

SPRING 2021

SHINE



Stopping tragedy before it strikes

For kids with undetected
heart disease, the key to
saving their lives may lie
in their genes

Also in this issue

Conquering childhood illnesses
through research



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Charitable Business Number:
11885 2433 RR0001

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

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SHINE is published two times annually by BC Children's Hospital Foundation.

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CONTENTS

2	THE HIDDEN SCARS OF HEART DISEASE	10	Q&A: A MOMENT WITH MALCOLM
6	SUPPORTERS WITH BIG HEARTS	11	KINDNESS & ONE MOM'S MISSION
8	LATEST STRIDES	12	SEEN & HEARD

ADVANCING OUR VISION TOGETHER

As the new president & CEO of BC Children's Hospital Foundation, this issue of *Shine* magazine marks a new beginning for me. But while my role here is new, my lifelong commitment to the health of our children is not.

And as we enter year two of the pandemic, the importance of pursuing a healthier future for our kids has become even more apparent.

In the last issue of this magazine, you read about our quest to conquer childhood illnesses. And in this issue, you'll learn about one illness in particular that we don't often associate with children: heart disease. Some kids may require life-saving surgery, while others are at risk of experiencing sudden cardiac arrest. But there is hope—experts here

are pursuing groundbreaking advances to help these kids beat the odds.

You'll also read about new research into serious childhood conditions like cancer, diabetes and mental health challenges, which can have lifelong impacts on our children.


In my many years of working at children's hospitals across North America, I have seen what a committed group of supporters can accomplish together. And I am truly excited to partner with you to advance our collective vision with innovation and care.

With gratitude,



Malcolm Berry
President & CEO
BC Children's Hospital Foundation





Daniela, age 13,
cardiac patient

The hidden scars of heart disease

One in 100 kids are born with heart disease—but some of them may not even know it

Many children who are born with a heart defect live with a physical scar. But for others, the scars can run much deeper—and the imprint they leave on the rest of a child's life is profound.

In November 2019, 14-year-old Mattias was swimming in the hotel pool while on a school trip in Vancouver. As he dove into the water, his heart stopped beating, and he went into cardiac arrest—abruptly losing consciousness and his ability to breathe.

Two classmates noticed he was in trouble, and immediately pulled him out of the pool and began to administer CPR. Minutes later, paramedics arrived and revived him with an automated external defibrillator (AED), before rushing to BC Children's Hospital, where Mattias went into cardiac arrest two more times. He spent the next week hooked up to a ventilator, as clinicians did everything possible to save his life.

A series of tests revealed that Mattias had a rare genetic heart condition called catecholaminergic polymorphic ventricular tachycardia (CPVT), which caused irregular heartbeats. While rare, the first sign of CPVT can be cardiac arrest. And if the heart isn't brought back to its normal rhythm within minutes, it can be fatal.

EVERY YEAR, HUNDREDS OF FAMILIES IN CANADA ARE AFFECTED BY THE SUDDEN DEATH OF A SEEMINGLY HEALTHY CHILD, WHO SUDDENLY SUFFERS FROM CARDIAC ARREST WITHOUT WARNING.

Stopping tragedy
in its tracks

Fortunately, Mattias recovered and returned to his home near Kamloops a few weeks later. As an active teen with a passion for skiing and mountain biking, he’s been able to return to the activities he enjoyed before his diagnosis—but with notable differences. Mattias must take two medications daily for the rest of his life, without missing any doses.

As Mattias was very keen to get back to the outdoors, he now carries a portable AED if he’s more than a ten-minute response time from paramedics or an on-site AED—and must be accompanied by someone who can administer CPR anytime he exercises.

While his recovery has been remarkable, Mattias’ outcome would have been different if it wasn’t for the quick action taken by his classmates. CPR and rapid access to an AED are the most important measures to save the life of someone who is in cardiac arrest.



Mattias pursuing his passion



Dr. Shubhayan Sanatani, who cares for Mattias

But now, through advances made in care, there is new hope for kids like him. “A lot of the heart conditions we treat at BC Children’s Hospital are inherited,” explained Dr. Shubhayan Sanatani, division head of cardiology at BC Children’s.

