



2016

# COMMUNITY IMPACT REPORT



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

# WITH GRATITUDE

Our sincerest gratitude to all of our major donors for their dedication to championing kids' cancer care. A special thank you to those who have committed to POGO with a multi-year agreement (indicated below with an \*asterisk). Your ongoing commitment provides stable funding for today and tomorrow, allowing POGO to plan ahead, knowing that we have your support.

## **POGO's Lead Partner: \$575,000**

Coast to Coast Against Cancer Foundation\*

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*List of donors continued on pages 30-31*

A MESSAGE FROM

# THE CHAIR OF THE POGO DEVELOPMENT CABINET



To start, let me say that I am thrilled to chair the POGO Development Cabinet, a group of highly talented, philanthropic individuals who have come together for a single cause: to champion childhood cancer care.

When I first learned about POGO, I was immediately impressed with the breadth and depth of the work they do in the field of pediatric oncology. The POGO motto—For kids with cancer, for now, for life—reflects this perfectly. It speaks to the longevity of POGO's relationship with each child who experiences cancer, during treatment and beyond, as well as

their commitment to the quality of care and quality of life for each and every patient, family and childhood cancer survivor.

I am equally impressed by the way its stakeholders understand, respect and act as ambassadors for the various programs and services POGO provides. As you read this report, you will hear directly from families about the invaluable support they receive during treatment. Two survivors describe two very different programs that help them manage their ongoing care and promote optimal quality of life. POGO education events engage experts in the field, as well as survivors with lived experiences, to communicate the latest and greatest achievements in pediatric oncology. And finally, POGO researchers describe the importance of ongoing surveillance and research to help advance the field of pediatric oncology.

POGO is at the forefront of development and innovation in this field that fights tirelessly to support kids with cancer, and I am very honoured and proud to be a small part of that.

A handwritten signature in black ink, consisting of a stylized 'F' followed by a horizontal line.

**Fay Wu**

Chair, POGO Development Cabinet



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at Kingston General Hospital, Kingston

# MAKE NEW FRIENDS, BUT KEEP THE OLD.

# ONE IS SILVER, AND THE OTHER GOLD.



Growing up, I remember this piece of wisdom passed down to us in the classroom, churches, clubs and organizations, and even in my home (my mom was a kindergarten teacher). I can't think of a more fitting mantra for the not-for-profit sector today, and in particular with our work at POGO.

In this year's report you will read stories that exemplify POGO's core strengths. As we continue to provide excellent service and programs to the community we serve, we are also engaged in developing the next five-year provincial plan to advance the existing childhood cancer system.

You will have already seen the introduction from our Chair of the newly formed Development Cabinet, Fay Wu. Now, as you read this, we will be welcoming our new Medical Director while saying thank you but not goodbye to our outgoing Medical Director Dr. David Malkin.

And of course heartfelt thanks to those donors and partners who have been supporting POGO for some time. Your contributions and commitment have helped build POGO to where it is today. Welcome to our new friends and donors who have joined our league of champions! In a time where choice is abundant, we are honoured and grateful you chose POGO. Silver and Gold.

Sincerely,

A handwritten signature in cursive script that reads "L. Wilson".

**Lynn Wilson**

Chief Development Officer, POGO

# **FAMILY SUPPORT**

# AT ANY GIVEN POINT IN TIME, THERE ARE CLOSE TO 4,000 FAMILIES IN ONTARIO WITH A CHILD IN CANCER TREATMENT OR FOLLOW-UP CARE.

While a cancer diagnosis comes as a shock at any age, when the patient is so young it seems incomprehensibly unfair.

Parents must face their frightened and bewildered child, while they themselves may feel helpless and vulnerable, struggling to negotiate unfamiliar areas of a complex healthcare system. It is a world of which few of us are fully aware, unless we have to enter it ourselves.



FAMILY SUPPORT

# SELENA'S STORY:

## Creating a Happy Home for my Child with Cancer

In 2014, both my husband and I were working long hours at high pressure jobs. It seemed as though our daughter Selena was spending more time with her nanny and grandparents than with us, and she was having behavioural problems at daycare. We made the decision that Selena needed more "mom time," so I took a leave of absence from my job in women's nursing apparel and I started working part-time at a restaurant. It paid off: Selena's behaviour changed 180 degrees in that first year. She was happy and well-adjusted, and I got the opportunity to really know my kid in a way I hadn't before.

So when our healthy child who never had so much as a cold said, "Mummy, I have a tummy ache," we didn't just blow it off like we might have the year before. We immediately took her to a walk-in clinic. The doctor pressed down on her stomach and noticed her liver was swollen. Although he attributed it to an infection, he was still curious so he made a requisition for an ultrasound. And for that, I will forever be grateful.

Selena's stomach ache went away and she didn't have a single symptom after that. If not for that ultrasound, they would never have detected a mass or ordered the blood work and CT scan that determined it was cancer. Selena was diagnosed with the worst type of Wilm's tumour; we were told to get ready for a bumpy road.

