

SPRING 2020

SHINE



A stronger future

Changing the future of pediatric orthopedic care—and of our children.

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IN THIS TOGETHER

During times of uncertainty, it is so inspiring to see people from all walks of life come together. I'm fortunate to witness this often, and especially now, I am humbled by the unique ways each of our supporters helps improve the lives of kids and families.

Whether it's front-line health care workers providing critical care to those who need it most, or resilient families who transformed heartbreaking experiences into a newfound passion to help others, we are proud to share these heartfelt stories in this issue—stories of supporters who are making a difference for kids, all in their own unique ways.

These heroes have something in common: every one of them is vital to our work to help kids receive the best health care imaginable. The progress we've been fortunate to see in clinical care and research has only been made possible through the collective support of every single advocate who has joined us along the way.

I'm excited for you to learn about many of these advances in this issue of Shine. As you read through these pages, you will discover how we're building a new future in pediatric orthopedic care, using immersive technology to transform the hospital experience for kids, and researching new diagnostic tools that may one day become standards of care. These initiatives, along with many others, are opening up tremendous possibilities in children's health care.

As we have seen in recent months, we will be faced with new and unexpected challenges that arise. But when it comes to the health of BC's kids and families, I truly believe that if we continue to rally together, like we have countless times before, there is no hurdle that is too great for us.

Thank you for being by our side as we create a healthier future for kids.

Teri Nicholas

Teri Nicholas, MSW, RSW
President & CEO
BC Children's Hospital Foundation



LOOKING AT THE LONG GAME

A decade ago, if children tore or sprained their anterior cruciate ligament (ACL)—one of the key ligaments in the knee—they would either have to stop sports or wait until they stopped growing before getting it reconstructed. This could take years and would impact many aspects of their daily lives. Fast forward to today, and surgeons at BC Children's can now safely reconstruct a child's ACL while they're growing—allowing them to get back to their favourite activities sooner than ever before.

That's just one of many examples of the remarkable progress in pediatric orthopedics.

While torn ligaments and broken bones often spring to mind when most think of orthopedics, at BC Children's, it means so much more. The hospital's orthopedic clinic sees hundreds of different types of conditions, ranging from serious spine and limb deformities to traumatic injuries. It's one of the busiest clinics in the province, with over 14,000 visits from patients each year.

Across Canada and around the world, the clinic's seven orthopedic surgeons are known as global leaders, pioneering new advances in many areas of clinical care and research.

For instance, Dr. Kishore Mulpuri, a pediatric orthopedic surgeon at BC Children's, spearheaded a screening program for kids with cerebral palsy that reduced the number of hip dislocations among these patients in BC from 15 to 20 each year down to zero—in just a few years.

In addition, the limb lengthening practice, led by pediatric orthopedic surgeon Dr. Anthony Cooper, was the first in Canada to use a non-invasive surgical technique for older children that lengthens the bone using electromagnetic technology. It has kids walking without support immediately,



Dr. Christopher Reilly
with a young patient in
the orthopedic clinic

"WHEN YOU DESIGN THEIR TREATMENT, YOU ALSO HAVE TO THINK ABOUT THE LONG TERM, BECAUSE THE EFFECTS ARE PERMANENT," SAID DR. REILLY

as opposed to the current recovery time: six months on crutches.

In these areas and others, like complex spine conditions and knee injuries, kids are getting back to walking, running and playing much more quickly than they would have otherwise. But for every life that is transformed, more kids still hope for a day when they will be freed of their limitations as they grow into adulthood.

Orthopedic experts at BC Children's are leading advances that will do exactly that. Beyond solving the problem at hand, they weigh

decisions on each child's treatment through the lens of their entire future.

"When you're treating a young child you not only see them as an eight-year-old, but also as a 30-year-old, a 50-year-old," said Dr. Christopher Reilly, head of the department of orthopedics at BC Children's. "And when you design their treatment, you also have to think about the long term, because the effects are permanent."

This is where research comes in. To determine the best therapies with a child's entire lifetime in mind, experts conduct what's called clinical outcomes research.

