



# Shine

Fall 2022

## How Little Fights Big

Quinn's life was almost over before it began, but the medical team gave her a chance to battle back

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Battling the loneliness of diabetes

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Foundation

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BC Children's Hospital Foundation  
 938 West 28th Avenue,  
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Managing Editor: Paul Park

Writers: Paul Park, Kelsey Davis, Ali Omelianiec

Graphic Design: Jennifer Pratt

Cover Photography: Justine Davies

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# Never doubt what small can do



You don't have to look far these days to hear about something tragic happening in the world. It's enough to make any of us feel weary. But I am encouraged time and time again, that when the problems seem daunting, we can find reassurance in the reminder that greatness starts small. Big things come from small beginnings. Every great achievement starts from taking that first small step, and then the next.

This month, BC Children's Hospital Foundation has launched our new brand story—a simple, but powerful idea: **small is mighty**. It speaks to the big challenges that we face when it comes to the health of our kids—whether it's kidney failure, cancer or heart disease— and how there are hundreds of health experts tirelessly delivering care at BC Children's and over 1,000 researchers working together on the next breakthrough.

It speaks to the resilience of children who, despite their size and life experience, endure illness and injury with a kind of resilience that kids innately possess. And it speaks to the power of each of you who, through your gifts, stand by our sides as we tackle each problem piece by piece.

This issue of Shine magazine contains stories about small steps, in research and clinical care, that are leading to mighty strides in advances in health care for children across BC.

Thank you for joining us on our quest—because of you, we are making small, mighty.

With gratitude,

Malcolm Berry  
 President & CEO  
 BC Children's Hospital Foundation

*“The hardest part for us was the shock of how quickly everything changed. We went from envisioning a life and a future for our daughter, to simply hoping she would survive.”*

— Heather, Quinn’s mother

# How little fights big

Up until the day of Quinn’s birth in July 2019 in Victoria, BC, there had been no indications of anything out of the ordinary. Heather and Ryan, expecting a typical, low-risk birth, were excited to meet their first child and welcome her into the world.

During the delivery, Quinn’s heart rate suddenly dropped and didn’t recover as expected. It turned out that an extremely short umbilical cord had prematurely severed the flow of blood and oxygen, and when she emerged there were no signs of life.

CPR had to be administered for 13 minutes before Quinn’s heart rate started to return, but the damage was already done. Those vital 13 minutes led to damage in multiple organs, as well as hypoxic ischemic encephalopathy, a type of brain dysfunction.

Quinn was suffering from seizures and abnormal brain activity. She wasn’t able to breathe on her own, her liver wasn’t clotting properly, her kidneys weren’t functioning and she had a condition that caused her bowels to perforate.

### “THE SICKEST BABY IN THE HOSPITAL”

Medical staff worked tirelessly to stabilize her and on the fifth day of Quinn’s life she was flown from Victoria to BC Children’s Hospital. After examining her, Heather





Quinn at 5 days old and her mother Heather



Heather and Quinn, age 2

*“It meant everything to me to be able to have that emotion-filled first cuddle. It was quite a production of cords and lines and it took so many people to make it happen, but I had waited such a long time for this moment.”*

— Heather, Quinn’s mother

overheard one of the doctors saying plainly that Quinn was “the sickest baby in the hospital.”

Within hours of her arrival, Quinn was rushed into surgery. The BC Children’s medical team had to work quickly to save Quinn’s life.

The surgical team removed the dead portion of her bowel and created stomas, openings that allowed waste to leave her body so her intestines could recover. The lack of kidney function was the greatest threat to her survival, so Quinn was outfitted with a line in her neck to provide dialysis, which replicates the kidneys’ cleaning function.

Fortunately, the surgery was a success. The “sickest baby in the hospital” was, thankfully, on her way to giving up that label.

#### CARE FOR THE ENTIRE FAMILY

Quinn was transferred to the Hudson Family Pediatric Intensive Care Unit and spent almost two weeks fighting for her life while under 24-hour care.

On Quinn’s ninth day of life, her respirator was removed and Heather was finally able to hold her child. It was a complicated procedure—Quinn had to stay connected to multiple machines and equipment—but the nurses helped navigate so Heather could make that crucial connection.

In helping Heather hold her baby for the first time, the nurses and the rest of the medical staff were doing more than just fulfilling a mother’s desire to cuddle her newborn. With all the fear and trauma Heather and Ryan had endured over the past few days, the medical staff knew it was vitally important that the parents have a chance to connect with their new baby.