SK

MEET OUR  
CHAMPIONS

WATCH SELENA'S STORY:  
Creating a Happy Home When  
Your Child has Cancer @[www.pogo.ca](http://www.pogo.ca)



*Her protocol was experimental and based on yet-unpublished research out of the United States.*

*Step 1 -* Removal of her kidney and tumour

*Step 2 -* 13 rounds of radiation

*Step 3 -* 12 cycles of aggressive chemotherapy



PHOTO BY TYNAN STUDIOS

Selena's treatment completely wiped out her bone marrow and she was in semi-isolation for nine months. It was challenging. She couldn't go to daycare, birthday parties or even the shopping centre. We decided to make home the best possible environment we could and we celebrated everything, from a single poke to the end of a round of chemo. We had a party every weekend with cake and lots of family (screened for even the slightest cold symptom) and the days were joyous and filled with laughter.

This last year was challenging in other ways. I quit my part-time job and managed all of Selena's medical care. I had already taken a serious pay cut to be home and now I had zero pay, no employment insurance or benefits, and our expenses were rising. My husband worked extra odd jobs so we could get by and our POGO Interlink Nurse\* connected us to every resource we were

eligible for, including POGO's Financial Assistance Program.

And now Selena's treatment is over and she is doing so well. She is excited to start school; I am thankful that I get to return to the same job after being away for two years; and my husband and I are determined to get back on track financially. It will be hard to return to "business as usual." You get attached to the reality you are in. There is so much readjustment after cancer, but we are looking forward to this next stage in our lives.

*- Natasha Koss*

*\*POGO Interlink Nurses play an important role between hospital visits. They provide excellent nursing support to the family and they work with schools to help them understand the needs of the young cancer patient.*

**FAMILY SUPPORT**

# STATS + FACTS

POGO's Financial Assistance Program, funded entirely by private-sector donations, supports families through the enormously financially challenging period of active treatment. The program provides a stipend for out-of-pocket costs such as food, accommodation and childcare for siblings. POGO will, for instance, help meet the cost of staying at a Ronald McDonald House (RMH); and has hotel partners that provide free rooms when the RMH option is unavailable.

**THE MARRIOTT, WESTIN HARBOUR CASTLE AND HILTON HOTELS PROVIDED**

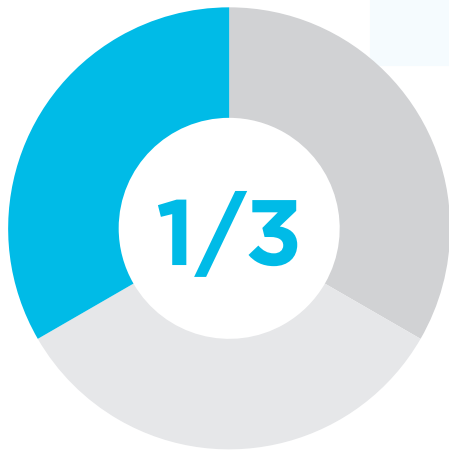
**355**

COMPLIMENTARY NIGHTS

FOR

**137**

FAMILIES IN NEED,  
SAVING THEM OVER \$42,000



POGO studies have shown that, on average, a family can lose 1/3 of its after-tax income when there is a child in treatment.

**THANKS TO DONOR SUPPORT, POGO PROVIDED**

**\$908,472**

FOR

**988**

Ontario families to help pay for out-of-pocket costs.



# THANK YOU

*PDGD gratefully acknowledges the outstanding financial support of our lead sponsor Coast to Coast Against Cancer Foundation. We would also like to thank the following new and returning supporters: The Ben and Hilda Katz Charitable Foundation, CIBC Children's Foundation, Derek Janzen, J.P. Bickell Foundation, Kitchener Rangers Clarky's Kids, The MacNamara Family, The McLean Foundation, The Melman & Yakobson Families, PDGD Leadership Connection, and Scotiabank.*

## FAMILY SUPPORT

# PROVIDING EQUAL ACCESS TO STATE-OF-THE-ART TREATMENT

While there are several children's hospitals in Ontario, many families live outside of a major city centre and must travel, sometimes long distances, for their child's cancer treatment. This can be even more distressing when the child is experiencing pain or nausea from radiation or the toxic mix of drugs they must receive. In an early analysis of approaches to pediatric cancer care in Ontario, POGO realized that not all components of treatment required visits to major treating facilities. In 1998, the concept of POGO's Satellite

Program was born. To date, POGO has created Satellite Clinics in communities across Ontario, bringing care closer to home for many families.

Providing components of care in smaller communities throughout the province vastly reduces families' overall levels of stress; disruption of work and school; expense; and the substantial demand for hospital beds in the specialty hospitals providing pediatric oncology care.

"I was on maternity leave with our new baby girl when our three-year-old son David was diagnosed with acute lymphoblastic leukemia. Our whole world turned upside down.