Dr. Anthony Cooper assesses a child with a limb condition



"OUR VISION IS TO DEVELOP A LEGACY, A STRUCTURE, WHERE EVERY CHILD'S TREATMENT INFLUENCES THE TREATMENT OF FUTURE CHILDREN," SAID DR. REILLY

"It's not research done in a petri dish or in a lab," explained Dr. Reilly. "It's research that's done in our clinic every day with the children that we treat. They partner with us every time they come, year after year, to define the outcomes."

Until now, one critical piece of this plan had been missing: dedicated resources and people to ensure that research can continue for years to come. That's why the team needs a comprehensive clinical outcomes research program

that will help expand and continue this research. "Our vision is to develop a legacy, a structure, where every child's treatment influences the treatment of future children," said Dr. Reilly. This has been no small task. For years, orthopedic surgeons managed to pursue ground-breaking research in their areas, while also carrying a full clinical and surgical load. But to establish a formalized clinical research program,

BC Children's Hospital Foundation is enlisting the help of supporters to make it happen. The impact of this funding on the future of clinical outcomes research at BC Children's will be enormous for kids and families across the province and around the world. "We're just getting started," said Dr. Mulpuri. "The support of donors will allow us to take on greater challenges and solve more problems that will transform lives."

WITHIN A SINGLE YEAR, THE ORTHOPEDIC CLINIC OVERSEES:



14,000
PATIENT VISITS



1,200
SURGERIES



MORE LIMB
CONDITIONS THAN
ANYWHERE ELSE IN BC



BC'S MOST
SERIOUS AND
COMPLEX CASES

Just days after Cassandra and Brad welcomed their daughter, Blayke, into the world, they learned that she had a rare chromosomal disorder called Turner syndrome, which affects only females. Out of every 100 babies with the condition, 99 don't survive birth.

BEATING EXTRAORDINARY ODDS

Those who do survive don't produce the normal amount of estrogen, which means they are often short in stature. They may also experience health issues that affect their heart, kidneys, hearing, ability to learn and more.

Blayke was referred to BC Children's Hospital for specialized care. Once there, she was diagnosed with a heart defect known as coarctation of the aorta, a narrowing of the body's largest artery.

She underwent heart surgery—and days later, Blayke's family was able to see her loving personality shine. Cassandra recalled how their daughter went from sleeping 21 hours a day, to just 12 hours.

"We didn't realize how sick she was until we saw her thriving after her heart was repaired," Cassandra said. "It was then that we truly got to meet our daughter."

But their journey with BC Children's was just beginning. When Blayke was three, a simple cold became so severe it caused her to stop breathing. After several hours in intensive care, she was rushed into surgery to have a tube inserted into her airway to help her breathe.



Blayke recovered, but her health challenges became more complex when an MRI revealed that in addition to the first heart defect, she had two more. Blayke had to undergo an open-heart surgery, in which her heart was stopped for almost an hour while areas of it were reconstructed.

Since the surgery, her health has greatly improved. Blayke currently manages her condition with growth hormones and continues to be seen by a multidisciplinary team ranging from endocrinology to cardiology at BC Children's Hospital.

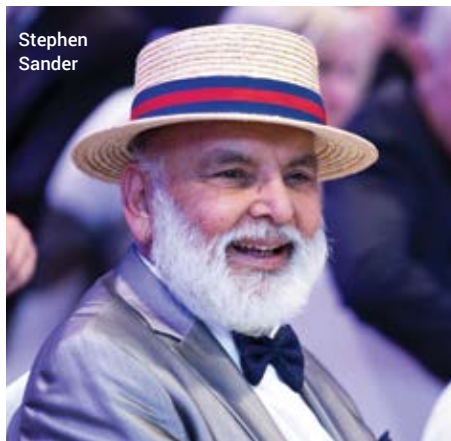
Today, the sassy and bold seven year old is doing everything she can to live her life to the fullest—which includes plenty of horseback riding, bike riding and video games.