"THROUGH GENETIC TESTING, WE CAN ACTUALLY IDENTIFY CHILDREN WHO MAY HAVE OR BE AT RISK OF DEVELOPING HEART DISEASE—OFTEN BEFORE THEY’VE EVEN SHOWN ANY SYMPTOMS."

—Dr. Sanatani, division head of cardiology

"This allows us to prevent the difficult and tragic consequences of heart rhythm disorders by getting treatments to children earlier," he continues.

Even once genetic testing confirms the possibility of heart disease, many questions remain in determining the best treatment. With several possible medication combinations for heart arrhythmias, experts must often take a trial-and-error approach to find what is best for each child.

This poses a certain degree of risk because the wrong treatment can result in recurrent cardiac arrest or even worse, sudden death. For years, health care providers at BC Children’s have dared to ask: what if there was a better way?

Fighting heart disease
in a dish

The answer to this question may lie in stem cells. As cells that are able to develop into many different cell types—including heart cells—they may hold the key to saving the lives of kids with heart rhythm disorders.

By taking a simple blood draw, researchers can turn a patient’s own blood cells into these stem cells, which are then transformed into beating heart cells that “come to life” in a petri dish. The heart cells contain the genome of each child, which enables experts to understand their unique condition in ways never before possible.

“While two children may have the same genetic mutation that’s causing a heart arrhythmia, one might go into cardiac arrest while another will be fine,” explained Dr. Glen Tibbits, an investigator at BC Children’s Hospital who is leading this work. “So, the idea is to screen children using their heart cells to understand who is at greatest risk with minimal discomfort for the child.”

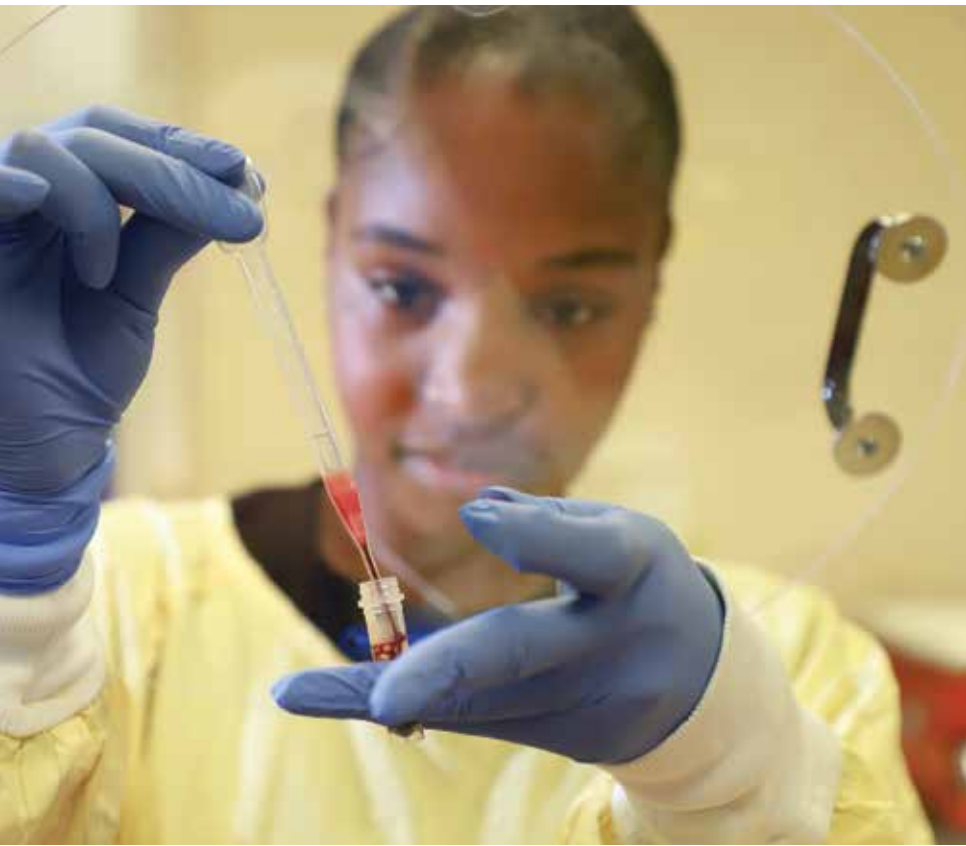
“If a child is at risk, we can then test which medications will work—and which ones won’t—on those beating heart cells, before we use a treatment on them,” Dr. Sanatani added. “It’s a truly personalized approach to medicine.”