It took time to adjust to the new normal: accepting the diagnosis and the treatment that our young boy would have to go through; learning this new "language" associated with childhood cancer; juggling our time and energy between home and hospital. The first year was very intense and when things finally settled down, we realized we really needed a break from cancer. Even though David was getting better, we were afraid to leave Toronto, to be too far from the hospital should anything go wrong. We were happy to discover that we could spend a few days in Orillia where we would be near the POGO Satellite Clinic at Soldiers' Memorial Hospital. In the end, everything went smoothly and we didn't need to go to the clinic, but the assurance of knowing we would get the same care as in Toronto if we needed it was priceless."

– Lisa Hascal

POGO's Provincial Pediatric Oncology Satellite Program was implemented in 1998 with the establishment of clinics in Orillia, Kitchener-Waterloo and Sudbury. Today, other POGO clinics are situated in Mississauga, Windsor, Scarborough and Newmarket.

**POGO'S 7 SATELLITE CLINICS ACCOMMODATED**

# 6,831 VISITS

keeping families closer to home for their child's cancer treatment and reducing the cost (and burden) of travelling to a major city centre.

## OUR PARTNERS IN CANCER CARE

★	POGO PARTNER HOSPITALS
✿	POGO AFTERCARE CLINICS
★	POGO SATELLITE SITES
■	POGO PEDIATRIC INTERLINK COMMUNITY CANCER NURSES



WATCH POGO SATELLITE NURSES:  
Making a Difference for Families  
[@www.pogo.ca](http://www.pogo.ca)



# **SURVIVOR CARE**

# MORE THAN 82% OF CHILDREN DIAGNOSED WITH CANCER WILL SURVIVE.

But even when they hear the best of all possible news, that they are now cancer-free, their journey is far from over, because young children are particularly vulnerable to the late effects of cancer treatment. As many as 60% of survivors will experience ensuing complications. The survivor of childhood cancer requires far more than an annual physical.



**SURVIVOR CARE**

# ME AND MY TWIN:

## The Unmistakable Effects of Childhood Cancer

Until the age of 11, most people could not tell me apart from my identical twin brother, Ben; we had the same friends, performed the same at school, and we have always had similar interests and tastes.

**At that age, I had heard of cancer, but I didn't think kids could get it.**

My official diagnosis was acute myelogenous leukemia and the doctors said that my best chance of survival was with chemotherapy, total body radiation and a bone marrow transplant. My odds were still only 55%. I actually had two unsuccessful bone marrow transplants before they tried an experimental treatment called lymphocyte donor transfusion. I have now been in remission for over 16 years.

Because of all of my time in and out of the hospital, I missed the majority of grades 6 through 8. Before I entered high school, I had to take a test to see if I met the basic requirements; I barely passed. The amount of school I missed, combined with the radiation to my brain, had set me back academically. They placed me in the special education class with a reduced course load and extra time to write tests.

A few months into grade 9, I developed cataracts, and due to my loss in vision I had to really struggle to complete assignments. Soon it became so bad I had to wait for my brother after school just so he could guide me to our bus!

J I

MEET OUR  
CHAMPIONS

WATCH JAMIE'S STORY:  
The Unmistakable Effects of  
Childhood Cancer @[www.pogo.ca](http://www.pogo.ca)



I ended up spending two extra years in high school, and it felt like I was being left behind by my friends and my brother. It was like I was stuck in time, which was made worse by my physical developments, or lack thereof. While my brother continued to have growth spurt after growth spurt, I slowly grew a few inches at a time and stopped growing once I hit 5'3 and 100 lbs. My brother stands at 6'1 and 200 lbs. And although my stunted growth did not affect me academically, it greatly lowered my self-confidence.

Now I have two degrees, with honours, and I am looking for a job in public administration. Even after this incredible achievement, I still had doubts. I wasn't getting called for any job I applied for and for a while I felt like I was unqualified for anything. At my lowest point, I reached out for help during my yearly checkup and was referred to Lucie, my POGO counsellor. With her support, I have been able to upgrade my skills, identify and apply for appropriate jobs and even get called in for interviews. My confidence has skyrocketed.

As a result of these efforts, I recently was hired by POGO as the Administrative Assistant to Conferences, Educational Events, and POGO's financial assistance to families' program. Boosted by this success, I will continue to build my skills and professional experience and work toward fulfilling my career goals.

- Jamie Irvine



PHOTO BY TYNAN STUDIOS

PHOTO BY TYNAN STUDIOS

## SURVIVOR CARE

# STATS + FACTS

Some cancers, such as brain tumours, require radiation to the head, and others involve chemotherapy that crosses the blood-brain barrier. These can cause late effects such as increased forgetfulness, persistent fatigue and cognitive impairment, resulting in learning difficulties that can affect the survivor's success at school.

POGO's academic and employment counselling, funded entirely by generous donations, helps young cancer survivors make the transition from high school to college, university or into a career path. POGO's trained counsellors work one-on-one with their clients to help them develop realistic education and employment goals; select tools and strategies for managing school work; improve their problem-solving and self-advocacy skills; and connect with relevant services and resources within colleges, universities or the community.

