



Shine

Spring 2023

Big answers start small

How experts
are unleashing
mighty advances
by tailoring cancer
treatments to
each kid

**ALSO IN
THIS ISSUE**

Brightening
the hospital
experience for
kids of all ages

A small glimpse
of the equipment
that's changing
lives

Revolutionizing
allergy care
with at-home
treatments


**BC
Children's
Hospital**
Foundation

02 The promise of precision medicine

06 Changing lives, one milligram at a time

08 Innovations

09 The healing power of art

10 Healing with compassion, in memory of Zach

12 Help when it's needed most

13 Micro moment

BOARD OF DIRECTORS

Darrell Jones, *Chair*
 Julia Kim, *Vice-Chair*
 Mike Brankston,
Secretary-Treasurer

Sophia Alibhai
 Dale Boniface
 Vanessa Flockton
 Raymond Li
 Don Lindsay, O.B.C.
 Catherine McLeod-Seltzer
 Dr. Steven Miller
 Ratana Stephens, O.B.C.
 Martin Thibodeau
 Will Westeringh, KC

EMERITUS PAST CHAIR

Lisa Hudson

FOUNDATION EXECUTIVE

Malcolm Berry
President & CEO

Raquel de Munain
*Vice-President,
 People & Culture*

Surina Sproul
*Vice-President,
 Marketing & Communications*

Rita Thodos
*Executive Vice-President,
 Philanthropy*

Joanne Waxman
*Vice-President, Strategic
 Partnerships*

For more information about the editorial content of SHINE or to make a donation to BC Children's Hospital Foundation, please contact 604.449.6333, toll-free at 1.833.315.2133 or info@bcchf.ca.

Charitable Business Number: 11885 2433 RR0001

BC Children's Hospital Foundation
 938 West 28th Avenue,
 Vancouver, BC V5Z 4H4

Return undeliverable Canadian addresses to address above.

SHINE is published semi-annually by BC Children's Hospital Foundation.

Managing Editor: Brittany Beaupré

Writers: Paul Park, Ali Omelaniec
 Kelsey Davis, Lauren Erdelyi

Graphic Design: Jennifer Pratt

@BCCHF



Turning small ideas into mighty leaps



Whenever I reflect on the distance we've come in the fight against childhood illnesses, I never fail to be filled with awe.

Take childhood cancer. Today, more kids with aggressive forms of the disease are getting a fighting chance through the promise of personalized medicine—like Rylie, whose extraordinary story you'll read about. For cancers that have seen remarkable progress in survival rates, the goal posts are moving. Beyond healing patients, clinicians are doing everything it takes to help them thrive for decades to come.

Across our campus, researchers are racing to unlock the mysteries of

many other complex conditions. Your support is bringing these discoveries to children at an astonishing pace—including a promising treatment that could transform food allergy care, which we also covered in this issue.

Many of these strides were unthinkable decades ago. Yet, they defied all odds and became giant leaps forward in child health, in large part because of donors like you. You give visionary minds the means to dare to try—to ultimately take that first step forward in turning a small, sometimes audacious, idea into something mighty.

As we look ahead, we will continue to boldly press on in tackling the biggest

health challenges facing kids. Because tomorrow's artists, inventors, and change-makers are today's children. And when put in this context, we can't move fast enough.

I hope you find these stories as inspiring as I do.

With gratitude,

Malcolm Berry
President & CEO
 BC Children's Hospital Foundation

Getting personal



The promise of precision medicine

When Toni saw five medical experts walk into the room to present test results for her young daughter Rylie, she had a sinking feeling that the news would change her family's lives forever. She was right—Rylie had cancer.

It had started with a mysterious limp when Rylie was just short of 3 years old in the summer of 2021. Normally an energetic and active child, she was struggling to put any weight on her leg, so her family took

her to a hospital near their home in the Okanagan.

After numerous tests, the medical team gave Toni the devastating news that Rylie's limp was caused by cancer spreading through her legs.

"We were in disbelief. In that moment, our whole world stopped," Toni said.

Rylie was immediately transported to BC Children's Hospital, where she was diagnosed with stage four

metastatic neuroblastoma—a rare, high-risk form of cancer.

THE POWER OF PRECISION

The family met with Dr. Rod Rassekh: oncologist and investigator, Michael Cuccione Childhood Cancer Research Program at BC Children's Hospital. As Dr. Rassekh and his team explained the hospital's progress in tackling rare and aggressive forms of cancer, they gave Toni a ray of hope.