“I was very guarded in the beginning to build the connection with Quinn for fear that she wouldn’t survive,” Heather admitted. “But the nurses really brought us back to Quinn and supported us. It meant a lot to me that they picked up on what our family needed, and helped make it happen.”

The family was in the hospital for two months, and in some ways it almost felt like home—partially because of the calming spaces, but mostly because of the kind, caring team who supported them every step of the way.

#### CONNECTING TO A BRIGHTER FUTURE

Three years later, Quinn is doing extremely well. Her kidney function has stabilized, and while she requires a gastrostomy tube, a tube inserted into the belly for feeding, it doesn’t

stop her from being a spirited, energetic and rambunctious toddler.

The family still visits BC Children’s for regular annual check-ups, and the hospital teams go out of their way to foster a relationship not only with Quinn’s parents but with Quinn herself.

“They follow her medically,” Heather said, “but they also just seem to genuinely care about how she’s doing and want that personal connection with her, which is really nice to see.”

#### SMALL NEVER GIVES UP

The family recently celebrated Quinn’s third birthday. While Heather was watching the toddler giggling and running around the backyard, she couldn’t help but reflect back on the first two months of Quinn’s life with an overwhelming feeling of gratitude for the team at BC Children’s Hospital.

As a newborn baby, Quinn faced enormous challenges—unexpected complications so severe they threatened to take her life before it even started. But Heather’s newborn baby battled back with all the strength in her days-old body, and with the extensive care provided by medical experts at BC Children’s Hospital, Quinn fought and won. Proof that small can be mighty. ✨

# A moment with Dr. Steven Miller

In April 2022 Dr. Steven Miller accepted the position of Chief of Pediatrics and Hudson Family Hospital Chair in Pediatric Medicine at BC Children's Hospital. We sat down with Dr. Miller to talk about the defining moments of his life, his vision of the future of BC Children's and his sources of inspiration.

**Q: WHAT WERE THE DEFINING MOMENTS IN YOUR LIFE THAT LED YOU TO WHERE YOU ARE TODAY?**

A: I went to medical school at McGill University, and late into my training I had an experience in Ghana as a global health elective student that changed everything. I saw how children there would come to the hospital severely ill from meningitis or cerebral malaria, and weeks later they'd be playing soccer in the courtyard. I hadn't expected to see that kind of recovery, and it made me wonder: who looks after brain issues in children?

That turned my attention to pediatric neurology. I trained in that field at Montreal Children's Hospital and then moved to the University of California, San Francisco to train in neonatal neurology.

After my fellowship I was recruited to BC Children's Hospital with my wife, Dr. Mina Matsuda-Abedini, a pediatric nephrologist. I started my faculty career here in Canada as a clinician scientist with a focus on neonatal neurology.

After seven years I moved to SickKids in Toronto. My time there really opened my eyes to the importance of the breadth of child health and the impact that one can have in bringing together people from different disciplines with a common purpose of supporting better outcomes for children and their families.

I was super excited when the opportunity to move back to BC Children's Hospital presented itself. The role of head of pediatrics really appealed to me—fostering the success of others and the opportunity to bring together people of different disciplines with the common purpose of promoting child health.

**Q: WHEN YOU IMAGINE THE FUTURE OF BC CHILDREN'S HOSPITAL, WHAT ENERGIZES YOU?**

A: I'd love to see true health equity for children and their families that's fostered by the diversity and inclusivity of our team. I want to see innovations in care that distinguish us and motivate people to come to BC Children's Hospital for the most innovative care as we work with our partners on a system that makes sure that everyone in British Columbia has excellent care.

**Q: WHO INSPIRES YOU, AND WHY?**

A: The families I am privileged to care for in the clinic are the most inspiring. Their courage and resilience are remarkable. I am grateful for the generosity of the many parents who engage in patient-oriented research to inform the future of our research directions.

**Q: WHAT'S ONE THING YOU'D LIKE EVERYBODY IN BC TO KNOW?**

A: I would remind everyone that kids are 20 per cent of our population and 100 per cent of our future, and it's going to take all of us working together to foster their health.★

Clockwise from left: Hana,  
Dr. Matsuda-Abedini,  
Dr. Miller, Sam, Coco

*"I would remind everyone that kids are 20 per cent of our population and 100 per cent of our future..."*

— Dr. Steven Miller





# Healing beyond the burn

It was a November afternoon in 2017 when 9-year-old Keira Mackenzie hopped into the car with her mom, Teresa, to go to the doctor's office. Teresa had a tradition of buying coffee and tea for the nurses and doctors at the family practice.