"Blayke may never be able to conquer Turner syndrome fully, but she fights every day to make sure it doesn't stop her from being her," Cassandra said. "BC Children's Hospital is helping make that possible."

Blayke is our 2020 Champion Child. Look for her during our annual Miracle Weekend broadcast on Global BC, airing on May 30 and 31. miracleweekend.com

Turning Hardship into Hope

Discover remarkable people who turned difficult experiences into sources of strength—helping improve the lives of countless others.



The Power of Kindness

Stephen Sander was just a teenager when the 1947 partition of India led him to lose everything—his family, the chance to go to school, and life as he knew it.

As a refugee, it was a very challenging time that was filled with adversity. But it was during these years that Stephen discovered something profound: how a small act of kindness can change a life. A pivotal moment in Stephen's life occurred as he was escaping the violence in Pakistan during the partition of India with his four younger brothers and sister. After the train they were on became stuck for several days, other passengers generously shared the very little food they had with his family. Without this generosity, Stephen's family likely wouldn't have survived the journey.

Stephen witnessed the power of compassion a few years later. While living on the streets of New Delhi, a shopkeeper let him keep his belongings in their store so that he could work during the day and attend night school—which allowed him to get a degree in education and chase his dream of immigrating to Canada.

Years later, that dream came true when Stephen moved to Bridgewater, Nova Scotia to teach. He never forgot the way residents welcomed him with open arms—inviting him to their cottages and even teaching him how to drive.

"It was really a re-building of his spirit," his daughter Karen said. "It gave him a sense of hope."

Stephen eventually moved to Vancouver, where he founded one of the country's largest property management companies, Hollyburn Properties. He was determined to make a difference in the communities that helped him rebuild his life—which he did in countless ways, contributing to every neighbourhood Hollyburn is part of. Stephen believed strongly in giving back. As someone who was deeply focused on his family, he instilled similar values in his eight children and 24 grandchildren—not to mention the employees of Hollyburn Properties.

Several months before Stephen's passing, the Sander family and Hollyburn Properties made a visionary gift to fund Canada's first 3D endoscopic system at BC Children's Hospital. This innovative technology provides surgeons with never-before-seen 3D views during delicate minimally-invasive ear, nose and throat procedures.

"My father loved the fact that this revolutionary technology was designed specifically for children, who have different needs than adults," Karen said. "He felt strongly that a healthy beginning for the children of our province is key to a bright future and thriving community."

We are forever grateful for Stephen's dedication to transforming the lives of children and families in BC.

Inspired to Give Back

It didn't take long for a beautiful summer afternoon in 2010 to become one that David and Cindy Primrose will never forget. While visiting relatives in BC, their 11-year-old daughter Natalie was out horseback riding when she was thrown to the ground and stepped on by the horse.

Natalie was immediately rushed to the emergency department in Mission—but her injuries were so severe that she needed to be airlifted to BC Children's Hospital. The family was living in Alberta at the time, and David recalls the moment he received the call at work: "As soon as I heard the word 'helicopter,' I realized this wasn't just a broken arm or dislocated shoulder. I took the first plane to Vancouver for what felt like the longest flight of my life."

Natalie suffered multiple internal organ injuries and spent the next 12 days receiving critical care at BC Children's. She was then admitted as an inpatient for a few weeks. While it was a challenging time for the Primroses, they knew there was no better place for their family to be. Natalie's recovery continued as they returned home to Alberta. After a year of follow-up care, she could once again live a normal life. But the family's connection to BC Children's Hospital didn't end there.

"While at the hospital, we saw other families who were worse off than we were," David said. "So we decided to do what we could to help make a difference in the lives of other families."

The Primroses began hosting fundraising dinners and joined the Foundation's monthly giving program. As Natalie and her younger sister Julia grew older, it gave David and Cindy the opportunity to plan for the future and express their values through a gift in their Will to BC Children's Hospital Foundation. It was a meaningful decision and easy to do.

"For us, family is important," Cindy said. "We want people to know the difference they can make in a child's life, like previous donors did for us, and how their legacy can create a better future."

