. In my whole career I had never seen blood counts so low.

I broke down; I knew right then that it was cancer.

I called my husband, Charles, and told him that we were heading to The Hospital for Sick Children in Toronto and to pack an overnight bag. With its siren blaring and lights flashing, the ambulance rushed me and Stella down the highway from Simcoe County. Charles and our other daughter, Sophia, followed by car.



We arrived in Toronto at around 7 p.m. This was the very beginning of the COVID lockdowns* and only one parent was allowed in the hospital. Charles spent the next several hours in the parking lot trying to keep Sophia distracted but also keep himself available for updates from me. Finally, at 11 p.m., with me at Stella's side and Charles on speakerphone, we were told that our daughter had leukemia.

The following morning, Stella had a spinal tap, a bone marrow aspirate and started aggressive chemotherapy. For the next month, one of us lived in a nearby hotel with Sophia and the other in the hospital with Stella. We would "change shifts" once a week at the door of the hospital—filling the other one in on Stella's medical progress, eating habits and how she was holding up. It was physically and mentally exhausting to be the parent at the hospital and emotionally traumatic not to be.

*Visitor restrictions were in place across all children's hospitals in Ontario to protect immunosuppressed children, prevent hospital outbreaks and ensure uninterrupted treatment and quality of care.

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“Waiting in the parking lot that day was the longest day of my life.”

It was isolating and devastating to receive the news and not be in the room with Sara and Stella. Sara has a healthcare background, so words like “blasts” and “hemoglobin” were familiar to her, but they were new and terrifying to me. And they were about my daughter. It is tough for any parent to hear their child is sick, but when you aren’t even in the room, and you can’t see the doctors’ faces and you can’t be with your wife and child, it’s agonizing.

After we got the news, I felt lost. I didn’t know what to do next, where to go, how I was going to manage with Sophia when we were so far from home and my wife and other daughter were in the hospital.”

-CHARLES VEENSTRA



Photo by Vaughn Barry Photography

LAST YEAR,
**POGO REIMBURSED
FAMILIES \$435,127 FOR FOOD
AND \$133,527 FOR ACCOMMODATION**

Early in her treatment, Stella had several complications that required attention and often led to hospital admissions.

After the first month of treatment, we were able to bring Stella home, but she had several bouts of vomiting and diarrhea, and a bloated tummy. With Charles at her side, she was readmitted to the hospital for tests, and when they discovered a strange bulge in her side, an MRI showed that she had a perforation in her bowel and an abscess behind her stomach. The doctors told Charles that she needed surgery immediately. I put Sophia in the car, drove two hours to Toronto and checked into a hotel. Even if I couldn't be in the hospital, I needed to be nearby.

As a result of the surgery, Stella has a colostomy bag. It's not forever, but we don't have a timeline for when it will be removed.

It's been over a year and we are still back and forth to the hospital for more than the regular treatment protocol because Stella's case is challenging. Now that Stella is further along in her treatment, our first stop is often the POGO Satellite Clinic at Soldiers' Memorial Hospital in Orillia. They determine how serious the issue is and if we need to travel all the way to Toronto for tests and treatment, or if we can get the care we need there, which is closer to home.

The staff at the POGO Satellite Clinic are amazing. Having the same nurse each visit helps Stella build trust and eases the stress associated with treatment. It also helps us as a family to know who and what to expect when we go to clinic. Our POGO Satellite nurse does more than just care for Stella; she always checks in to make sure the whole family is doing okay.



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



Photo by Diana With Love Photography

The Veenstra Family

The POGO Financial Assistance Program helps pay for meals and hotel stays when our family travels to Toronto for treatment. POGO Interlink Nurses have been great at providing information about services and support available to us in our own community. And the POGO Satellite Clinic has been essential to Stella's treatment and care—without it, the travel to Toronto would be incredibly difficult to manage.

Our family has spent a lot of time apart since Stella's diagnosis. POGO has helped keep us together.

SURVIVOR CARE

THE ROAD TO INDEPENDENCE

BY EMELIA GRAHAM

I was diagnosed with medulloblastoma (a brain tumour) when I was four years old. During my treatment, I stopped growing, so I developed scoliosis, actually double scoliosis—my tailbone is curved in two different directions. It got so bad that I had to wear a body brace for 23 hours a day for most of elementary and high school. My treatment also led to hearing loss and now I have hearing aids in both ears.

It has been almost 20 years since my brain tumour, but I am still monitored regularly for long-term effects. I see an ophthalmologist for the cataracts I developed in both eyes, a neurologist to keep an eye on two benign tumours that remain in my central lobe and a cardiologist to monitor the irregularities in my heart. My doctor at the POGO AfterCare Clinic streamlines all of this information and helps me organize and understand it. It is very comforting to have one person whose job it is to keep an eye on everything as a whole and not just the individual parts.

My AfterCare doctor also referred me to get support from POGO's School and Work Transitions Program.

I graduated high school but did not have college-level English. That meant that I didn't meet the admission criteria for most college programs.

My POGO Transitions Counsellor helped me by connecting me to the CICE (Community Integration through Co-operative Education) college program. I had to live away from home for the first time, but it made me a better person and helped me learn more about being independent.

Last year, **89**

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

EG

It was amazing to discover that college was still an option for me!



I studied recreation. I love working with children and seniors and I was able to gain real-world experience through field placements at schools and nursing homes. Last year I applied for and was offered a one-year position as a workshop facilitator in POGO's Survivor-to-Survivor Network. I received an honorarium and was able to use my personal experience to lead discussions on pathways to college for other childhood cancer survivors. This was my first paying job!

I am very happy that I have had the opportunity to give back to other survivors and I feel lucky that I have my family, friends, doctors, schools and organizations like POGO to help me find my path.



In this short video, Emelia Graham describes her cancer journey and thanks POGO donors for their support.
Scan or [click here](#) to watch.

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 pediatric cancer program. The centres work collaboratively to provide integrated, seamless care for children and families in treatment.

POGO Interlink Nurses provide excellent nursing support to the young cancer patient; work with schools to educate and support faculty 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



**In this video,
POGO co-founder
Dr. Mark Greenberg
illustrates how POGO's story
reflects the childhood
cancer experience.**

POGO
PEDIATRIC ONCOLOGY GROUP OF ONTARIO
**FOR KIDS WITH CANCER
FOR NOW, FOR LIFE.**

FOR MORE INFORMATION VISIT US AT WWW.POGO.CA

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