Over the past several years, experts at BC Children’s Hospital have brought this innovative work to children who need it most. But the process of creating heart cells from blood cells not only requires a state-of-the-art facility, it also takes significant investments in time. As a result, many children who would benefit from stem cells haven’t been able to—yet.

Through generous support from Mining for Miracles—the BC mining industry’s long-standing fundraising campaign for BC Children’s Hospital Foundation—the hospital is on a quest to change this reality by establishing a Cellular and Regenerative Medicine Centre (CRMC). A first of its kind in Western Canada, the facility will enable experts to test more children at risk of sudden cardiac arrest, preventing tragic outcomes before they occur.

“Being at the forefront of new technology and knowledge is the key to improving health care,” explained Dr. Sanatani. “This centre will be a world-class platform for scientists and clinicians to come together to study patient conditions in the virtual labs that stem cells allow.”

Interested in how you can help conquer childhood illnesses like heart disease? Visit bcchf.ca



Supporters with big hearts



It's a match

We are so grateful for our donors committed to kids' heart health—like Canadian Pacific, who named us as their primary charity partner for the 2021 CP Women's Open and matched all online donations during Heart Month this past February.

Here are a few ways that some donors with big hearts are making a difference for the smallest ones.

Stronger hearts for a better tomorrow

From the moment Randle Jones met Dr. Shubhayan Sanatani, division head of cardiology at BC Children's Hospital, he was deeply moved by the clinician's heart and dedication to improving cardiac care for children across BC.

"His passion, caring and energy inspired us greatly," says Randle. "Since then, we have supported the initiatives that he recommends will most benefit the cardiac department at BC Children's."

This is why Randle, through the Windsor Plywood Foundation, generously donated \$100,000, which will be matched dollar for dollar by Canadian Pacific (CP) for a total investment of \$200,000. This gift will be used to help train the brightest minds who can provide the best possible care in the future by supporting cardiology fellowships and trainees.

"We hope that we can help to improve the level and quality of care that can be delivered to sick children and their families," says Randle. "Supporting young doctors leads to better outcomes, improved treatments, and a strong future of health care in BC," says Randle.

BC Children's Hospital is incredibly grateful for this gift, and for its impact on improving cardiac care for all kids.

A heartfelt legacy

It started off perfect—in August 1982, Tom and Sue McLean had just given birth to their firstborn, Jenny, in Kelowna. Just two hours later a nurse noticed Jenny's lips turned blue and local doctors suspected a heart condition. That evening Jenny was flown to BC Children's without her mom and dad.

"There really are no words to describe the fear and anxiety we were feeling, but we remained hopeful," says Tom. "I remember her doctor telling me that she was on her way to the best hospital in the province for this kind of thing." Sue and Tom caught the next flight out.

At BC Children's, the experts diagnosed Jenny with tetralogy of Fallot, a rare heart condition. She had a hole between two chambers of her heart, and her pulmonary artery was



Jenny (left) today, with her happy and healthy family

narrowing—gravely limiting her ability to oxygenate her blood.

Next steps included a complex heart operation—to Tom and Sue, a terrifying prospect at first.

"The surgeon told us that it's a common surgery and they do over 300 of these heart operations every year and that was important to know," says Tom. "Even 38 years later, I still get emotional talking about it. We feel so blessed to have a resource like BC Children's."

Throughout the rest of her childhood and into her teens, the McLeans would travel back to BC Children's for check-ups

and other surgeries, including a five-hour open-heart surgery when Jenny turned two years old. She came through with flying colours, and just three days later was seen running around in the cardiac ward.

Today Jenny is a mother of two beautiful children, and Tom and Sue are eternally grateful for the care she received. Thinking of their grandkids and creating a healthier future for all, they chose to leave a gift in their Will to BC Children's Hospital Foundation.

"Saving a child's life is indeed a priceless gift and one that can hardly be ignored," says Tom. "Our legacy gift serves as a deep, heartfelt thank you."

A miner with a heart of gold

Each and every day, clinicians at BC Children's work to better understand the genetic causes of heart disease and other serious childhood illnesses. And as mentioned in the previous story, they are now expanding these efforts through establishing a Cellular and Regenerative Medicine Centre—thanks to generous support from the BC mining community.