"The biology behind each child's tumour is different. That's the mystery that research helps to solve."

— Dr. Rod Rassekh



Rylie, age 3

“Over the past decade, remarkable gains have been made in many areas of pediatric cancer care,” Dr. Rassekh said. “Some kids are surviving cancers once thought to be incurable.”

This is in large part because of the strides made in bringing safer, more personalized treatments to kids—an area called precision medicine. Through genetic sequencing, medical experts are creating treatment plans based on a child’s unique genes, as well as the genetic profile of the cancer. In other words: scouring for the nuances in each child’s cancer to pinpoint the Achilles heel that could result in a cure.

“The biology behind each child’s tumour is different,” Dr. Rassekh explained. “That’s the mystery that research helps to solve. It answers the question: how do we best treat Rylie’s tumour?”

But that isn’t all.

For kids like Rylie, some treatments can be accompanied by a significant chance of devastating side effects, including heart damage and hearing loss—worries that keep Toni up at night. Research is key in determining whether a child’s unique genetic makeup may result in complications, allowing them to develop a treatment plan that ensures a healthy life for decades to come.

The promise of this work has never been greater. “We’ve built such incredible momentum,” Dr. Rassekh said. “The incremental speed of research is getting faster and faster—and we’re bringing advances to the clinic more rapidly than we’ve ever been able to.”

TAKING A TARGETED APPROACH

Guided by the principles of precision medicine, Dr. Rassekh and his team took knowledge gained from treatments applied to children in the



Rylie, age 3

past with rare cancers and combined it with an in-depth analysis of Rylie’s neuroblastoma to craft a personalized treatment plan. This gave Rylie the best possible chance to overcome the cancer, while minimizing the risk of side effects.

Rylie required 18 months of intense care at BC Children’s. In the first of many gut-wrenching decisions, Toni decided to stay in the hospital with Rylie while her husband remained in the Okanagan with Rylie’s older brother, Cameron.

The treatment plan was daunting: high-dose radiation therapy and two stem cell transplants, with high dose chemotherapy and immunotherapy.

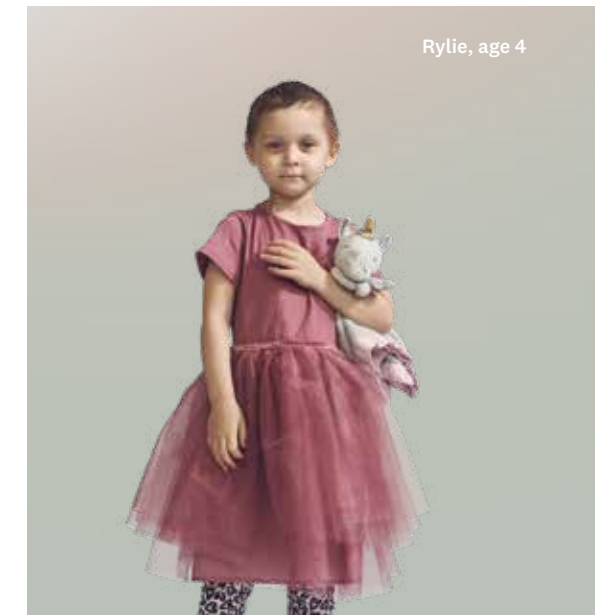
“You feel like you’re torturing your kid when you’re doing the best for her, but she doesn’t understand everything,” Toni said. “As a parent, that was one of the most difficult things.”

During the 18 months of treatment, Rylie’s journey took many turns. The medicines inflicted a toll on her body, causing damage to many of her organs including her kidneys, liver and lungs. The treatment also affected her growth—Rylie is about the size of a large 2-year-old, even though she’ll be turning 5 this summer.

Small as she is, Rylie refuses to let anything get in her way. She has a big, sassy personality, loves to sing and easily makes friends. Despite all she’s been through—or maybe because of it—Rylie is very loving and supportive of others. “She’s mighty in every sense of the word,” Toni said proudly.

“She’s mighty in every sense of the word.”

— Toni, Rylie’s mother



Rylie, age 4

ON THE ROAD TO RECOVERY

Rylie completed her last cancer treatment in December 2022, and a recent scan provided incredible news—no traces of cancer in her body. The first thing Rylie wanted to do when she heard this was relax in a hot tub, one of her favourite things and something she couldn’t do during her treatment.