Learn more about legacy giving at bcchf.ca/legacy



The Primrose Family

A Heart of Gold

Jan Rooks was known for her big heart. She loved music, hiking, friends and family. Most of all, she loved the children she helped, working as a cardiac nurse at BC Children's Hospital. She was known by colleagues and patients alike as someone who went out of her way to help families during their most difficult times. She was a light in their darkness.

Jan's light will never go out. Although she is no longer with us—she passed away in 2014 doing what she loved, hiking in Nepal—her legacy of love lives on.

Jan's family wanted to honour her memory in a way that would reflect her heart. They decided to support a pilot project to bring on a psychologist at BC Children's Heart Centre who would help families at the clinic navigate through their experience dealing with a heart condition. As well, their donation would support research assessing the long-term emotional and psychological impact of heart surgeries on kids and their families.

Through their generosity, Jan's family has found a way to honour her memory—even with children and families who will never meet her.



Jan Rooks

LATEST STRIDES

Here's a look at a few recent and ongoing advances that generous donors like you are making possible.

THE NEW (VIRTUAL) REALITY OF CARE

It's your child's birthday. Normally, she would have a party with her closest friends and family. This year, however, is different. She's far from home, recovering from surgery in the hospital.

But what if you could visually transport her to that birthday party? With the power of immersive technologies—including virtual and augmented reality—it's possible. And BC Children's Hospital is working to harness its benefits for kids receiving care.

From transporting patients to see their far-away friends and families to mimicking the MRI experience ahead of an actual scan, which can be scary for kids, immersive technologies can positively impact a child's hospital experience.

Through a three-year pilot project, John Jacob, senior director and head of the Digital Lab at BC Children's, hopes to make immersive technologies available across the hospital.

"Immersive technologies open up brand new opportunities at BC Children's Hospital to enhance the experience and quality of care for patients and families," said John.

The project will be led through a partnership between the Child and Youth Therapeutic Services Department, staffed by child life specialists, and the hospital's Digital Lab. For child life specialists—who work to help make the hospital experience as positive

as possible for kids—preparing children for something like an MRI scan can be one major benefit of immersive technology.

"We know that preparation prior to a procedure is an important part of helping children feel at ease and confident in their ability to cope well with medical tests and procedures," said Lisa Daechsel, certified child life specialist.

In the oncology clinic, children are whisked away into an alternate digital universe, diverting their attention away from the pain and discomfort they may experience.

"Virtual reality in the oncology clinic has been amazing," said Dr. Caron Strahlendorf, head of

A NEW TEST FOR STREP THROAT
BEING EVALUATED AT BC CHILDREN'S



CAN PROVIDE A DIAGNOSIS
IN AS LITTLE AS
3-10 MIN

the division of pediatric hematology, oncology and bone marrow transplantation. "It allows the team to perform painful procedures with the children distracted, happy and cooperative."

Beyond the pilot project, John is hopeful that immersive technology will continue to shape a positive patient experience.

"Our long-term vision is to ensure that all patients and providers who can benefit from this technology, are able to do so seamlessly and with the greatest impact to outcomes," said John.

To learn more about The Digital Lab at BC Children's, visit bcchdigital.ca

TACKLING STREP WITH SPEED

Strep throat is challenging for many kids. Along with symptoms like throat pain and trouble swallowing, a small percentage of kids with the illness can also develop serious complications, such as heart valve disease or kidney inflammation.

Because of this, strep throat is the only sore throat condition requiring antibiotic treatment. Until now, the gold standard of using a throat culture swab to diagnose strep throat has required a three-day wait for results. Even with other types of tests claiming faster diagnoses, results still need to be confirmed with a culture swab.

But now, a new molecular test is being evaluated at BC Children's Hospital that provides a diagnosis within minutes, without needing confirmation from another test. The results are just as precise—if not more so—than the traditional culture swab.

Because the test would provide an answer even before an appointment ends, it could help reduce overuse of antibiotics while still ensuring appropriate treatment.

That's exactly what Drs. Quynh Doan and David Goldfarb, co-investigators at BC Children's, and their team are on a mission to find out through their research.