Through their connection with Mining for Miracles, Brett and Carole Knelson have for years hosted an annual barbeque in support of BC Children's—that is, until last year when the pandemic hit. Yet even when they had every excuse to stop, Brett and Carole instead used their creativity and grit, and stepped up.

They transformed their annual in-person event into a digital fundraiser. Brett connected with friends and colleagues online and asked them—if they could—to make a donation to continue to support the hospital.

The response was beyond anything Brett had imagined.

"I WAS TOTALLY BLOWN AWAY," SAYS BRETT. "WE RAISED \$114,000 WITHOUT REALLY OFFERING MUCH IN RETURN. I WAS ONCE AGAIN SO INCREDIBLY IMPRESSED BY MY FRIENDS AND COLLEAGUES, BECAUSE THIS WAS RAISED PURELY IN THE SPIRIT OF GIVING."

Thanks to philanthropists like Brett, Carole, and their friends and colleagues, kids at BC Children's are given a better chance at a healthier future. Thank you.

LEGACY GIVING PROVIDES MORE THAN HEALTH CARE TO KIDS. IT HAS THE POWER TO IMPACT GENERATIONS OF CHILDREN AND THEIR FAMILIES. TO LEARN MORE PLEASE VISIT [BCCHF.CA/LEGACY](https://bcchf.ca/legacy)

LATEST STRIDES

A closer look at how supporters like you are taking on some of the biggest health challenges facing kids today: cancer, diabetes and mental health.

MENTAL HEALTH IN A PANDEMIC

The COVID-19 pandemic continues to impact everyone's lives, but kids and youth in particular are faced with unique challenges.

BC Children's investigators Drs. Evelyn Stewart and Hasina Samji are leading an online survey to gauge how kids and adults are affected over time by COVID-19—with focus on the underserved or previously ill. The goal is to learn about specific needs and preferred resources from both child and parent perspectives.

They will then provide decision-makers with evidence to help guide clinical and policy decisions for this and future pandemics. Everyone is eligible to participate.



Take the survey at
bcchr.ca/POP/our-research/pics

Through an online tool developed at BC Children's, another study led by Dr. Quynh Doan, director, clinical research, is seeking how often, how severe, and what types of mental health concerns children and youth are having during the pandemic. From this, they will learn how best to connect families with needed resources. This study was supported in part by Rio Tinto, who was inspired to support kids and families struggling during this difficult time.

WHEN CANCER STRIKES BACK

Twenty per cent of children with cancer relapse or don't respond to traditional therapies—and when this occurs, the chances of surviving drops dramatically. Inspired by generous support from the Michael Cuccione Foundation and the Murray family, researchers at BC Children's Hospital are determined to find out why this occurs in children with medulloblastoma, the most common malignant childhood brain cancer.

"The key to beating this horrific disease is understanding why some cases of medulloblastoma

relapse and become drug resistant," explained Dr. James Lim, an investigator at the Michael Cuccione Childhood Cancer Research Program at BC Children's Hospital. "So, we set out to uncover what factors may help cancer cells escape the effects of chemotherapy."

To do that, Dr. Lim and his team grew medulloblastoma cells in a lab and then exposed those cells to increasing levels of chemotherapy to see how they responded to the treatment.

That eventually led to a striking discovery: a particular molecular signal could help cancer cells

enter a "survival mode" that enables them to resist the effects of treatment.

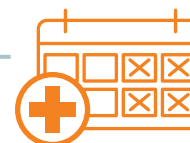
Although the research is still in its early days, it demonstrates the potential of blocking these "survival mode" signals to increase the effectiveness of chemotherapy—and reduce the chance of the cancer recurring in children.



Experts at BC Children's treat **four to five children with medulloblastoma each year.**

CONQUERING DIABETES

Children with type 1 diabetes not only need to take insulin injections several times a day and monitor blood sugar levels around the clock, but they and their families also live with a constant fear of serious and life-threatening complications.



A child is diagnosed with diabetes at BC Children's every **three to four days.**

The condition occurs when the immune system attacks and destroys the insulin-producing beta cells of the pancreas, which are needed to control blood sugar.

