RIDING FOR RECOVERY

Sickids

E

GREAT CYCLE CHALLENGE 2022 PROGRESS REPORT



TARGETING TEENS

A virtual safe space and learning hub for cancer patients.

IT'S HARD ENOUGH to be a healthy teen, let alone a teen with cancer. Imagine trying to meet the developmental milestones of adolescence – independence, adopting peer lifestyles, accepting one's body and establishing personal and future career identities – all while also undergoing the mental and physical hardship of intensive cancer treatment.

The Canadian cancer care system isn't designed to address teens' unique psychosocial needs. Teens are caught between paediatric centres, where the average age of a cancer patient is four, and adult centres, where the average age of a cancer patient is 60. These common challenges define the teen cancer experience and can leave them feeling isolated from family, friends and even the medical system. Without intervention, this isolation can progress to serious mental health issues, impacting treatment, long-term follow-up and readjustment to life after cancer.

Virtual communities have been successfully established and leveraged to enhance psychosocial and physical health in young adult cancer patients. However, no such program has been developed for teens with cancer—a group poised to benefit greatly from this support model. The COVID-19 climate only amplifies the need for creative ways to bring young people together to navigate their cancer journeys. That's why SickKids, with the support of Great Cycle Challenge (GCC), developed Teens4Teens—an innovative, virtual pilot program to

WITHOUT INTERVENTION, THIS ISOLATION CAN PROGRESS TO SERIOUS MENTAL HEALTH ISSUES, IMPACTING TREATMENT, LONG-TERM FOLLOW-UP AND READJUSTMENT TO LIFE AFTER CANCER.



connect teens with cancer. The program includes a weekly, 30-minute drop-in Zoom session led by a health care professional to help address common unmet informational, practical, and psychosocial needs identified by teens, and a private, confidential, monitored group chat that explores patients' fears, thoughts and concerns.

SickKids developed and disseminated a survey to teen cancer patients and survivors to inform the creation of this virtual intervention. Feedback confirmed most patients were interested in information about how to talk with friends about their illness, navigate schoolwork, manage emotions, and engage in physical activity. Education on the transition to the adult health care system was also of interest and could be readily facilitated given our close relationship with the Adolescents and Young Adults (AYA) program at Princess Margaret Hospital.

Thank you to GCC participants and donors for partnering with us to bring Teens4Teens to cancer patients. Together, we are helping to strengthen connections between teens with cancer, combat isolation, and support to manage the disease. Your generosity is helping to bridge a gap in cancer care in Canada with an inspiring step forward in psychosocial support for teens. Addison, angiosarcoma patient

IN TRIBUTE RIding for Addison

Addison, known as "Addy", was diagnosed with an aggressive form of cancer called angiosarcoma in October of 2021. She was 13. Her strong spirit and bravery endured as she underwent surgery, treatment and suffered severe side effects from the medications. Through it all, Addy continued to fundraise to help kids with cancer.

Sadly, Addy died in July of 2022. She will be deeply missed and her memory will be an inspiration to many. We ride for kids like Addy, who remind us of the resilence and possibility that comes from a united fight against childhood illness.

A NEW TYPE OF TRIAL

Real-time research for better treatment options.

SICKKIDS IS COMMITED to our uncompromising pursuit of paediatric cancer research and care: advance our understanding of why and how cancers develop and find personalized treatments to fight them. Thanks to the generous support of GCC donors and participants, we can move forward towards this aim. Your funds have allowed us to soon participate in a unique, multicentre, international clinical trial called FaR-RMS. The FaR-RMS trial will study several aspects of treatment for rhabdomyosarcoma (RMS)—the most common soft tissue tumour in children —both for newly diagnosed patients and those at the time of relapse.

The FaR-RMS trial is designed as a rolling program of research with new treatment arms introduced in concert with emerging data and innovation. The trial will attempt to answer big questions, like: Does the addition of new

drugs to standard chemotherapy for patients newly diagnosed improve survival? Does giving maintenance chemotherapy for longer improve survival? Can we use molecular data and models from FaR-RMS patients'

RHABDOMYOSARCOMA IS THE MOST COMMON Soft Tissue Tumour In Children.

tumours to derive, screen, and test potential new treatments for high-risk RMS patients? And, does the timing of radiotherapy improve outcome and quality of life?

SickKids is profoundly grateful to GCC donors and participants for the chance to participate in such an exciting trial, and we look forward on sharing an update soon.

DIGITAL DIAGNOSES

A new approach to pathology at SickKids.

ONCOLOGISTS OFTEN share the news of a cancer diagnosis, but it's the pathologists who makes the diagnosis. Pathology, the study of disease, is the bridge between symptoms and clinical care and underpins the patient experience—from cutting-edge diagnostic testing to treatment plans. "We have to get it right from the start. A cancer patient's journey to recovery depends on the diagnosis," says Dr. Gino Somers, Paediatric Pathologist and Head of the Division of Pathology at SickKids.

SickKids has the most extensive and specialized paediatric pathology department in the country. From the over 1,700 cases of childhood and adolescent cancer diagnosed in Canada every year,



the department receives hundreds of secondopinion consultations from health providers across the country. "Glass slides are couriered from all over Canada. But sometimes they arrive broken. And even if they don't, it takes too long to receive them. We need a better process to provide the care we're capable of on a national scale," Dr. Somers explains. They needed to adopt new practices and engage digital pathology—a rapidly evolving niche whereby pathologists digitally analyze, store, and share information. And so, in partnership with seven other Canadian paediatric health care institutions, the Canadian Pediatric Digital Pathology Network at SickKids was born.