Rylie’s journey at BC Children’s will continue for years to come. As high risk neuroblastoma carries a 50 per cent chance of relapse, Rylie will travel to Vancouver for periodic testing.

Despite everything life has thrown at them over the past two years, Rylie and her family have kept moving forward, taking small steps along the path to recovery. With her indomitable strength of spirit and the loving support of her family, Rylie has proven she can tackle any mighty challenges that stand in her way.

“We’re really lucky that Rylie’s as tough as she is,” Dr. Rassekh said. “She’s so young, but has so much fight in her, to get through what she did.”★



Rylie, age 4



Imagine being overcome by worry every time your child walks out the door to go to school. Or growing up shrouded in fear that the very thing that sustains you could also threaten your life. That's the reality for some 58,000 kids and youth in British Columbia and their families.

The culprit: serious food allergies.

Even a trace of an allergen like peanut or cow's milk has the potential to push a child's immune system into overdrive, triggering itching, hives and, in worst-case scenarios, a potentially fatal reaction called anaphylaxis.

As it often goes, though, sometimes the smallest things can make the mightiest difference. One promising advance is sublingual immunotherapy (SLIT), a food allergy treatment that takes the form of a miniscule amount of food allergen applied in a drop of liquid under a child's tongue. Over time the dose is incrementally increased—essentially nudging their body to tolerate it.

In the summer of 2020, Canada's first-ever virtual food allergy immunotherapy research pilot program (FAIT) was launched by BC Children's Hospital's Allergy team. This was prompted by the sudden halt of in-person appointments due to COVID-19. Since the existing program was monitored by an allergist onsite for reactions, the shutdown of all clinical operations had a devastating impact on kids and families who had long relied on FAIT.

Determined to find a solution, Dr. Edmond Chan, Head of the Division of Allergy at the University of British Columbia and Clinical Investigator at BC Children's Hospital Research Institute, connected with global researchers who were studying SLIT—and was impressed by its effectiveness. Even better, it was safe enough for patients and their families to do from the comfort of their own home.

Through SLIT, kids and their families are virtually guided and monitored by

trained nurses as they take a small drop of the allergen and hold it under their tongue for a minute before swallowing. This approach has provided a sense of control over a condition that has dictated almost every part of their lives.

For many, consuming even a tiny drop of peanut solution is a giant step toward a changed life. It can open doors that had seemed forever shut—trips overseas, restaurant meals and above all, the chance to simply be a kid again.

That's exactly what Dr. Lianne Soller, FAIT Program Manager and Allergy Research Manager at BC Children's, hopes families will gain.

"Travel, going to the grocery store and high school trips can all cause a great sense of worry," she said. "FAIT is helping to increase a child's tolerance, giving families peace of mind."

Since its inception nearly three years ago, the virtual program has become available to families across BC. "We now have 190 SLIT patients who have worked their way up to maintenance doses," Dr. Soller said, "and we're enrolling at least 10 to 15 new patients per month."

ONLY THE START

The FAIT pilot program is aimed at delivering care during the window of time it matters most—something that's especially important as food allergy diagnoses increase.

"As children get older, allergy care becomes harder. There are more reactions and there's less adherence to treatment," Dr. Chan said.

As Dr. Chan points out, there is a golden age between 4 to 11 months old where you see the greatest safety and effectiveness in treatments—ensuring best possible outcomes for kids.

"We want to continually take a step back and address the full spectrum of a child's journey: from birth to their teenage years, advancing not only treatment but also primary prevention of food allergy to leave no stone unturned," Dr. Chan said. "That continuity in care is what transforms the lives of families."*

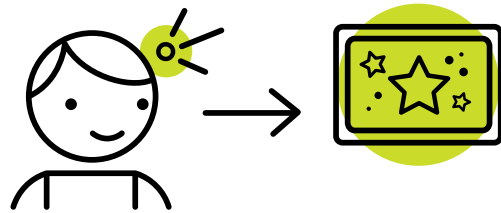
patient name:

Mighty equipment changes lives

When we think about progress in child health, scientific breakthroughs and novel treatments usually come to mind. And yet, there's something else that also has an immense impact on health outcomes: the right equipment. At a children's hospital, a diverse range of medical devices and surgical tools are vital for the care of patients of all sizes—from a newborn who just took their first breaths to a 16-year-old teenager.