Dr. Francis Lynn, a researcher at the Canucks for Kids Fund Childhood Diabetes Laboratories at BC Children's, is on a quest to conquer diabetes. His vision? Generate a readily available source of lab-grown insulin-producing cells that could be transplanted into children with type 1 diabetes.

Recently, Dr. Lynn and his team received a major boost to advance this research—becoming one of two groups awarded a total of \$6 million in funding from the Government of Canada and JDRF Canada to accelerate the development of stem cell-based therapies for type 1 diabetes.

"If successful, this would be utterly transformative for children with type 1 diabetes—allowing them to live healthy lives and reducing the need for painful insulin injections," Dr. Lynn said.



You first heard from Malcolm Berry in his letter on page one; here's a chance to learn a bit more about the Foundation's new president & CEO.



Q What brought you to BC Children's Hospital Foundation? What excites you about your new role?

A The opportunity to live and work in beautiful British Columbia, alongside an amazing team supporting one of the best children's hospitals in the world, is like a dream come true for me. I'm excited to bring my leadership and philanthropy experience into this new role—most recently, I was chief development officer at St. Louis Children's Hospital in Missouri, USA, and before that, I spent over a decade at SickKids Foundation in Toronto.

A MOMENT WITH MALCOLM

Q How did you become involved in philanthropy?

A Our first child, Paige, was diagnosed with a rare condition—haemophagocytic lymphohistiocytosis (HLH)—just weeks after being born, and from that point on, the hospital was her home. Despite experts working tirelessly to help her, even then I could see where advances in her clinical care were still needed. Paige died peacefully later that year. My wife Laura and I lived every moment we could while Paige was with us—she gave us perspective on what mattered, and taught us so much.

After Paige's passing, a passion grew within me to do everything I could to help families like ours. To make a long story short, I turned my passion into a lifelong career.

Q When it comes to children's health care, what are you most passionate about?

A The quest to help every child, family and pediatric health expert reach their hopes and dreams. For kids, that might mean helping them reach their fullest potential. For experts here, it may mean giving them what they need to pursue their vision for a life-saving treatment or technology. And by extension, helping members of our hospital community here reach their hopes and dreams will help the community at-large reach theirs.

Q What is your biggest learning during this pandemic?

A A deeper realization that authentic connections are incredibly vital—and is what will enable us to be able to adapt to the changes we face, tackle challenges with creativity, and come out stronger on the other side.

KINDNESS CAN NEVER COME TOO EARLY

Sometimes the biggest hearts come in the smallest packages. When 10-year-old Jonathan, or "Bear" as he's often called and his friend Landon Brown, 18, first learned about closed playrooms and limited visitors at BC Children's Hospital due to the pandemic, their hearts went out to the young patients facing increased isolation.

Moved by these challenges, the two friends were encouraged and supported by the team at BC Children's Hospital Foundation. They hatched a plan to reach out to their community and to leaders from top Canadian corporations with requests for tablets, toys and donations. Their message was heartfelt, passionate, and profoundly inspiring.

"We told everyone that we think all of these kids are very brave, but since they couldn't see all their family and friends, that they needed other ways to stay connected with loved ones," says Bear.



Their message caught the attention of leading companies like LEGO, Canadian Tire, Rogers and LG. Bear and Landon also partnered with Dreams on Wheels and Porsche Club of America Canada West to host zero-contact toy and tablet drop-offs.

The results were incredible. Packing up trailers to the brim, they hauled hundreds of tablets, electronic devices and toys to BC Children's. They also inspired more than \$14,000 in donations.

From all of us at BC Children's Hospital Foundation, thank you Bear and Landon for your incredible compassion, creativity and leadership.

ONE MOM'S MISSION

While Barbara Insley drove to work one morning in the spring of 2009, a woman on the radio suddenly caught her attention.

"I heard a mom speak about how she had lost her six-year-old daughter due to an illness," Barbara recalled. "She talked about the wonderful care she received at BC Children's Hospital and the need to come together to advance research."

Those words sparked her desire to help. Barbara became a monthly donor to BC Children's Hospital Foundation that very morning, contributing to the ongoing funds that experts count on to solve the greatest health challenges facing kids. But after she had a daughter of her own, those gifts took on an entirely new meaning.

By the time Makeda was three years old, she was experiencing developmental delays—which

led to an eight-year quest for a diagnosis.