High-resolution slides are now digitized using a scanner. Pathologists can analyze results in real-time using novel techniques available and accessible at SickKids. Slides are also being stored in a digital archive to help residents and fellows develop better expertise in research and diagnoses. Newer developments are promising increased efficiency, error reduction, diagnostic assistance, automated quality assurance, optimized molecular testing, and even replacement for various current special testing.

GCC participants and donors have been paramount in the growth and evolution of programs like this, which improve the journey from diagnosis to treatment with the hope of better outcomes for kids with cancer and a model of care to share with other institutions.

"GLASS SLIDES ARE COURIERED FROM ALL OVER CANADA. BUT SOMETIMES THEY ARRIVE BROKEN. AND EVEN IF THEY DON'T, IT TAKES TOO LONG TO RECEIVE THEM. WE NEED A BETTER PROCESS TO PROVIDE THE CARE WE'RE CAPABLE OF ON A NATIONAL SCALE."

MEET ELLIANA

A long road to recovery.

P

IN JANUARY 2021, Elliana (Ellie) was fighting an intermittent fever. In the wee hours of one terrifying morning, things took a turn: Ellie's legs were in excruciating pain. She was on the floor screaming, "My legs are breaking!" Her parents rushed her to SickKids, where they began to run diagnostic tests, including X-rays. A few hours later, the family received the shocking news: Ellie had leukemia.

She began chemotherapy immediately. The road has been long and fraught with challenges, but Ellie is now in remission and on her fourth cycle of long-term maintenance therapy. "She takes medicine like a champ now – it used to take more than 20 minutes to give her one medicine, but now she'll administer the syringes to herself and does so fast too," says her mom, Amy.

Finally, Ellie is easing back into her favourite activities like swimming and summer camp. She's also mastered the alphabet! Ellie still struggles with some mental health challenges as a result of the treatment, which was grueling.

Ellie's parents created a team in 2021 called "Elliana VS Leukemia," who completed the Great Cycle Challenge in 2021. "We're thankful for donors and their commitment and willingness to fund paediatric cancer research and care. We hoping that one day treatment can be less invasive and much shorter in duration for kids just like Ellie. Gifts to cancer research help to move this along," Amy shares, with gratitude.

"SHE TAKES MEDICINE LIKE A CHAMP NOW — IT USED TO TAKE MORE THAN 20 MINUTES TO GIVE HER ONE MEDICINE BUT NOW SHE ADMINISTERS THE SYRINGES TO HERSELF AND DOES SO REALLY FAST, TOO." - AMY. ELLIANA'S MOM

Elliana, SickKids leukemia patient

DOWNLOAD NOW

A cancer app to support patients and caregivers when they need it most.

CAREGIVERS ACROSS Canadian paediatric health care institutions need better ways to receive and collect information on their child's care. That's why The Children's Oncology Group (COG) created the KidsCare App-developed by nurses, physicians, families, and psychosocial team members. Now, Canadian parents and caregivers can download the app, and with a few clicks, they're able to access critical content. For example, a diagnosis guide and family handbook offers streamlined. searchable content about diagnoses, treatment, aftercare and a glossary of terms and illustrations. The appointment Calendar stores and tracks the activity of a child's care (it syncs with your smartphone), and a virtual emergency room card gives health care team members quick access to critical information. Users can also access the journal to keep notes on their child's vital signs, labs, treatment, and mental heath changes.

To further customize the app, COG recruited SickKids to pilot institution-specific content so caregivers in 16 health care institutions across Canada can access the most relevant information from their centre. Details include essential details like phone numbers for urgent calls during and after hours and links to educational resources and the hospital's patient portal. The customization, soon to be translated into French and Spanish, would not have been possible without the generosity of GCC participants and donors.



BY THE NUMBERS:

SICKKIDS REGISTERS APPROXIMATELY 275 NEW CANCER CASES IN KIDS UNDER 18, ABOUT 20% OF NEW PAEDIATRIC CANCER CASES IN CANADA

TO DATE, OVER 2,500 PATIENTS HAVE BEEN SEEN BY OUR CANCER GENETICS PROGRAM

NEXT GENERATION SEQUENCING (NGS), ALLOWS TESTING OF **1000s** OF GENES AT THE SAME TIME FOR BETTER, FASTER TREATMENT DISCOVERIES

SICKKIDS PERFORMS ABOUT 100 Bone Marrow transplants every year, and has the only cellular therapy facility in canada

LEUKEMIA IS THE MOST COMMONLY OCCURING CANCER IN KIDS, FOLLOWED BY BRAIN AND NERVOUS SYSTEM CANCERS AND LYMPHOMAS

THANK YOU.

Every day, SickKids is working towards improving the lives of children, and our success depends on the generosity of donors like you. Your commitment to the cancer research and care at SickKids though Great Cycle Challenge ensures that we can continue to offer the best possible health outcomes for children a so they can live longer and healthier lives. Thank you for your remarkable generosity.



fundthefight.ca