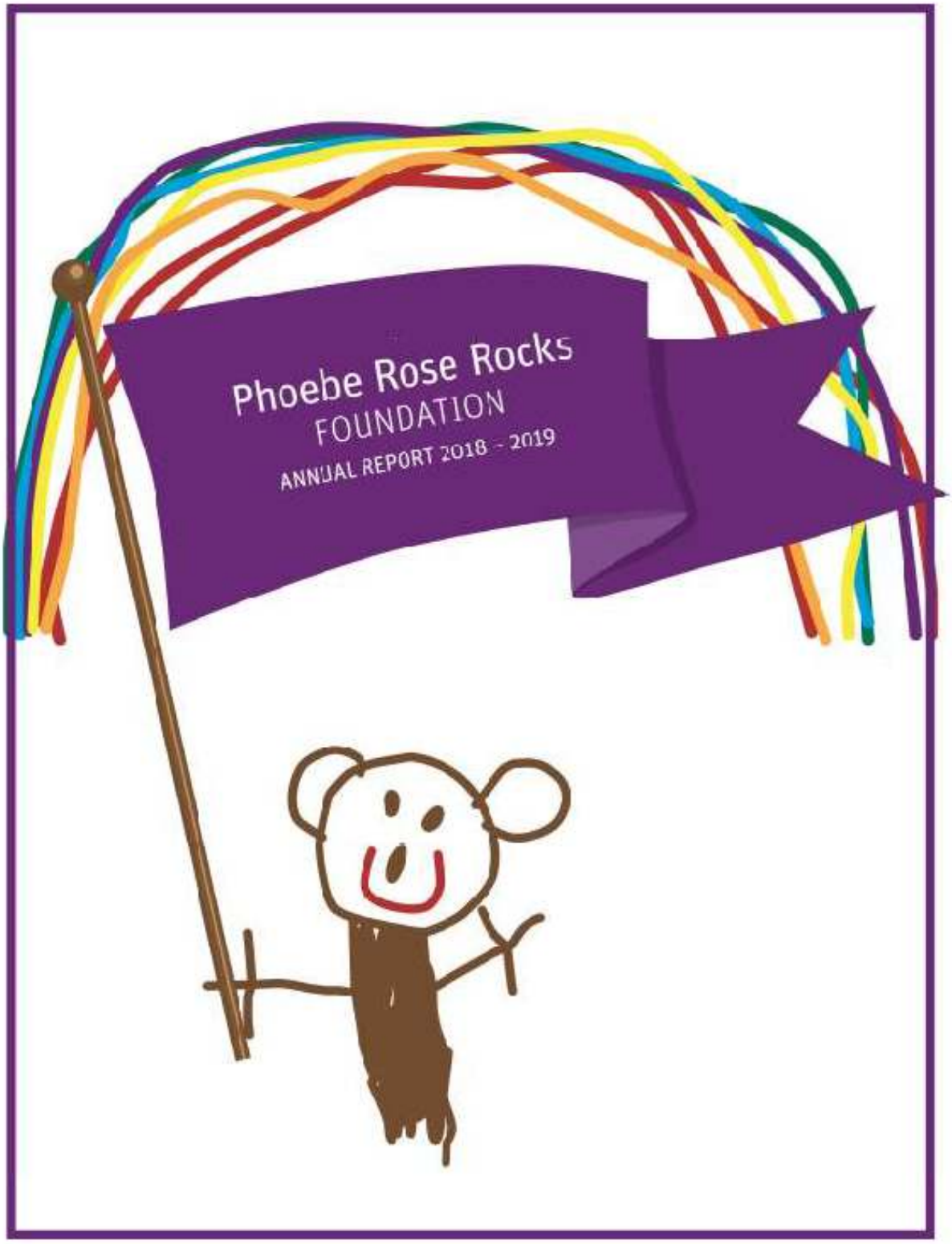

Phoebe Rose Rocks
FOUNDATION
ANNUAL REPORT 2018 - 2019

PHOEBE ROSE ROCKS FOUNDATION
2018-2019

WWW.PHOEBEROSEROCKS.COM

CARE PACKAGES

Phoebe loved getting mail. This year the foundation sent 13 care packages to children in treatment in cities across Canada and the United States. Packages full of support items & smiles.

$148,000 RESEARCH

This year the PRR foundation gave $148,000 to childhood cancer research in Canada. We funded innovative projects focused on hard to treat and cure cancers and new technologies like genomic sequencing.

FUNDRAISERS

We danced, baked, ran (GesineRuns ran 205 km non-stop!), cheered, laughed, smiled for the camera at Photos for Phoebe, golfed, and worked really hard to #makeitok for kids like Phoebe.