At the local drive-through, five drinks were placed in a four-drink holder. As Teresa handed the tray to Keira, the unsecured drink tipped. Startled by the sudden pain, Keira jerked away, causing the remaining four piping hot drinks to fall into Keira's lap.

"It hurt so much, I couldn't even cry, I just screamed," Keira recalled.

The family raced to the local hospital for treatment. When her second and

third-degree burns sent her into septic shock, a sudden and dangerous drop in her blood pressure, Keira was transported to BC Children's Hospital.

Keira was admitted to the Hudson Family Pediatric Intensive Care Unit and, once stable, was moved to the surgical ward where the family was introduced to Dr. Sally Hynes, the Burn Director at BC Children's.

Dr. Hynes leads a burn care team that supports patients like Keira as they navigate both the physical and emotional trauma that is often associated with burn injuries. This highly-trained team plays a critical role in caring for the unique needs of patients and families before, during and after treatment.

Each year at BC Children's Hospital, approximately 150 children are treated for new burn injuries each year. "Children recovering from a burn injury are faced with many challenges," Dr. Hynes said. "Our multidisciplinary burn care team is walking alongside patients and families during a very overwhelming time, helping to navigate their fears, anxieties and physical healing."

Few professions understand the challenges of burn injuries better than fire fighters. Motivated to help transform pediatric burn care at BC Children's Hospital, the BC Professional Fire Fighters' Burn Fund made an incredible \$1 million gift. The Burn Fund gift will upgrade and enhance the burn care suite to better meet patient needs by relocating the waiting area so families can be closer to their children, enhancing the space with purposeful art to create a healing environment and much more.

It has been five years since Keira's accident. The bright young teenager

has become a passionate advocate for burn care in BC, holding school fundraisers and speaking at events to educate others on the important resources needed for young patients with burn injuries.

"Somebody asked Keira recently what her favourite part of her childhood was," Teresa said. "She actually, surprisingly, said her burn. I think the reason is because of the team she had at BC Children's and the community support she has gotten from it."★



## Five years of possibilities become reality

When BC Children's Hospital opened the new Teck Acute Care Centre (Teck ACC) in fall 2017, it was a "game-changer"—a state-of-the-art facility designed to transform how health care is provided to children across BC. Five years later, Teck ACC has exceeded expectations, creating a campus of care for the over one million patients and families it serves from across the province, supported generously by donors.

What happens within the walls of Teck ACC each day is changing and saving lives. It was designed so the expert medical staff could provide the best care in a purpose-built, healing environment. When COVID-19 struck, Teck ACC was ready—its design helped ensure staff could safely continue to care for patients, including the most vulnerable.

Teck ACC is an example of what is possible with the dedication and commitment of our generous donors, hospital and government partners. We are grateful and honoured that the community came together to ensure BC has a world-class facility to treat and heal kids.

Thanks to your vision, passion and generosity a new era of possibility has been enabled that created a legacy for the province and most importantly, the children and families who rely on BC Children's when they need it most.★



# Battling the loneliness of diabetes

Over 2,500 kids in BC live with diabetes, and that number is growing. Many families have shared that they feel alone in their diagnosis, and that their friends, teachers or colleagues simply don't know how to be supportive.

Feedback like this inspired the Diabetes Transformation Project (DTP) at BC Children's Hospital. This initiative is taking a multi-faceted approach to transforming pediatric diabetes care through family-to-family connections, education, training, research, and communication with experts who truly understand the challenges of a diabetes diagnosis.