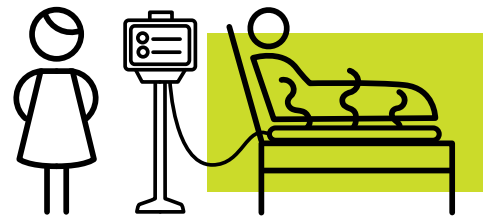
Each year, donations to BC Children's Hospital Foundation support over 1,000 pieces of specialized pediatric equipment. This generosity keeps BC Children's at the cutting edge of care, helping medical teams press forward as they confront the most serious health challenges facing kids.

Here's a glimpse of the equipment supported by some of the biggest hearts we've encountered—donors like you.



VIDEO VRA SYSTEM \$7,000

They may be small, but video VRA systems perform a powerful job: testing for hearing loss in kids. Used over 1,000 times a year, the diagnostic systems encourage patients to look at a particular spot if they hear a sound. When they do, they're rewarded with a video that holds their attention. By encouraging these responses, audiologists can more easily and accurately make diagnoses—leading to timely treatments that can halt hearing loss.



PATIENT WARMER \$28,000

When faced with illness or injury, maintaining a child's body temperature is crucial as it prevents complications like hypothermia and delayed wound healing. This life-saving equipment is used every day at BC Children's, including Leducor Children's Emergency. Harnessing an air- and water-free warming system through blankets and mattresses, these state-of-the-art warmers keep kids snug and safe from head to toe.



MOBILE X-RAY MACHINE \$241,000

Accidents happen. When they culminate in a broken bone, kids are rushed to the hospital for an X-ray. But sometimes, they may be too fragile to transfer from one unit of the hospital to the radiology department—which is where a mobile X-ray comes in. The compact and easy-to-maneuver diagnostic tool can be used at a patient's bedside or in the operating room.*

The healing power of art

Art may not be the first thing you connect with a hospital—but for some kids, it can be the salve that soothes the most. Take the Teck Acute Care Centre, for example. When it opened in 2017, the world-class facility healed kids' minds and spirits like never before with hundreds of pieces of purposeful art created to ease stress, distract anxious minds and lift moods.

As the first project of its kind in Canada, the donor-funded Children's Healing Experience Project was an extraordinary success—so much so that a similar project was launched when Sunny Hill Health Centre moved to the Oak Street campus. Throughout these projects, 27 Canadian artists and five iconic community partners

contributed their expertise and passion to create a space of healing for patients (who also gave their stamp of approval on each piece).

Hummingbirds in the Garden, a house post created by Chrystal Sparrow, a Musqueam Coast Salish artist, is one of them. Sparrow's piece is the first house post at BC Children's Hospital, joining the curated collection of original paintings, murals, interactive installations and sculptures.

"Hummingbirds are beautiful birds that often symbolize playfulness, resiliency and optimism. These Salish-inspired hummingbirds are feeding on flowers, surrounded by layers of green grass with elements of pink

Salish crescent designs," Chrystal Sparrow said. "The overall house post design represents positivity and perseverance to help Sunny Hill patients and their families get through difficult challenges by leading with good hearts."

The awe-inspiring piece stands proudly in the DFF Leung Family Mobility Park, providing an area where patients and families can take a moment to enjoy the quiet peace of the outdoors. "It's a meaningful reminder of our connection to the lands and the resiliency of all those who find healing here," added Malcolm Berry, president and CEO, BC Children's Hospital Foundation.*



Healing with compassion, in memory of Zach

When a child or teen is diagnosed with a serious illness like cancer, it can feel like their world has been turned upside down. Field trips and birthday parties are replaced with endless prods and debilitating treatments. As physical side effects progress, the emotional toll sets in. Younger children might become frightened by the foreign environment, while teens often grapple with an overwhelming sense of isolation.

That's where Child and Youth Therapeutic Services (CYTS) comes in. In the division of hematology, oncology, blood and marrow transplant at BC Children's Hospital, this dedicated team makes a powerful impact on children, youth, and their families by harnessing a powerful mix of evidence-based techniques—including therapeutic play and music therapy. These programs make being in the hospital a brighter experience for children, while reducing fear and anxiety.