FUNDS RAISED

In our second year we raised $166,950.48!!

Phoebe Rose Rocks

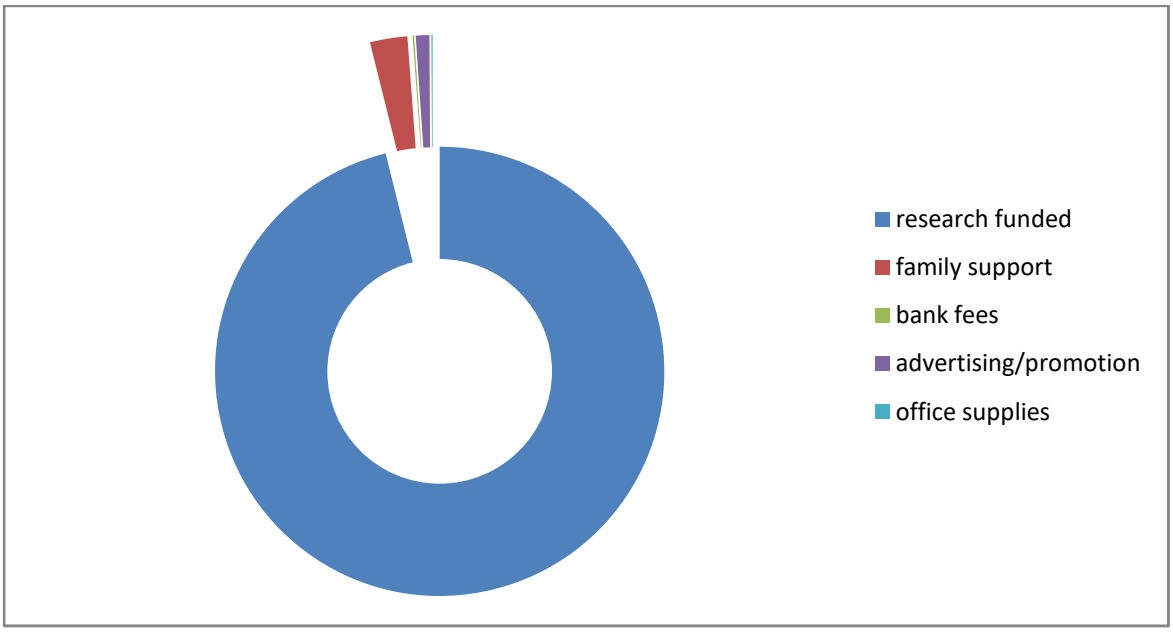
OUR MISSION– TO MAKE IT OKAY

For everyone at the Phoebe Rose Rocks Foundation, “making it okay” is more than just a hashtag, it is our purpose and commitment to our Phoebe. Making it okay means funding research that is innovative, ambitious, and cure focused. Making it okay means working to drive research towards rare, hard to treat, and low prognosis childhood cancers. Making it okay means finding the perfect toy or treasure to send in a care package to bring a spark of joy to a child in treatment far from home. Making it okay means helping to pay for gas, groceries or a much-needed coffee break to the caregivers of those children. At Phoebe Rose Rocks, making it okay is what drives us. Every new child diagnosed with cancer becomes our mission.

OUR IMPACT

In 2018-2019, the Phoebe Rose Rocks Foundation marked our second year as an official Canadian charity. As a foundation, we continued our commitment to keep our administrative costs low to maximize impacts for all of our donors.

This year we raised $166,950.48. We donated 88% of these funds to research and 2.5% to support families travelling to access treatment for children with cancer. Our administrative costs remained at 1% of total funds raised. Note, the remaining 8.5% of funds (to total 100% of funds raised) are carried forward for future commitments.



OUR VOLUNTEERS

The engine of the Phoebe Rose Rocks Foundation is our volunteers. If you attended a Phoebe Rose Rocks Foundation event this year you would have met one of our great volunteers. We could not do what we do without them. Our volunteers tell Phoebe's story proudly and with heart, and for that we are grateful. Our volunteers welcomed all the many amazing donors at our 3rd Annual Golf Tournament, were ambassadors for the foundation at events across the city and cheered their hearts out at Ottawa's famous race weekend. Their time, skills, and efforts are why we are able to keep our costs low and our impact high. Here they are in action:

RESEARCH WE FUNDED

Advances in research gave Phoebe time and we know many children in the Phoebe Rose Rocks community who are racing against time today. The pace of research will never be fast enough for many of our friends which makes the research we have funded this year so vitally important. This year we are proud to continue our commitments to research projects we began funding last year. By committing to multiple years of funding we recognize that discoveries take time and consistent funding helps to sustain progress. This year we are also proud to fund our first graduate student researcher. This investment in researchers early in their careers creates an important pipeline to encourage continued research into cures for childhood cancers.