POGO's  
**5 counsellors** across  
Ontario received **266**  
**referrals**, creating a  
caseload of **419**  
**new and returning**  
**survivor clients**

# 104

applied, are attending  
or have been accepted  
at a post-secondary  
institution

**IN 2015, POGO LAUNCHED A SERIES OF WORKSHOPS** to address various topics of concern for survivors including **stress management, employment or college preparation, volunteerism, and financial literacy**. We also began a credit course in partnership with **Mohawk College** titled **Strategies for Success in Higher Learning for Pediatric Cancer Survivors**.

**CONGRATULATIONS TO THE FIRST 6 GRADUATES OF THE COURSE!**

Of the 266 clients  
referred  
in fiscal 2016



67

are still in  
high school, exploring  
post-secondary options

21

are employed or  
receiving community  
support for employment

30

are employed or are  
exploring career or  
volunteer opportunities

**THANK YOU TO OUR DONORS**

POGO gratefully acknowledges the outstanding financial support of our lead sponsor **Coast to Coast Against Cancer Foundation** and our returning partner **TD Securities Underwriting Hope Charity Auction**.

SURVIVOR CARE

# MONITORED FOR LIFE:

## It Doesn't End with Cancer-free



At four, I was diagnosed with stage 4 rhabdomyosarcoma, in my case a tumour the size of a baseball in the lower abdominal area near my bladder. At 20, I have lived almost my entire lifetime in cancer care. And alongside my parents, POGO, through its many programs and services, has been with me every step of the way. POGO teams have supported me through treatment, which included eight rounds of chemotherapy and a series of surgeries at the age of four. And now, 16 years later, as I manage the late effects that have developed as a result of my treatment, POGO AfterCare Clinics continue to support me.

Most people know that cancer treatment can be fairly aggressive, but what many don't realize is that it can have serious side effects many years later.

I continue to be monitored by oncology for second cancers. I need to see a cardiologist every six months because the toxic mix of drugs I was given has the potential to seriously lower my Ejection Fraction Index, which is the fraction of blood pumped out with every heartbeat. And I visit my internist annually because the surgeries that removed my tumour also left a lot of scar tissue.

MD

Until a few years ago, all of my follow-up care took place at SickKids where I was diagnosed and treated. When I turned 18, I graduated from the all-encompassing children's hospital system, with its seamless management and coordination between departments, to the adult system (in most situations I am by far the youngest person in the waiting room!). While I have three new doctors spread across the city, luckily for me, and every childhood cancer survivor in Ontario, all of my follow-up care is still coordinated through a POGO AfterCare Clinic. So when my cardiologist wanted to change my medication, POGO teams were able to determine that it wouldn't do any damage based on the treatment I had as a child. And when my internist wanted to do an exploratory procedure, POGO teams again intervened noting it could do more damage than good with the scar tissue that was built up over many surgeries.

As you can see from my personal story, childhood cancer requires a lifetime of follow-up care. I know POGO will be there for me over the next 20 years, 20 more after that and counting. Without the seamless care of POGO's AfterCare Clinics, and survivor care programs, many young cancer survivors would fall through the cracks.

*By Myles Davis*

Surveillance and monitoring can help identify if a particular form of treatment is the cause of a particular late effect in cancer survivors. With such findings, current treatment practices can be modified so that future survivors will be less likely to develop the identified late effect, ultimately contributing to future advances in treatments for childhood cancer.

**POGO'S 7 AFTERCARE CLINICS ACCOMMODATED**

**2,698** PATIENTS





# **KNOWLEDGE TRANSFER**

# PEDIATRIC ONCOLOGY IS A RAPIDLY ADVANCING FIELD.

It is essential that POGO's healthcare professionals be at the forefront of that progress and that survivors and their families are kept up to date with the current state of knowledge. Investing in knowledge transfer is at the core of POGO's mission. POGO achieves this through its annual multi-disciplinary symposium, bi-annual survivor conference and various workshops and education events throughout the year.

KNOWLEDGE TRANSFER

# STRAIGHT TALK

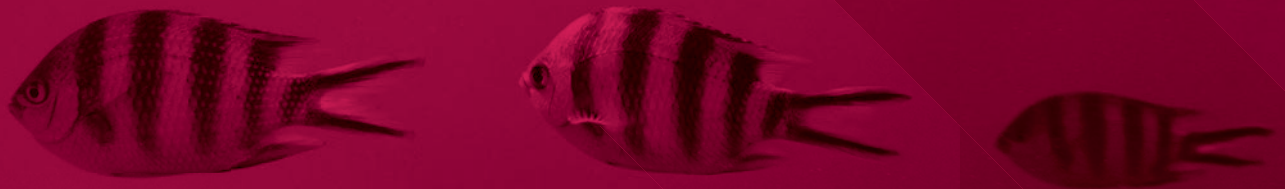
Two notable advancements in the diagnosis and treatment of childhood cancers are the science of genomics (how genetic changes occur in tumour cells) and the use of developing cancers in model organisms, such as the zebra fish, in order to develop new drugs to test and translate to human use.