"The potential impact of this test is huge for families. For one, they will have assurance of what is affecting their child's symptoms and get a head start on appropriate treatment," Dr. Doan explained. "Secondly, this test could significantly impact how we use antibiotics, and curb the effects on resistance growth."

While research initiatives within the hospital's Ledcor Children's Emergency are temporarily halted to ensure all clinical resources are available for the care of kids in light of COVID-19, the goal is to cross the finish line strongly once research activities resume.



YOUNG AND RESTLESS

While sharing a room on a vacation, Finn’s family noticed something unusual with the way the toddler slept. He snored loudly, slept with his mouth wide open, and changed positions constantly throughout the night. He would also complain of being tired after a full night’s rest—not to mention a three-hour nap. Finn’s grandmother, a pediatric nurse, suspected that the culprit was enlarged adenoids.

That hunch turned out to be right. Months later, Finn received specialized care at BC Children’s Hospital that consisted of a nasal steroid and then an adenoidectomy, a routine procedure to remove the adenoid glands in his throat.

Still, his symptoms persisted. Finn’s medical team at BC Children’s decided to schedule a sleep assessment, called a polysomnogram (PSG), to find out what was going on. So his mom, Denise, packed an overnight bag and the two made the trip from Squamish to BC Children’s. Around 8 p.m., the four year old was hooked up to a multitude of sensors that measured his brain waves, heart rate, movements and more as he tried to doze off.

While considered the gold standard for sleep assessments, PSGs do have limitations. For one, it can be difficult for a child to fall asleep in unfamiliar

environments, making it hard to assess the very thing they are there to have examined. The cost and time spent travelling can also be a huge burden for families who live far away. But most importantly, the wait for these assessments is often significant. It’s little surprise: BC Children’s is home to the province’s only pediatric sleep lab.

600

kids need sleep assessments each year—but only 300 can be seen

30%

come from outside of the Lower Mainland

100

more kids could be assessed with the Sleep Lab at Home

Now, a new solution is in the works. BC Children’s Hospital Foundation is currently raising funds to help the hospital’s sleep experts pilot a new research program that could allow kids to receive high-quality overnight sleep assessments in the comfort of their own beds. It would be the first of its kind in Canada.

The Sleep Lab at Home program could offer a host of benefits. It would minimize disruption in families’ lives, reduce waitlists, and help improve the quality of a child’s sleep as they undergo assessments—something that would also improve the quality of data collected.

Finn’s parents were fortunate to participate in an initial pilot of this research program. After Finn’s assessment, health care providers continued to monitor their son’s sleep patterns through the pilot Sleep Lab at Home program. Results from the PSG revealed that Finn was still snoring and experiencing obstructed breathing—but ultimately, doctors decided that he didn’t require any further treatment as he was growing and the lymphatic tissue in his throat was shrinking, creating more space for breathing at night.

The possibilities of this model extend well beyond sleep assessments. If successful, it could be replicated and expanded into countless areas of health care—for example, monitoring kids after low-risk surgeries so they could return home sooner.



Finn getting ready for his sleep assessment



Bo Kindree

REMEMBERING BO KINDREE

Bo Kindree was almost 11 months old when he was diagnosed with acute myeloid leukemia (AML), which is a rare and aggressive type of blood cancer. While living at BC Children’s Hospital for five months, Bo endured four rounds of very intense chemotherapy. BC Children’s became Bo’s second home. He learned to walk in the eighth floor playroom on his first birthday despite being isolated to his room for over a month. There was hope.

But with several relapses, the additional chemotherapy, radiation and a cord blood transplant Bo received weren’t enough, and he transitioned to palliative care. Bo passed away in his mom’s arms alongside his dad on November 21, 2019 at the hospital.

To honour Bo, his family is raising funds to support childhood AML research at BC Children’s Hospital. Through this tribute fundraiser, Bo’s determined spirit lives on. “His spirit put up a truly remarkable fight to give us every extra minute with him that his body would allow,” Bo’s parents said. “We will miss him deeply every day, and will always be inspired by his strength and bright light.”