## SUPPORTING EACH OTHER AND LEARNING TOGETHER

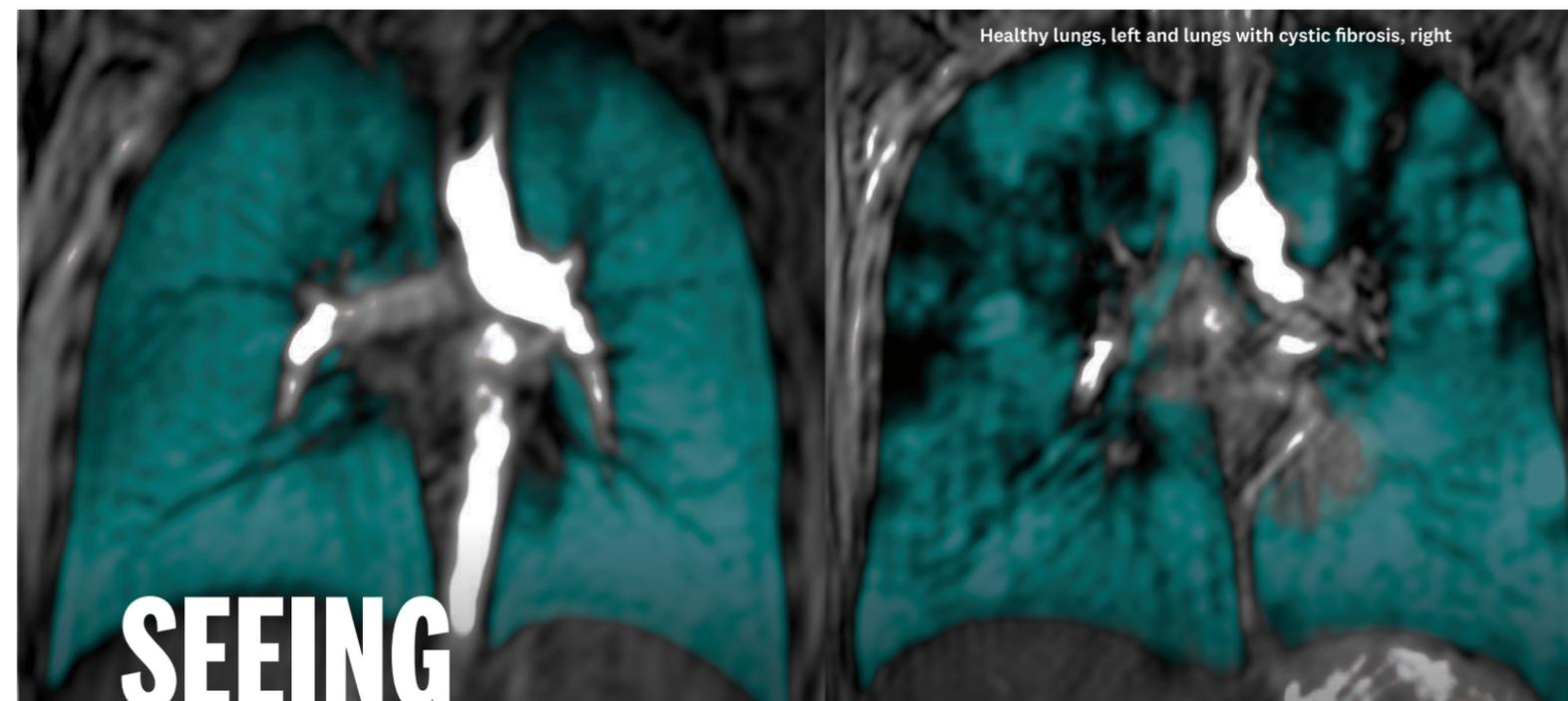
The DTP is using technology to bring families together with two peer-support projects: Huddle4Parents, for families of young children with diabetes, and HuddleNextGen, focused on adolescents and their families as older youth become more independent in managing their diabetes. These projects provide online sessions and group chats to create close connections between families across the province.

LearnDiabetes, another pillar of the DTP, is making reliable information more available to families managing diabetes. It features digitized learning materials so parents, caregivers and children can learn in a convenient and meaningful way.

## SHARING DATA TO SUPPORT RESEARCH

The BC Pediatric Diabetes Registry was started at BC Children's Hospital to transform the care of diabetes patients today and tomorrow by capturing daily data on their experiences with the disease. This data could reveal key insights that might lead to new discoveries. In order to gather more information the DTP is expanding this data collection across the province, and there are currently 758 patients enrolled in the registry.

With the guidance of patient families and experts across the province, BC Children's Hospital and the DTP team aim to improve the experience of children and families with diabetes so they can spend less time focusing on diabetes and more time living their lives.✳



Healthy lungs, left and lungs with cystic fibrosis, right

# SEEING THE DETAILS

"The technology difference is like comparing a Tesla to a horse and buggy," said Dr. Jonathan Rayment, researcher and pediatric respirologist at BC Children's Hospital, referring to how a new lung-scanning technology compares with older tests.

In 2020, Dr. Rayment and his team were the first in western North America to generate hyperpolarized xenon functional pulmonary magnetic resonance imaging (XeMRI) scans of human lungs. This cutting-edge technology, which was partially funded through donor support, represents a huge advancement in characterizing lung diseases by revealing a much higher level of detail than other lung function tests, allowing for more precise diagnoses.