In *Straight Talk about Childhood Cancer*, POGO's former Medical Director Dr. David Malkin discusses how now, more than ever, it is important to develop and fund collaborative research groups, across Canada and internationally, in order to catalyze significant leaps forward in the field of pediatric oncology.

Dr. David Malkin was the POGO Medical Director and POGO Chair in Childhood Cancer Control from 2011 to 2016, and is Professor of the Department of Paediatrics and Medical Biophysics, School of Graduate Studies at the University of Toronto. He is also a Senior Staff Oncologist of the Haematology/Oncology Department for The Hospital for Sick Children. He spoke at the 2013 POGO Multi-Disciplinary Symposium on Childhood Cancer.

*Straight Talk about Childhood Cancer* is POGO's series of video shorts featuring the insights of experts whose leading-edge work impacts the care, treatment and quality of life of childhood cancer patients, survivors and their families.



*The 2015 POGO Symposium, An Integrated Approach to Relapse, was made possible by lead sponsor The Garron Family Cancer Centre, as well as the following sponsors: Amgen Canada Inc., Artificial Intelligence in Medicine Inc., The Children's Wish Foundation of Canada, Hamilton Health Sciences Foundation, Hearth Place Cancer Support Centre, Lundbeck Canada Inc., The Ontario Institute for Cancer Research, Pfizer Canada Inc., Princess Margaret Cancer Centre Radiation Medicine Program, University Health Network - Division of Medical Oncology and Hematology, and Windsor Regional Hospital.*

WATCH

STRAIGHT TALK: New Cures and Approaches to the Diagnosis and Treatment of Childhood Cancer  
[@www.pogo.ca](http://www.pogo.ca)



## KNOWLEDGE TRANSFER

# THE BURDEN OF SURVIVING CHILDHOOD CANCER

When I was 10 months old, I had persistent raspy breathing that everyone thought was a cold or allergies. Then one night I stopped breathing. I was rushed to the hospital, x-rayed and sent to The Hospital for Sick Children where they found a tumour the size of a grapefruit wrapped around two vertebrae in my upper spine—neuroblastoma was the diagnosis. I was rushed into surgery to remove the tumour and a large portion of muscle and tissue out of my back. My chances of surviving were 5 - 10% and my parents were told that if I DID survive, I would likely be paralyzed.

After cobalt radiation treatment, I went into remission at 18 months old and never relapsed. As I grew up, my doctors explained to me the side effects I was experiencing, those that might still come, my inability to have children, and the fact that my life expectancy was not the same as my peers. For the rest of my life cancer and I will walk together in some form. That is my basic medical story, but it is not my whole story. While most childhood cancer survivors become well-adjusted adults, many have an affected sense of self and some may experience depression, anxiety or other mental health issues.

**One rarely discussed issue is something I have been through, and most survivors I know have experienced: survivor guilt. It's a hard concept to wrap your head around until you understand where it originates from.**

Growing up, many of the children who were treated alongside me did not survive; including a friend who was very special to me. For a long time after he passed I felt guilty for living, in fact I still do sometimes when another life is lost. But the feelings of responsibility don't end there. Logical or not, many survivors feel guilty for the sacrifices our parents had to make, for the social and emotional challenges our siblings went through, and even for being who we are, rather than super humans doing extraordinary things. There is a burden to be better than "normal."

As an adult, the feelings have never really gone away, but I have found ways to deal with them. As a teenager and young adult, the guilt, coupled with the deeper understanding of my own mortality and no one to relate to, was very isolating. That is why I try to address the topic with other childhood cancer survivors, especially the younger generation. It has catalyzed many interesting and emotional conversations, and in some cases, provided a space for people to voice something they have never said aloud before.

*Leanne Brown has been a speaker at the biannual POGO Survivor Conference and POGO AfterCare Education Day. Although she was told she would never have the physical strength and endurance of her peers, she embraces life by skiing, running, hiking, camping and canoeing, and she even completed a half marathon in 2013. Leanne is the Director of the National Capital Chapter for The Children's Wish Foundation of Canada and lives with her two children in Ottawa.*



**RESEARCH**

**THE POGO RESEARCH  
UNIT CONDUCTS AND  
SUPPORTS RESEARCH  
IN A WIDE VARIETY OF  
DISCIPLINES, ENHANCING  
OUR UNDERSTANDING  
OF CHILDHOOD  
CANCER'S EFFECTS  
AND DEVELOPING THE  
NEXT GENERATION OF  
PEDIATRIC CANCER  
RESEARCHERS.**

This work is underpinned and supported by the extraordinary data  
in POGO's unique childhood cancer database called POGONIS,  
Pediatric Oncology Group of Ontario Networked Information System.