Eventually, experts at BC Children's discovered that Makeda had a rare, fatal neuro-degenerative disorder called aspartylglycosaminuria, or AGU, believed to affect only 200 children worldwide. It has no known treatment or cure.

"As I found out more about it, I realized that I would watch my daughter deteriorate before my eyes—that she would slowly lose her cognition, speech and mobility," Barbara said. **"That same rollercoaster of emotions that inspired me to donate 12 years ago has now become my life."**

Barbara continues to tirelessly advocate for her daughter's health. In addition to her monthly contributions, she has started a charity, called the Rare Trait Hope Society, to raise awareness and support research for Makeda's disease.

SEEN & HEARD

It is only through the generous support of individuals and organizations across the province that we are able to help transform the lives of kids and families receiving care at BC Children's Hospital. Here's a closer look at some of the amazing ways supporters like you are making a difference.

Ellie with
Dr. Rebecca Deyell



TURNING WINE INTO GRATEFUL GIFTS

On New Year's Eve in 2017, then two-year-old Ellie's grandfather noticed a lump under her jaw. This moment soon turned into an eight-month journey at BC Children's Hospital to treat the rare, cancerous tumour that would nearly claim Ellie's life.

After 25 radiation treatments, six total rounds of chemotherapy, and surgery to remove the tumour, Ellie is now in remission. Instead of a hospital room, Ellie is spending time in kindergarten and dancing.

Grateful for the expert care Ellie received at BC Children's, Ellie's mother Racyne and their family are donating the tasting fees from their winery—Adega on 45th in Osoyoos—to give back to the hospital that gave Ellie a second chance.

Despite a tough 2020 for the hospitality industry, the family has donated \$12,000 to support Precision Oncology for Young People (PROFYLE). The PROFYLE program aims to find new personalized treatments and give new hope for oncology patients with tough-to-treat cancers who don't respond to traditional therapies.



BEYOND THE SURGICAL TABLE

Every day, the pediatric surgical team at BC Children's spends countless hours applying their expertise to accomplish one goal—saving and improving the lives of kids in BC.

But each year, this group of passionate go-getters, comprised of surgeons, anesthesiologists, and dentists, go above and beyond their demanding professions by also fundraising for their hospital. And last year, the team broke their all-time record, raising more than \$550,000.

Our warmest and most heartfelt thanks to this generous and compassionate team of leading experts. We are so grateful for your support, which is bringing surgical care, education, training and research to new heights.

SAVING LIVES THROUGH GAMING

There's no doubt that gaming has always been popular—and even more so during the pandemic. But for a young girl named Blayke, it's become a way to help kids who need it most.

As the pandemic forced families to stay home, the eight-year-old was determined to still find a way to support the hospital that saved her life. Along with her two brothers and parents, Blayke became involved in Extra Life, an online fundraising initiative that unites gamers across North America to play games and support their local children's hospital all year long.

In November, Blayke and her family took part in Extra Life's biggest annual event: a 24-hour, live-streamed gaming marathon. "The kids loved it," Blayke's mom, Cassandra, said. "They got to play video games all day and there was no bedtime."



Blayke, age 8
and her brother
Ethan, age 10

Their efforts raised over \$2,800 for BC Children's Hospital, helping to fuel groundbreaking research, support life-saving equipment, and more.

"Our house is made up of gamers," Cassandra said. "It was the perfect time to discover this style of fundraising, which lets us do something we love as a family while staying home."



TAKE A STEP FOR BC'S KIDS

Help raise funds for childhood cancer and mental health initiatives at BC Children's Hospital. raceforthekidsbc.com

EVENTS CALENDAR

April 20—The Pulse

Join leading experts from BC Children's as they discuss mental health and youth

Month of May—Jean Up (formerly **Jeans Day**) This May, help kids get out of their hospital gowns and back into their jeans

May 9—SHINE Mother's Day Tea: At Home Celebrate mom with classic high tea treats—all while supporting advances at BC Children's

June 6—RBC Race for the Kids Home Edition

June 12—RISE for BC's Kids on Global BC 7-11PM

Tune into Global BC and watch stories of heroic patient families, clinicians and researchers

Visit bcchf.ca/events

JEANS GO WITH EVERYTHING. INCLUDING HOPE.

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**This May, let's help BC's kids get
out of their hospital gowns and
back into their jeans.**

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