100% Fund 2018 Recipient

Dr. Sumit Gupta Infant Leukemia Research, Sick Kids Hospital, Toronto

$60,000

The Phoebe Rose Rocks Foundation is a founding partner of the 100% fund. The 100% fund is a partnership between the C17 Council, the council of all 17 pediatric oncology programs across Canada, and other family run foundations: Team Finn Foundation, Melia's Memory, The Fight Like Mason Foundation, and Team Naomi. The 100% fund is a competitive peer reviewed research program. The first recipient of the Infant Leukemia portion of the100% fund is Dr. Sumit Gupta from Sick Kids Hospital in Toronto.

Children diagnosed with acute lymphoblastic leukemia (ALL), the most common form of childhood cancer, have a 90% chance of survival. However, the likelihood of survival for infants can be as low as 10%. Infant ALL is the only type of ALL for which there has been no significant improvement in survival over nearly two decades.

Dr. Gupta recently encountered two infants with ALL originally found not to have MLL-r during standard diagnostic testing, but were later found to have MLL-r using advanced DNA sequencing techniques. Based on these two cases, Dr. Gupta suspected that there are other cases for infant leukemia with undetected MLL abnormalities. Dr. Gupta's research focuses on using advanced sequencing techniques to test samples from infant ALL cases that are considered to have normal MLL after standard diagnostic testing. If new forms of MLL abnormalities are detected, hospitals will potentially have to change the way they detect such abnormalities so that patients receive appropriate therapy and best outcomes.

One of the strongest predictors of low survival for infant ALL is a rearrangement of the MLL gene (called MLL-r; when part of the MLL gene is fused onto a different gene). If an MLL

rearrangement is detected in an infant with ALL, their projected survival rate drops to under 40%. If the infant has MLL-r plus additional clinical characteristics that point to poor prognosis, survival rates drop to below 20%.

Correctly identifying infants with ALL with the MLL-r is extremely important because failing to detect MLL-r may result in under-treating a patient. Clinical trials have shown that infants with MLL-r will have a better chance of survival if they receive more intense therapy. Also, new drugs have been developed that target the different biology of cancer cells with an MLL-r.

Dr. Gupta has just completed the required steps to receive ethical approval to begin this important research at Sick Kids Hospital in Toronto. The infant ALL samples to be tested were collected from patients as part of a larger Children's Oncology Group clinical trial. Dr. Gupta is in the process of completing the steps required to access to these patient samples and clinical information. Once the infant ALL samples arrive at Sick Kids, the process of physically extracting the genetic material from the samples and performing advanced sequencing techniques is expected to take about 9 months.

We will continue to report on the progress of Dr. Gupta's research in our next annual report.

Year 2 Pediatric Cancer Genomics Program - Children's Hospital of Eastern Ontario (CHEO)
Total Funding: $43,000/year for three years

Last year we funded the first year of research in support of the pediatric oncogenomic research and the PROFYLE program at CHEO. In 2018-2019 we funded the second year of this project. We committed to three years of funding to support the research team to make sustained progress. Oncogenomics for pediatric cancer was recently profiled in the journal Science as the key breakthrough for pediatric cancers. We are proud to support this cutting-edge technology that focuses on finding better and less harmful treatments for kids with cancer.

> "*With your support a Pediatric Cancer Genomics Research Clinic has been established at CHEO, with the goal of making genomics part of the standard of care for all patients with cancer.This research program allows Dr. Ramphal, Dr. Sawyer, Dr. Holcik and their teams to continue giving hope to more families whose children have a difficult to diagnose, refractory or metastatic cancer that is not being investigated through mainstream research.*" CHEO Foundation

For children with difficult to diagnose, refractory, or metastatic cancer there are no evidence-based therapies, and families struggle with an unknown or poor prognosis. This research program uses cutting-edge sequencing technologies to look for the genetic changes responsible for cancer development and progression in the patient's blood and tumour. This information may provide a diagnosis, and/or suggest new therapies that can give hope to families. In addition, this program allows the researchers to culture cells from tumours, removed during surgery or biopsy, to find existing therapies that will work for these patients. This is done by studying the response of cells in vitro to known chemotherapeutic drugs and experimental treatment options.

Genomic interrogation of pediatric tumours is not currently available at CHEO on a clinical basis, and only a few hospitals in Canada have started to set up similar research programs. Thanks to the support of the Phoebe Rose Rocks Foundation, CHEO is able to continue this very important initiative directly benefitting several families who otherwise would not have answers to their questions or tailored treatment protocols.