## RESEARCH

# THE POWER OF POPULATION-BASED RESEARCH

In 1995, POGO's childhood cancer database (POGONIS) transformed into a fully networked information system. This has allowed us to observe the population, know if certain cancers are increasing in incidence, monitor treatment, follow survival, and understand how these things change over time. In 2004, POGO was designated one of just eight 45.1 entities under Ontario's Personal Health Information Protection Act, allowing POGO to collect, use and disclose personal health information, including the ability to link its database to other administrative databases, plan for Ontario's pediatric oncology system and launch invaluable research.

There are multiple study designs, but when we talk about research in medicine, many people think about randomized clinical trials. This type of research can be a very powerful tool when it comes to understanding how X affects Y in a highly selected subset of the population. Drug testing is a perfect example of this. Not every child is eligible for the clinical trial, but the hope is that what we learn from this unique subset we'll be able to extrapolate to everybody. Of course this is not always the case with clinical trials.

POGO's database allows us to perform what is called population-based research. This type of study design looks at a population as a whole, in our case all children with cancer in Ontario, and examines what the experience is for everybody. It can help answer questions where outcomes are small and need to be studied on a large scale to understand the answers.

MEET OUR  
CHAMPIONS

WATCH DR. POLE'S RESEARCH  
HIGHLIGHTS: The Power of Population-  
Based Research @[www.pogo.ca](http://www.pogo.ca)

## RESEARCH

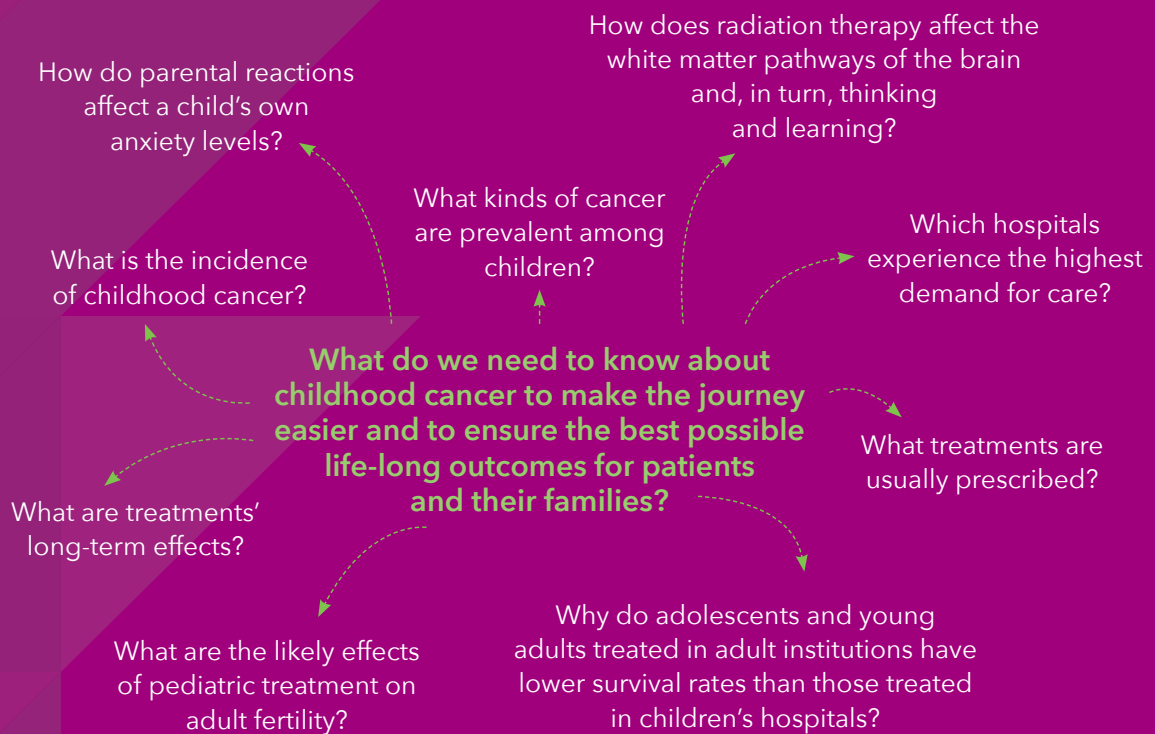
For me, population-based research is exciting because it can be just as transformative as biomedical research.

The data we have collected in POGONIS, combined with the fact that we can link it to other datasets that are already being collected (Statistics Canada for example), can produce very rich and detailed information that would otherwise be too expensive and/or too labour intensive to collect. It is a very efficient way to utilize all the data that is out there and actually answer questions that can translate more immediately into improved care and better outcomes for the individuals we serve: patients, families and survivors of childhood cancer.

- Dr. Jason Pole



*Dr. Jason Pole is Scientist with the Pediatric Oncology Group of Ontario and is an Associate Professor in the Dalla Lana School of Public Health, University of Toronto and an Adjunct Scientist with The Hospital for Sick Children Research Institute and the Institute for Clinical Evaluative Sciences, Toronto. Dr. Pole has a background in epidemiology and health services research with an emphasis in the use of administrative data and complex survey instruments.*



## RESEARCH

# HOW CAN WE IMPROVE CONTROL OF CHEMO-INDUCED NAUSEA & VOMITING?

In a survey supported by POGO, chemotherapy-induced nausea and vomiting was identified as one of the top concerns of parents of children receiving chemotherapy. The antiemetic aprepitant—a relatively new and effective drug used to prevent these distressing side-effects in patients receiving chemotherapy—is only available in capsule format, so children who cannot swallow capsules cannot benefit from this medicine in its current form.