The larger CYTS team includes Child Life specialists like Kristina Jackson, who has captured the hearts of many families, including Dana Prince who co-founded the Zach Prince Foundation along with Zach's mother Elana in memory of their son. The Zach Prince Foundation's endowment has provided more than \$845,000 in support of oncology education, training and programs including CYTS since its inception.



Kristina Jackson,
Child Life specialist

During their journey at BC Children's Hospital, Dana and Elana saw first-hand the difference CYTS was making in the lives of children and youth. This inspired them to make a generous gift in honour of Kristina and her efforts as part of this amazing team.

"With her pure heart and magical smile, Kristina makes a big difference in the lives of children, every day," Dana said. "Her exceptional care and support of oncology patients and their families at BC Children's exemplifies the purpose of the Zach Prince Foundation: excellence in oncology care. With much gratitude, we recognize and thank Kristina for making such a meaningful difference to so many of BC's most vulnerable children and their families, including ours."

Being a member of the CYTS team is challenging work, but for Kristina, it comes with a unique set of rewards. "We're surrounded by families who are faced with uncertainty, but still end up teaching us about hope, kindness, gratitude and the capacity for joy," she said. "It's hard not to appreciate life to the fullest when this is your perspective every day."*

"We're surrounded by families who are faced with uncertainty, but still end up teaching us about hope, kindness, gratitude and the capacity for joy."

— Kristina Jackson

Help when it's needed most

Picture this: your child is suffering from excruciating pain and you need to go to BC Children's Hospital. Perhaps you live hours away and need to travel. Once you arrive in Vancouver, unexpected costs begin to pile up for daily needs like meals and accommodations.

Hundreds of vulnerable families who require care at BC Children's each year face these very challenges. For many, their financial hardships are further intensified by the fact that they have no support system to rely on.

Within the hospital's walls, there's a lifeline for these families. The social work team moves quietly behind the scenes, supporting those in need with emotional supports and simple—yet critical—resources. Powered by the generosity of donors, they provide a range of supports including parking passes, gas cards, grocery vouchers and at-home medical supplies to those who need them most.

The social work team at BC Children's Hospital sees first-hand how

donations help support patients and families with the cost of medications, nutritional supplements, feeding supplies and other essential needs critical to a child's health.

"Families are too often faced with difficult decisions when a child requires medical attention and unexpected costs arise," said Christene Buchanan, Interim Professional Practice Leader at BC Children's Social Work Department. "Without the generosity of donors, many families would miss urgent critical appointments as they face barriers like transportation costs and the high costs of medications. In addition, parents without these vital financial supports have chosen to

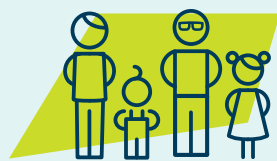
forego their own meals in order to be at their children's bedsides."

In the past year, teams across BC Children's have made connections with over 450 families. More than 400 grocery store vouchers were provided while their child received care and over 250 gas vouchers were given to help ensure families could travel to their medical appointments. These seemingly small acts of generosity have made an incredible difference in alleviating stress when the unimaginable happens. And most of all, it's helped parents focus on what matters most: the health of their child.*



MICRO MOMENT

Lee Family Medical
Imaging Department,
Teck Acute Care Centre,
BC Children's Hospital
Oct. 26, 2022, 9:30 AM



CONNECTIONS WITH OVER

450

FAMILIES



MORE THAN

400

GROCERY STORE
VOUCHERS PROVIDED



OVER

250

GAS VOUCHERS
GIVEN

"My little guy Atticus is 5 and he was diagnosed with myasthenia gravis, a chronic autoimmune disorder, in September of 2022.

Today we came to BC Children's to get an MRI done, but Atticus has a very big fear of needles.

The nurse was an absolute angel—instead of a needle, she gave him the option of using what they call a 'sleepy mask' and let him choose the scent of the gas.

She also allowed him to draw on the mask, which changed his whole mood—and mine! He was so calm by the time they took him back that he held his own mask to fall asleep."

— Brittney, Atticus's mother

Never doubt what small can do. Big things come from small beginnings.
Everything groundbreaking or world-changing starts this way.

The kids we help may seem small, but they face huge challenges. A sample of cells in a petri dish is small, but it could be the key to the next big breakthrough.
You might think your impact is small, but your support could be just what we need to push the next medical advancement over the finish line.

Together, we'll show the world:

Small is MIGHTY.



MakeUsMighty.ca