"The current tests, such as spirometry, provide 'whole-lung' measurements," Dr. Rayment said. "They don't indicate if you have a little patch of disease in one specific spot, which may not show up on spirometry until the disease is really bad or has spread. But these XeMRI scans show very detailed lung function maps and can pinpoint specific areas of concern early on in the disease's progression."

Dr. Rayment and his fellow researchers at the BC Children's Hospital MRI Research Facility are using this tool to find ways to improve care for children's conditions like asthma, cystic fibrosis and other lung diseases. Along with other leading MRI research centres across North America and the U.K., they are part of the XeMRI Clinical Trials Consortium, which is working to integrate XeMRI technology into the clinical care of people with these serious conditions.

***"The technology difference is like comparing a Tesla to a horse and buggy."***

— Dr. Jonathan Rayment

"Understanding the patterns of regional lung function in children with different conditions can give us hints on how best to treat them," Dr. Rayment said. "This concept of 'treatable traits' is central to our advanced diagnostics program in Respiratory Medicine at BC Children's Hospital and I'm very excited to see how far we've come in such a short time."✳

Hennessy, age 15 and her mom Jordan, left and Jayden, age 15, right



## A gift that spans generations



Joan Glass, legacy donor

*We salute Joan, and thank her for a life well-lived.*

As a long-time Girl Guides leader, it makes perfect sense that Joan Glass planned out her life for decades, including a legacy gift to express the gratitude she felt for BC Children’s Hospital Foundation.

When Joan’s daughter, Nadine, went into premature labour at 25 weeks, she had to be urgently airlifted from Prince George to BC Children’s Hospital. Baby Nicole was born one day later—she weighed barely two pounds, couldn’t breathe on her own and had to be tube-fed.

History repeated itself as Nadine’s second child, Kieran—named after the paramedic who helped Nadine during her first pregnancy—was born at just 30 weeks.

Despite starting life as fragile, premature infants, both Nicole and

Kieran are now thriving, healthy young adults. Whenever she thought of her grandchildren, Joan felt deeply grateful for the team of specialists who gave her grandkids the chance to live vibrant and active lives.

As a long-time member of the Legacy Circle and proud grandmother of nine, Joan knew her legacy gift for BC Children’s would represent her most precious values: family and community service.

“My legacy helps other kids take on the world tomorrow,” said Joan.

Even for those who aren’t as organized as a Girl Guides leader, establishing a legacy gift can be an easy process.

Follow the simple checklist at [bcchf.ca/legacy-resources](https://bcchf.ca/legacy-resources) to create a legacy you can be proud of.★

## Helping hands and hearts

Lauren was only five and a half months old when she experienced cardiac arrest for the first time. Upon arriving at BC Children’s Hospital, she was diagnosed with ALCAPA, an extremely rare congenital

heart defect with a 90% mortality rate if not diagnosed before the age of one. After two heart surgeries, three days on life support and being outfitted with a pacemaker, Lauren began her recovery.

“It was a terrifying experience, but no one at the hospital ever gave up on her,” said Matt, Lauren’s dad.

To mark the 10 year anniversary of Lauren’s ALCAPA diagnosis and give back to the hospital for their life-saving efforts, the family organized a fundraising garage sale, sponsored by Matt’s employer, National Bank, and supported by a powerful community of family and friends. The garage sale brought in an incredible \$50,429 for the Heart Educational Hub, an upcoming online resource for cardiology patients and their families at BC Children’s.

“We are so excited to see the ‘Heart Hub’ coming to life and to address some of the first thousand questions families from across the province have when their child is diagnosed with a heart condition,” Matt said. “Our hope is that this will help future families by providing modernized, far-reaching support.”★



Lauren, age 10 and her sister Elyse, age 8



8th Floor, Oncology, Teck Acute Care Centre, BC Children’s Hospital  
Sept. 24, 2022, 2:30PM

“It’s been a busy day—as most are, it’s never a dull moment—but one cool thing happened today. Two teenage patients came in to get their ports removed because they are done treatment and in remission.

The kids get some pretty harsh treatments that make them sick, and yet they walk out, bouncing down the hallway, going on to live healthy teenage lives.

Whenever anybody asks me about my job, they always say, ‘Wow, how can you do that? It must be so hard.’ What I say to them is that the good days outweigh the bad days.

Even on the bad days, you’re working with kids—and they’re so resilient. They still smile through those bad days. So how can you not?”

— Kelsey, RN, Oncology, Hematology and Bone Marrow Transplant outpatient clinic

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](http://MakeUsMighty.ca)