When a liquid form of a drug is not commercially available, pharmacists often manipulate dosage forms that are made for adults so that children can take those drugs. They do this by breaking up capsules or crushing tablets to make a liquid formula that children can swallow. This is called extemporaneous compounding. Some drugs become unstable as soon as you mix them with a liquid. In other words, they degrade so rapidly that the liquid forms are not useful; others might get absorbed into the bloodstream too quickly or not at all. Ideally when a pharmacist makes an extemporaneous compound, they use a formula or a recipe which has been studied so we know the drug's stability. Even better is to understand how the extemporaneous liquid formulation is absorbed from the stomach into the bloodstream compared to the original tablet or capsule made by the pharmaceutical manufacturer.

In 2016, POGO awarded Dr. Priya Patel, RPh, PharmD, a MSc student with a Clinician Scholar Fellowship for her project: *Relative Bioavailability of an Extemporaneous Oral Suspension of Aprepitant in Children*. Priya, her supervisor, Dr. Lee Dupuis, and their co-investigators Dr. Paul Nathan, Ms. Sue Zupanec, Ms. Jocelyne Volpe and Mr. Scott Walker, will be studying a liquid form of aprepitant designed for use in pediatric cancer patients to determine how well it is absorbed from the stomach into the bloodstream compared to the original capsule. This study will either give the current "recipe" a stamp of approval or help define what needs to be done to ensure that its performance is comparable to what we see in children who are able to take a capsule format.

POGO is recognized as a world leader with regards to the topic of chemotherapy-induced nausea and vomiting in children. In addition to supporting research studies like Priya's and creating new evidence around the topic, POGO leads in the development of clinical practice guidelines\* to help physicians make informed decisions to optimize control of chemotherapy-induced nausea and vomiting for their pediatric patients. Until recently there were no clinical practice guidelines that focused on children for this purpose.

It's all about creating new evidence-based information so it can be incorporated into the current practice guidelines and then implementing those guidelines so that children don't experience nausea and vomiting due to chemotherapy. We are trying to get better at that.

\* Endorsed by the Children's Oncology Group, the world's largest organization devoted exclusively to childhood and adolescent cancer research.

## RESEARCH

# STATS + FACTS

Established in 1998, the POGO Research Unit (PRU) focuses on investigations of the trajectories of human lives, including health economics, patterns and outcomes of cancer in childhood, and the impact of cancer and its treatment on child development and on the well-being of families.

In addition to Priya Patel's research on chemo-induced nausea and vomiting, our donors also helped fund other research studies in the 2016 fiscal year:

- Dr. Samaan Constantine: A Study of the Determinants of Metabolic Health and Outcomes in Survivors of Childhood Brain Tumours
- Dr. Lillian Sung: A Feasibility Study Examining the Impact of Out-patient Yoga on Distress and Well-being in Children Receiving Chemotherapy
- Tanya Hesser (PhD candidate, supervised by Dr. L. Sung): Anxiety: Severity, Risk Factors and Change Over Time in Children with Cancer or Undergoing Hematopoietic Stem Cell Transplantation

Unmatched by any other in the world, POGO's childhood cancer database, POGONIS, contains more than 30 years of standardized and comprehensive information on diagnosis, treatment, complications and long-term outcomes of all children diagnosed with cancer in Ontario.

In fiscal 2016, data from POGONIS supported 38 investigators/individuals from these disciplines: hematology, oncology, epidemiology, not-for-profit and government organizations, health economics and nephrology. In fiscal 2016, POGONIS data was presented in a variety of international publications and presentations.



# THANK YOU

A special thank you to all of our friends and donors for your support.

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### Donations: \$500 - \$999

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### Top Fundraisers:

Mariangela Cortese / Brayden & Alyssa Cruz / Avram Denburg / Emma Heck / Renee London / Gwen Rodney / Jodi Rosner / Madison Skobel