To learn more about tribute giving, please contact tributeprogram@bcc hf.ca

“Childhood cancer forced us into an immensely difficult and complicated journey,” Bo’s parents said. “We have been supported by BC Children’s along the way. Now, we would like to be able to further their AML research in hopes that other children may have a better prognosis.”

A KID’S BEST FRIEND

Fudge is a fun-loving dog—but he takes his volunteering at BC Children’s Hospital very seriously. Whether comforting one child before surgery or distracting another during a blood draw, Fudge is a happy and calming presence as a volunteer with the hospital’s Dog Visitation Program.

According to Beth, his owner, Fudge is a “mellow fellow” who thinks that he’s a lap dog—even though he’s a full-size labradoodle. “If there is a really upset child, I will get a blanket and Fudge will go right up on the bed and snuggle with the child until it’s time for surgery,” she said.

With the support of PetSmart Charities® of Canada, the Dog Visitation Program at BC Children’s is poised to expand—helping to meet the emotional needs of even more kids receiving care.

“It just makes all the difference to have a dog there to hold on to when [children are] feeling scared,” said Beth.

All volunteers and pets in BC Children’s Dog Visitation Program are evaluated and certified by St. John’s Ambulance and BC Pets and Friends.

To learn more, please contact BCChildrensTDP@SJABCY.ca



Fudge the labradoodle with Dr. Patrick McDonald

SEEN & HEARD

Generous support from people across the province is the reason why we can continue to help bring children's health care to new heights. Here's a look at the amazing ways members of our community are making a difference.



TO OUR "HELPERS"

Mister Rogers once said that when he was a boy and would see scary things in the news, his mother would say to him:

**"Look for the helpers.
You will always find people who are helping."**

Always, but especially now, we don't need to look far to see them. Health care providers, from right here on BC Children's campus, to across BC, the country and around the world, are selflessly stepping up to help the people who need it most. All of them—our "helpers." We are immensely thankful for them.

Supporters like you have been our "helpers," too. At a time when our health care system is more vital than ever, we take great comfort in knowing that because of your support, you've helped BC Children's be in the best possible position to continue providing critical care for BC's kids. Your help has enabled them to help, and for that, we are profoundly grateful.

STAY CONNECTED WITH US

Visit our social media channels to stay engaged with inspiring and courageous stories from our community.

   @bcchf

We are also now on WeChat—where our Chinese-language community can connect with us. Simply scan the QR code here.



HELP KIDS GET BACK INTO THEIR JEANS

Jeans Day is now Jean up. The annual one-day BC-wide fundraiser has evolved into a month-long initiative that's held each May. It's a chance for everyone in BC to rally together and wear jeans to show what they stand for—helping sick and injured kids get out of their hospital gowns and back into their own jeans.

Ready to be part of the movement? It's easier than ever to do so. After 29 years of buttons and pins, we're going digital with virtual stickers that show your support for BC's kids. Donate online at **JeanUp.ca**



SMALL BUT MIGHTY

Vanderhoof is a small town filled with big hearts.

Since 1992, this community in BC's north has rallied together to fundraise for BC Children's Hospital in many ways. The Vanderhoof Community for Kids is celebrating ten years of its successful dinner and auction night—which, along with other fundraising initiatives, has raised over \$600,000 since 2010.

"It's pretty powerful," said Michelle Roberge, Chair of Vanderhoof Community for Kids. "And it's hard to find a family that doesn't have some connection to the hospital."

In 2015 alone, 71 children from Vanderhoof visited BC Children's a total of 215 times. Michelle's children are among them—her daughter, Olive, and son, André, have both received specialized care for a rare genetic intestinal disorder.

"I'm proud that each year the community supports us as strongly as the year before," Michelle said.



Vanderhoof's Anita Bailey and Anna Manwaring at the annual fundraiser

TAKE A STAND FOR BC'S KIDS

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

raceforthekidsbc.com

JEANS GO WITH EVERYTHING. INCLUDING HOPE.

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

DONATE AT

JeanUp.ca