Understanding the genetic changes and biology of a tumour has the potential to provide personalized and targeted treatment for children, which may result not only in improved therapies, but also in lower morbidity rates resulting from treatments that don't work. This approach also provides information about other cancers that we might need to screen a patient for, and gives families answers about possible cancer risks to siblings.

The cancers this research team are studying are rare, so data sharing and collaboration are essential to making progress. CHEO has partnered with the Terry Fox PROFYLE Program to maximize the impact of this work and share data and discoveries across Canada.

> *"Oncogenomics is a rapidly growing field with new technologies being developed every year. This field is already changing the way medicine is practiced and will do so for decades to come. Treatment is tailored to individual patients rather than treating all patients with the same diagnosis in a generic manner. As technology evolves, medical breakthroughs follow. By investing in this research, you are investing in the future*." - Dr. Ramphal, CHEO

MLL+ Leukemia Research Project: Engineering a genetic zebrafish model of the human MLL-AF9 fusion protein frequently found in infant and childhood leukemias

$20,000

Graduate student researchers are the engine of research. This year, the foundation funded Keon Collett, a graduate research student working at Dr. Jason Berman's Zebrafish laboratory. It is vitally important to invest in early stage researchers to support sustained research into childhood cancer.

Keon is studying infant leukemia, an aggressive form of blood cancer that occurs in children under the age of one. Working with Dr. Jason Berman, a Pediatric Oncologist at the IWK Health Centre and Professor at Dalhousie Medical School, Keon is using zebrafish to model and study the progression of infant leukemia, and to test different compounds to treat it.

The goal of this research is to establish a zebrafish model of infant leukemia that will be an efficient and effective platform for screening new potential therapies. This work is in collaboration with Dr. Todd Druley and his team at Washington University School of Medicine. Dr. Druley's laboratory sequenced samples from 115 infant leukemia patients and identified mutations to another MLL gene, MLL3. We hypothesize mutations to MLL3 may play a role in the rapid onset of the disease and predispose infants to developing leukemia. We have created

a zebrafish line with mutations to the MLL3 gene to test this hypothesis and investigate the role of MLL3 in blood development.

> *"The five-year survival rate for infant leukemia is less than 50 per cent, even with chemotherapy. Our ultimate goal is to find a novel treatment to change that*."
>
> Keon Collett, Dalhousie University

Dr. Annie Huang, Rare Brain Tumor Consortium, Sick Kids Hospital, Toronto

$25,000

The funds provided by the Phoebe Rose Rocks Foundation have helped improve the infrastructure and the development of the Rare Brain Tumour Consortium (RBTC). The RBTC is now one of the largest international bio-repositories for rare paediatric brain tumours. Over the years, the RBTC has grown substantially and now has a bio-repository of more than 2000 brain tumor samples from approximately 70 affiliated international centers. The support from the Phoebe Rose Rocks Foundation was used to aid in the collection, shipping and storage of samples in addition to the development of a web-based registry for improved logging, record-keeping and data collection. Collectively, this has helped the RBTC in recruiting more patients and collaborators to further our mission.

The main goal of the RBTC is to collect and store blood, tissue and cerebrospinal fluid from pediatric patients with rare brain tumours. Due to the scarcity of these tumours, maintenance of the RBTC is essential to provide researchers with the means to study these tumours. Access to these precious samples aids researchers in understanding more on how these tumours develop and facilitates the identification of novel therapies. This resource has served multiple large-scale genomic studies internationally. Through the RBTC, landmark publications enabled deeper scientific programs worldwide that are informing changes in therapeutic approaches for different types of rare brain tumours.

WE SEND SUPPORT – CARE PACKAGES

This year we sent 13 care packages to children travelling for treatment across Canada and to the United States. Care packages are catered to each child and include comfort items and financial support for parents.

WHAT'S NEXT

In 2019, we will continue to support innovative research of rare and hard to treat childhood cancers, and to monitor the progress made to find more effective and less harmful treatments for all children with cancer. We will work to drive research towards rare and hard to treat childhood cancers.

We will work to increase our fundraising, so that we are able to fund even more innovative research and provide support to more families. To do this we will continue to work to improve our networks across Canada to ensure that families know about our care package program and know how to access support when they need it. We will also host more events and increase our network of amazing people to continue to raise awareness about childhood cancer.

We will continue to be volunteer-driven and to work with integrity, accountability, transparency and collaboration to reach our goals.

Above all, we will work to continue Phoebe's legacy of hope and to make it okay for kids with cancer.

Join us!

www.phoeberoserocks.com