\*Indicates multi-year pledge

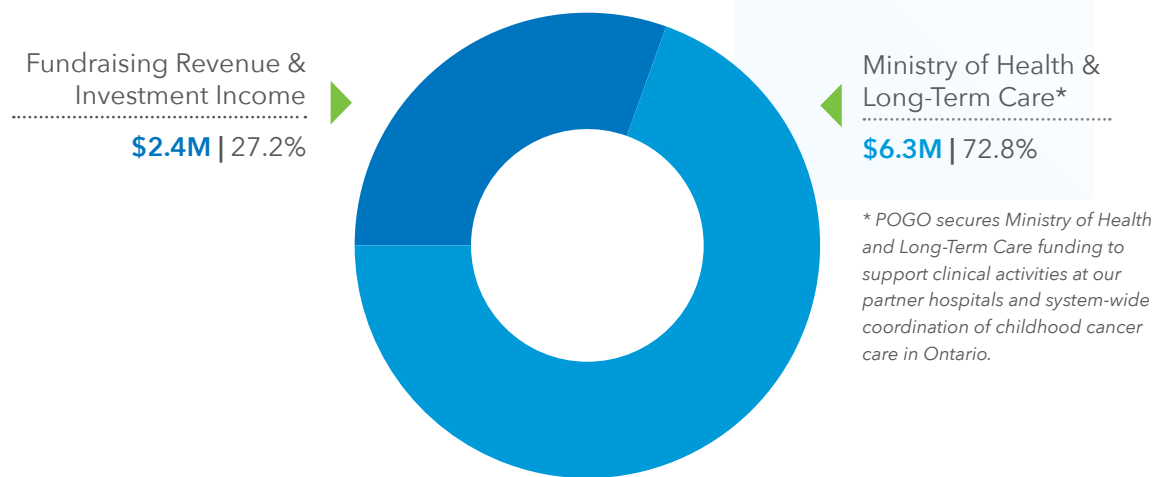
**Donors recognized above made contributions or pledges of \$500 or greater to POGO between April 1, 2015 and March 31, 2016. The Pediatric Oncology Group of Ontario publishes this roster in order to recognize the generosity of the individuals, corporations, foundations and third-party events that support our organization. In the event of an error or omission, please contact the POGO fundraising department at (416) 592.1232 or 1 (855) 367.7646. POGO also wishes to gratefully acknowledge the ongoing support of our many in-kind contributors.**

2015 - 2016

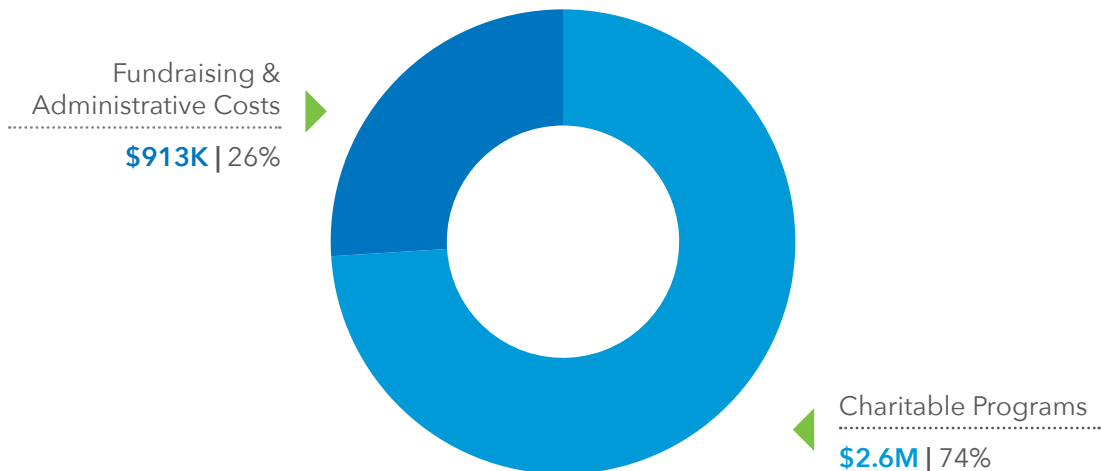
# FINANCIAL HIGHLIGHTS

Gross fundraising program revenue	\$2.4M
Total charitable activity	\$2.6M
Fundraising and administrative expenses	\$913K

## SOURCES OF REVENUE | \$8,700,000



## FUNDRAISING EXPENDITURES | \$3,513,000





## YOUR INVESTMENT AT WORK \$2,567,000

POGO's Financial Assistance Program **\$938K** | 37%

Survivor Care Programs **\$416K** | 16%

Education **\$204K** | 8%

Research **\$533K** | 21%

Other **476K** | 19%

Fiscal 2016 financial statements were audited by Schwarz Levitsky Feldman LLP. To receive a copy of POGO's financial statements and accompanying notes, please contact Ian Kennedy at 416.592.1232 x 240 or by email at [ikennedy@pogo.ca](mailto:ikennedy@pogo.ca). POGO also publishes its financial statements online at [www.pogo.ca](http://www.pogo.ca)

# GROWTH IN OUR COMMUNITY

POGO relies on the support of our friends in the community to help raise awareness and funds in support of kids with cancer. POGO has seen continued growth in both the number and size of community events. These events have taken place across Ontario and have included a diverse range of activities such as birthday parties, theatre productions, sporting events, and more. Your creativity can turn a fun event into a meaningful and cost-effective way to support childhood cancer care in Ontario.

FISCAL	# 3RD PARTY EVENTS
2010	25
2012	30
2014	29
2016	36



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**Pediatric Oncology Group of Ontario**

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**POGO**

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

**FOR KIDS WITH CANCER  
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